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Living Longer and in Need of Care: Should Long-Term Care Benefits be Introduced in Malaysia's Social Protection System?

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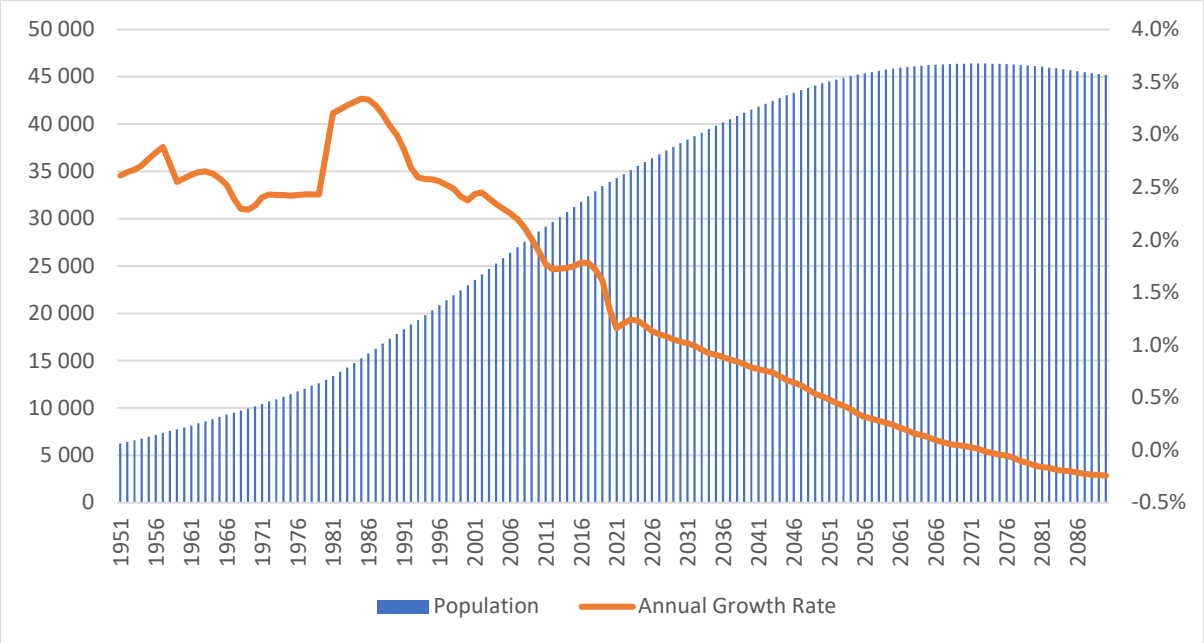
Keywords: *Long-term care, social security, ageing, social insurance, burden of disease, pension*

1. Background

Over the past decade, Malaysia's population has grown at an average annual rate of 1.55%, compared to 2.13% in the previous decade. Annual population growth has declined since the early 1990s and is projected to reach zero or negative growth by 2070 (Figure 1).

This trend stems from two factors: falling fertility rates and rising life expectancy. Since independence in 1957, the Total Fertility Rate (TFR) has decreased by nearly 70%, from 6.1 children per woman to 1.7 in 2023 (DOSM, 2024). Meanwhile, life expectancy at birth has risen steadily, reaching 75.2 years in 2024, up from 71.2 in 1991.

Figure 1. Malaysian Population (in Million), and Fertility rate (%), from 1950 to 2090



Source: Based on data from UN World Population Prospects, 2024

Both trends essentially culminate in a situation where, without significant changes, a growing number of older people will require the support (directly or indirectly) of a shrinking number of younger people. The declining share of the working-age population and additional dependency burden is a relatively new development that Malaysia must come to grips with and prepare the necessary structure and systems for.[1]

Universal social protection for older persons is part of the Sustainable Development Goals (SDG) and the UN 2030 Agenda, in particular SDG 1.3, which calls for the implementation of national social protection systems for all, including floors, with special attention to the poor and the vulnerable. Much has been said about the present fiscal limitations concerning public transfers (pensions and cash assistance programmes) and contributory programmes such as the Employee Provident Fund (EPF) in the face of the ageing trend.

[1] Macroeconomic effects of ageing has been discussed extensively and they include lower labour intensity (as the mix of younger and older labour force changes over time); less working age people and if the labour force participation rate of people in the 55+ age category remains low (lack of silver economy adjustment efforts) and innovation; all of which will at the end force a constraint in fiscal space for supporting the level of social services needed for an aging population.

What happens if long-term care needs are thrown into the equation? Long-term care falls under the category of **contingencies**, **chance occurrences**, or **uncertain outcomes,** arising as a consequence of sickness or frailty, causing dependency on others. According to the definition of the WHO, OECD and the EU, people in need of care are persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period on help with basic activities of daily living (ADLs).

ADLs are typically divided into two categories: basic and instrumental.

- **Basic ADLs (BADLs):**[2]
  1. personal hygiene - bathing, grooming, oral care
  2. dressing - ability to select appropriate clothes and dress/undress
  3. mobility - walking, transferring (for example, from bed to chair), and using stairs
  4. eating - feeding oneself
  5. toileting - get to and use the toilet, and clean themselves
  6. maintaining continence - the ability to control their bladder and bowel function

- **Instrumental ADLs (IADLs)** include household tasks: cooking, cleaning, and laundry; managing finances: paying bills and managing money; shopping: grocery shopping and other errands, transportation: driving or using public transport; communication: using the phone or computer. Functional impairment, which is measured by difficulty in performing IADLs, constrains an individual's ability to live independently and undermines autonomy and quality of life.

Being old does not guarantee loss of functional capacity, at least not until very advanced old age. In fact, the link between the demand/use of long-term care with age is not straightforward. There are many people of advanced age and even with some form of disability, who can lead completely independent lives without the need for care services. Hence, 'age' is not a precondition for long-term care, although specific causes of disability may become more prominent with increasing age.

The long-term care provided should involve a comprehensive approach to ensure their safety, health and quality of life. Managing loss of ADLs, in particular, would mean that the elderly person needs one or more of the following types of support:

1. Occupational therapy: helps individuals regain or adapt skills for ADLs
2. Assistive devices: walkers, hearing devices, grab bars, wheelchairs, reading and hearing aids, special beds, incontinence products, rollator shower chairs, lumbar corsets
3. Home modifications: ramps, stairlifts, or bathroom safety features
4. Caregiver support: to assist with ADLs like bathing, dressing, and meal preparation, to provide counselling, dementia care
5. Medical interventions: treatment of underlying conditions (for example, physical therapy for mobility issues, nursing assistance for wound care or palliative care)
6. Digital products: software and apps that serve remote monitoring, medication reminders, cognitive remediation and connection to emergency support

[2] According to Katz Index of Independence

Depending on the prevailing costs and levels of care needed, not all long-term care must be provided at nursing homes. It is extremely important that the strategic direction for managing elderly long-term care in Malaysia is to encourage a wide range of settings in which the elderly individual can receive care that suits their needs and budget. This means that there should be ample choices in the following types of care settings:

1. In-Home Care: Home Health Aides, Skilled Nursing Care, Companion Services, Adult Day Care
2. Assisted Living Facilities
3. Nursing Homes
4. Memory Care Units -specialised care for elderly individuals with dementia or Alzheimer's disease

Government-run homes for the elderly, such as *Rumah Seri Kenangan* and *Rumah Ehsan,* focus on providing long-term accommodation to homeless or destitute elderly persons, and only take in those who are physically independent and free from major medical issues (JKM).[3] As such, long-term social care in Malaysia is almost always entirely borne through out-of-pocket expenses (OOP), or philanthropic sources (faith-based or non-faith-based) through non-profit care organisations. Lately, demand for paid or specialised care services has intensified and shows potential to contribute more to the Malaysian service sector's GDP.

In developed economies, market for paid care services have grown exponentially under the close guidance and supervision by relevant regulators propelled by strong demand from a highly discerning public. These services, in turn, employ many men and women, across all ages, income and skill ranges - from women involved in food preparation and cleaning services, to rehabilitative therapists and geriatric nurses, doctors and specialists – providing both formal and informal job opportunities.

2. Long-term Care Burden

2.1. Growing Old-Age Dependency

According to DOSM's data, the country is set to become an aged nation by 2040 at which point 14.5 per cent of its population will be aged 65 and over.[4] In 2024, already 7.7 per cent of the population, or 2.6 million people, are aged 65 and over. It is expected that the Old Age Dependency Ratio (OADR) will exceed the young dependency ratio in the next two decades (see Figure 2 below).[5]

There are at least two socio-cultural nuances regarding OADR in the Malaysian context. First, the financial burden of the sandwich generation - adults caught between supporting their ageing parents and their own children - is becoming increasingly heavy as both the life expectancy of the parents and the costs of living relative to income increase. Second, while there is still a

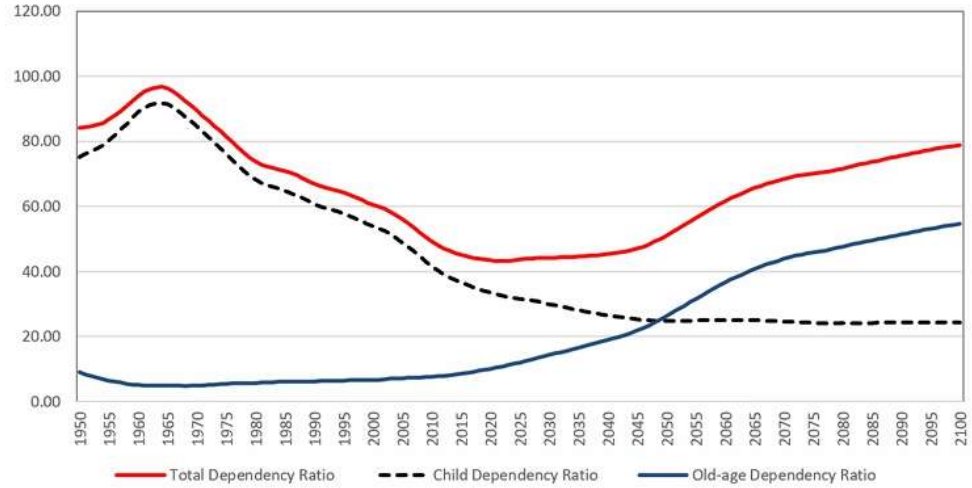
[3] Info Warga Emas, accessed at https://wargaemas.jkm.gov.my/portal

[4] Population Projections (revised), Malaysia, 2010-2040, Department of Statistics Malaysia

[5] The old-age dependency ratio is the number of elderly dependents (who are generally economically inactive and 65 years and older), as a percentage of the number of people of working age (15-64-year-olds). The youth dependency ratio is the ratio of the youth population (ages 0-14) per 100 people of working age (ages 15-64).

strong emphasis on filial piety and family support for the elderly, in reality, socio-cultural norms tend to inhibit the elderly from expressly seeking financial or care support from their children, preferring to prioritise their children and grandchildren's needs over their own health and care. This makes it difficult to assess the full extent of long-term care needs at both micro and macro levels, including the levels of investments and types of support necessary.

Figure 2. Number of dependents per 100 working-age persons (15-64), 1950-2100



Source: Calculation based on UN (2022), from Rabi et al. (2024).

2.2. Old-age Savings Adequacy

Whether the elderly themselves can save enough money to support long-term care needs after retirement largely depends on the pension system in place and its level of coverage and adequacy. Pension adequacy refers to the ability of retirement savings or benefits to cover essential needs, which in turn already depends on many factors such as prevailing costs of healthcare, food, housing and transportation, and the individual's physical, emotional and cognitive state.

Each of Malaysia's old-age savings options faces its challenges.

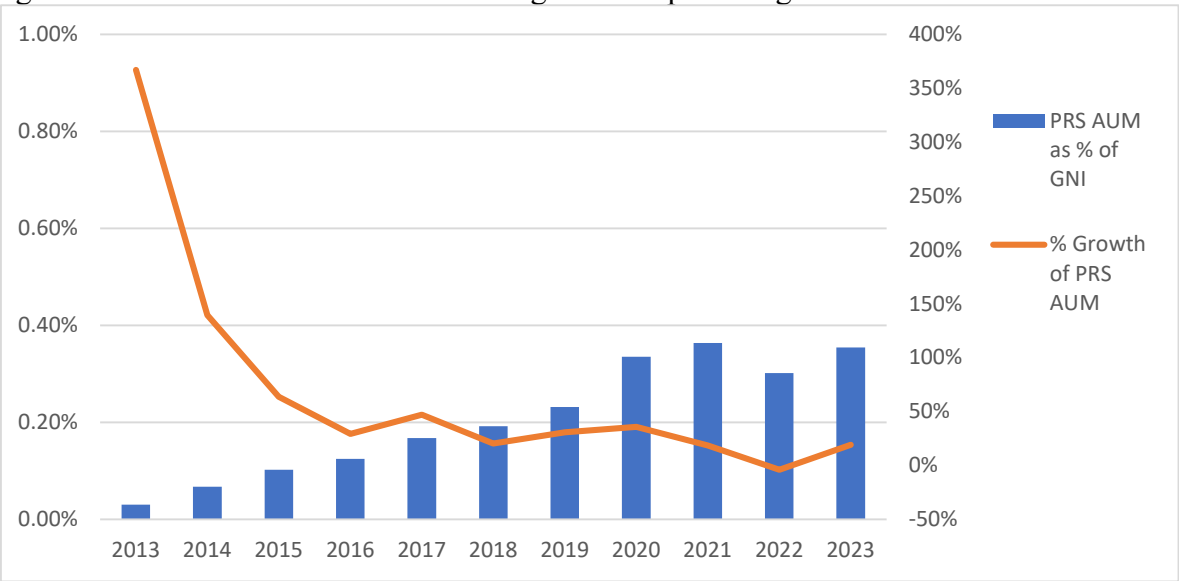
- The Government's pension system for public servants is paid out of tax revenues collected from working-age citizens. This intergenerational social arrangement works as long as a balance between younger and older people is maintained. However, when there are fewer and fewer workers to sustain the increasing obligations that the society demands, that social arrangement will come under considerable strain.

- The Employee Provident Fund system for non-public sector workers accommodates retirement and savings objectives. The latter by allowing pre-retirement withdrawals for education, housing, health care and pilgrimage needs. Notwithstanding this flexibility, the majority of its members do not have the recommended level of savings in their retirement account, for several reasons. One is that, out of its 16,073,317 members, only half (8,524,975) are active contributors (EPF, 2024). The lack of annuitization is only one of the many policy points currently being considered by EPF, since more than one-third of EPF contributors withdraw their retirement savings as a

lump sum at the time of retirement and would likely run out of the savings in less than 5 years.

- The Private Retirement Scheme (PRS) was introduced in 2012 as a much-needed solution to address the pension coverage gap, particularly amongst individuals not actively contributing to the EPF system. The total value of assets under management (AUM) in the PRS scheme has remained less than 0.4 per cent of gross national income, suggesting that the scheme has not been able to garner the levels of savings as hoped for (Figure 3). AUM growth has been stagnant in recent years (19 per cent in 2023) compared to the first few years of its roll-out. It is also very likely that the majority of PRS members come only from the middle- or high-income brackets, this being a voluntary old-age savings instrument.

Figure 3. PRS Value of Asset Under Management as percentage of Gross National Income



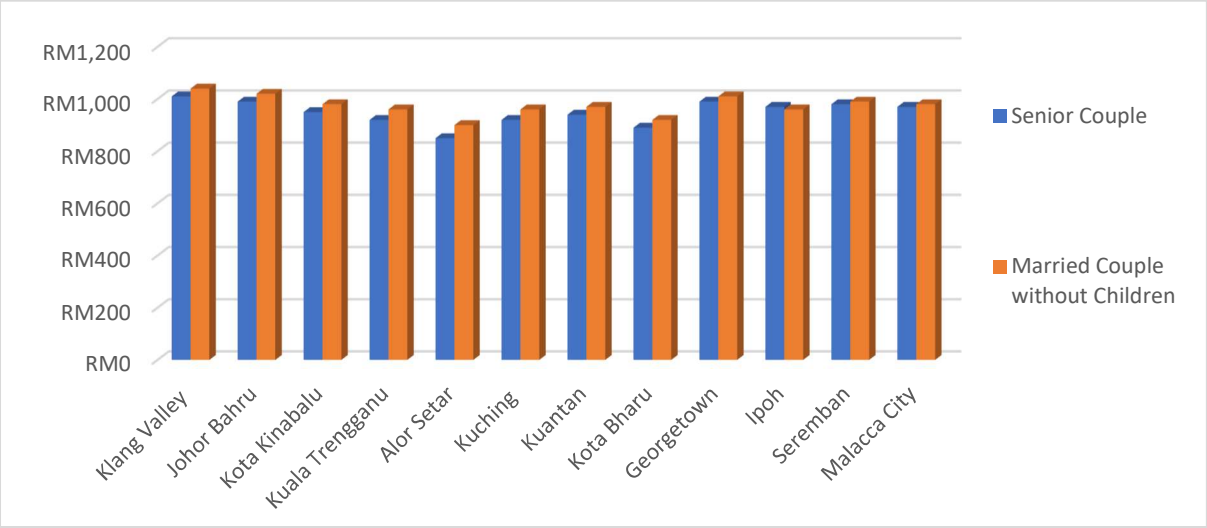
Source: Calculated using data from Annual Report of Securities Commission Malaysia and National Accounts from the Department of Statistics, various years

2.3. Post-retirement Living Expenses

It is misleading to assume that older people spend or need less than younger people, and therefore could easily carve out long-term care-related expenses from their budget when needed. Even factoring in in-kind or family-based transfers and government-financed healthcare services, the cost of living for the elderly does not drop in sync with the drop in income after retirement. This leads to an imbalance between total consumption and income earned by elderly people. Using information from Belanjawanku 2024/2025 (Mansor et al., 2024), it can be shown that the budget between an elderly couple (living by themselves) is not that much smaller than, say, a younger couple without children (Figure 4).[6]

[6] We use the 'couple without children' category as a comparator group, since senior couples usually do not incur costs typical of raising small children. Even if their children still stay at home, it can be assumed that the child is earning his or her own income to some extent.

Figure 4. Belanjawanku's Total Estimated Monthly Expenses for a typical 'Senior Couple' and 'Couple without Children'



Source: Data from Belanjawanku 2024/2025

Food costs are almost the same across all cities for both groups (Figure 5), while housing costs is substantially lower for senior couples (Figure 6). This is mostly because most senior households are no longer servicing housing loans or because they are living in smaller dwellings compared to the younger couples. In terms of health expenditure, senior couples typically spend more compared to their younger counterparts (Figure 7).

If food costs are the same, but healthcare higher (not inclusive of long-term care expenditures), elderly people will be financially vulnerable if their pensions are inadequate. Savings from lower expenditure on housing does not seem to translate into overall lower monthly expenditures (as shown in Figure 4 earlier). Monetizing their house or land assets to cover long-term care expenses is not as easy as thought. Such decisions are still largely influenced by relational and family values, where the older individuals tend to adopt an attitude of self-restrain when considering financial decumulation decisions.

Figure 5. Belanjawanku's Total Estimated Monthly Food Expenses

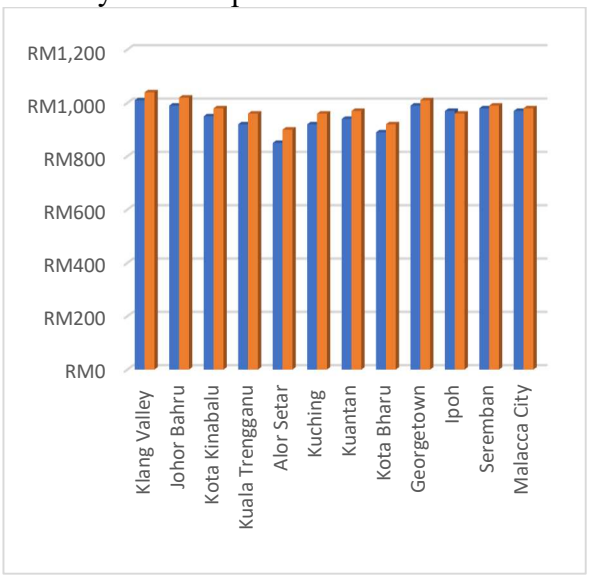


Figure 6. Belanjawanku's Total Estimated Monthly Housing Expenses

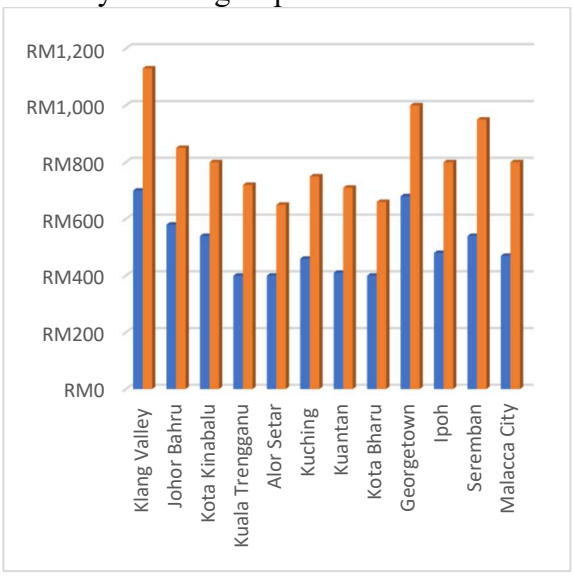
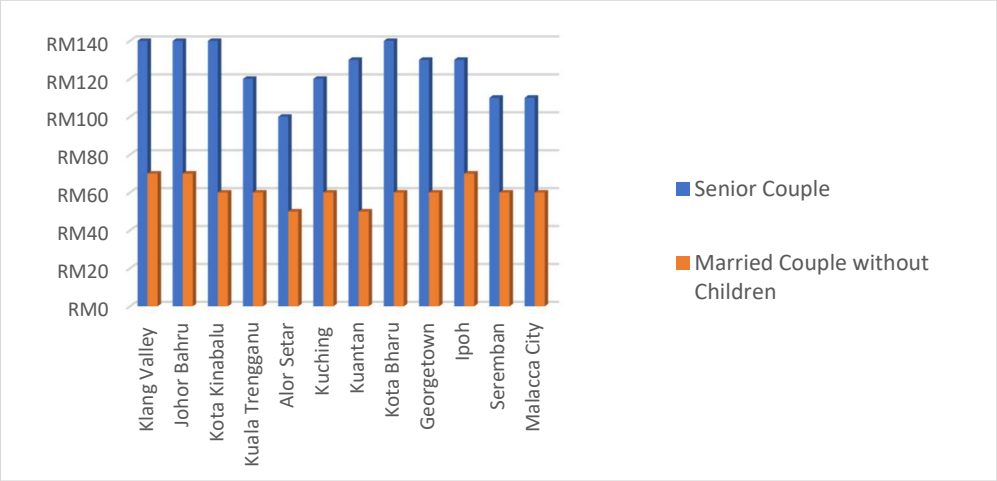


Figure 7. Belanjawanku's Total Estimated Monthly Health Expenses



Source: Data from Belanjawanku 2024/2025

2.4. Market for Private Long-term Care Insurance

In an ideal setting, individuals could choose to purchase private long-term care insurance (LCTI) to protect themselves and their families from the high costs of long-term care and to ensure access to quality care without depleting savings or burdening loved ones. LCTI is normally sold in the private insurance market as a separate product from medical and health insurance for two main reasons. Firstly, medical insurance does not cover long-term care needs at home or at care facilities. Secondly, medical insurance does not cover medical or care needs once the policy's maximum coverage age is reached, which in general is rarely set beyond 70.

Standalone LTCI is not currently available in Malaysia, unlike in countries like Japan or the U.S. and Singapore. Traditional health or life insurance policies in Malaysia often exclude long-term custodial care (e.g., assistance with daily living activities) but may bundle some form of long-term care riders within their life or critical illness insurance. For instance, Great Eastern's GREAT Generation Care allows the policyholder to extend complimentary critical illness coverage to their parents by adding on the optional Parent Protect Rider. Prudential's PRUMy Critical Care is a critical illness plan that has a coverage term up to 80 and 100 years old (with varying premium payment structures).

Factors contributing to low demand for LTCI standalone products include:

- Low Awareness: Many Malaysians underestimate long-term care costs and rely on family support.
- Cultural Norms: Families often provide informal care, reducing perceived urgency for insurance.
- High Costs: Premiums for LTC-linked policies can be expensive, especially if taken at a later age. Premiums are also subject to upward revisions from time to time, causing it to gradually become relatively unaffordable or less prioritised in the context of other expenses.
- Regulatory Gaps: Currently, there is no standardized long-term care framework or subsidies to incentivise uptake of LTCI.

- Premium rates and underwriting standards: LCTI premium rates typically depend on the policyholder's age at enrolment, gender (women pay more than men because they typically live longer and are more likely to need extended long-term care), coverage period (number of years long-term care will be needed), the waiting period, if inflation rider is included and so forth. In addition, the policy holder must disclose their medical records and, in some cases, agree to a home interview, as part of the LCTI policy's underwriting standards.

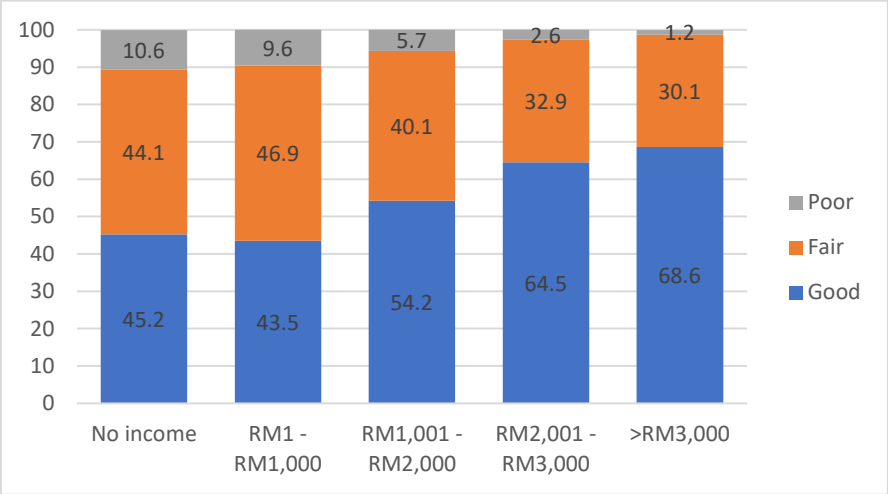
On the supply side, insurance companies are wary of introducing LCTI due to Malaysia's demographic profile: longer life expectancy but high prevalence of poor health at advanced age. This is because in principle, it would not be commercially viable for insurers to underwrite or to maintain coverage for an age group that reports a high incidence of hospitalisation or care needs.

LCTI's market barriers are not unique to Malaysia. In the U.S., while there were more than 100 companies selling LCTI products in the early 2000s, today fewer than 10 companies sell proper stand-alone policies for long-term care. This current lack of market volume means that if there is an existing market for LTCI, the premium prices and insurance claim conditions are likely prohibitive and therefore might not be accessible to the people most in need of the insurance in the first place.

2.5. Income Inequality's link with Health Inequality

Intuitively, people from higher socio-economic status are better able to delay the loss of ADLs through good healthcare, nutrition, and positive social interactions. The Malaysian Ageing and Retirement Survey Report (2023) showed a positive correlation between income and self-rated health status of adults aged 40 years or above (Figure 8).[7] The proportion of respondents who rated their health as 'good' is only 45.2 % among respondents earning no income compared to 68.6 per cent among respondents earning more than RM3,000 monthly.

Figure 8. Self-Rated Health Status by Income



Source: Malaysia Aging and Retirement Survey Wave 2, 2023

[7] Social Wellbeing Research Centre (SWRC), University of Malaya. (2023). Malaysia Ageing and Retirement Survey Report (MARS) Wave 3 [Unpublished study].

Numerous other studies similarly indicate that poor health status is highly concentrated among older people with low incomes, regardless of age (see, for instance, the National Health and Morbidity Survey, 2023). Older people with low incomes face a considerable financial burden due to high out-of-pocket (OOP) costs at the point of service, which are often provided outside of the highly subsidised public health system.

The scope to expand the Government-funded only social transfer programme for the elderly, i.e. *Bantuan Warga Emas (BWE)* is very limited, given that it is already the largest programme by value under Malaysia's Department of Social Welfare (JKM). BWE alone consumes 33.35% of the total allocation for all JKM's 11 social assistance programmes in 2022. Its cost to the government increased by 4.55 times between 2008-2022 and currently covers a total of 141,114 old-age recipients (MWCFD, 2023). The RM600 monthly assistance, even when added together with the Government's larger-scale *Sumbangan Tunai Rahmah* or other social transfers, still barely scratches the surface when it comes to the cost of specialised long-term care, should it be incurred.

Because the risk of long-term care is heavily skewed towards those on lower incomes, the costs will fall on their extended families. Children of care-dependent older persons will have to draw on their savings, sell assets, or ask family members to stop working to provide unpaid care at home, all of which, in the end amplifies the household's poverty burden.

2.6. Gender Inequality in Care Provision and Financial Capacity

Malaysia is still one of the lowest in terms of its female Labour Force Participation Rate (LFPR) in the region and in comparison to many countries in the high-income bracket. Malaysian male-female LFPR differential stands at 26.1 basis points, which is higher than its Southeast Asian neighbours and even Japan and South Korea, countries with traditionally low female LFPRs (Table 1).

Table 1. Percentage of population (ages 15+) in Labour Force (national estimate), 2023

Country	Female LFPR (%)	Male LFPR (%)	Difference
Sweden	64.4	70.629	6.2
Norway	62.1	69.196	7.1
Denmark	59.7	67.699	8.0
United Kingdom	58.1	66.55	8.4
Australia	62.8	71.677	8.9
Netherlands	64.1	73.087	9.0
Germany	56.4	66.716	10.3
Japan	54.8	71.4	16.6
Korea, Rep.	56.1	73.39	17.3
Viet Nam	67.9	76.652	8.7
Thailand	60.6	76.614	16.0
Singapore	62.6	74.904	12.3
Malaysia	**55.8**	**81.88**	**26.1**
Brunei Darussalam	54.4	72.289	17.9
Philippines	50.2	72.54	22.3

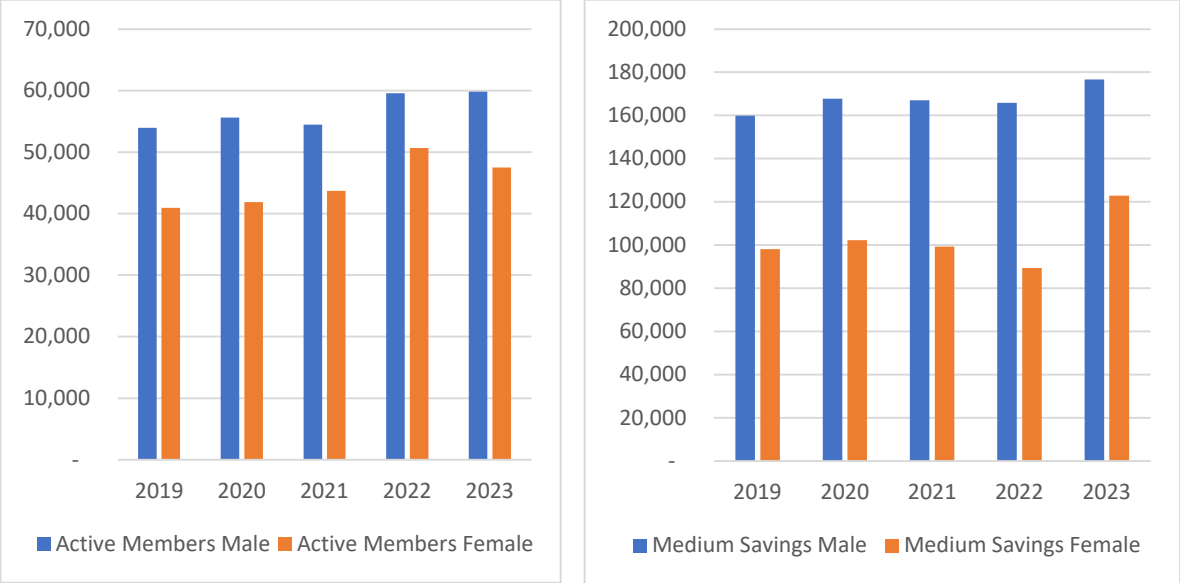
Source: Labour Force Statistics database (LFS), ILOSTAT.

Women experience more interruptions in their careers and tend to have less access to decent work opportunities and are disproportionately represented in the informal economy. This means that while women live longer than men, they are also less likely to have income security in old age, which in turn affects their ability to stay healthy longer.

In 2023, over 4.81 million women were outside of the labour force (compared to 2.19 million men), with an additional 134,500 women (compared to 91,800 men) engaged in part-time work.[8] A lot of this has to do with domestic obligations. Being more likely to have a lower average income, older women tend to be more marginalised and disadvantaged than older men, with higher rates of poverty present among older women. At the same time, older women are more likely to live alone (higher life expectancy means they are more often widows) and are not able to rely on support from other household members

Unpaid full-time caregivers of the elderly are mostly women who themselves are elderly, or are unmarried, or have never worked or not worked for extended periods to focus on their caregiving responsibilities. Working caregivers tend to either accept lower wages or flexible hours work or choose to work in the informal economy to gain a better work-life balance. EPF statistics (Figure 9), show there are 21% fewer female members (aged 54) compared to male, on average between 2019 and 2023. Active female members' median savings are lower by 38.9% compared to active male members on average during the same 5-year period (EPF, 2024).

Figure 9. Gender distribution of Active Members aged 54 and their Median Savings (RM)



Source: EPF Annual Report 2023

3. A Looming Crisis

Regardless of our economic success as a country or as individuals, we should avoid falling victim to an ill-prepared care economy. Malaysia's absence or lack of comprehensive social security provisions of care does not make sense given its twin problems of rapid ageing trend

[8] In the Labor Force Survey, these individuals are those who report working less than 30 hours per week.

and poor health outcomes amongst the population. Using a risk register (based on the probability of older persons developing long-term care dependency) and an expected monetary value approach, it is possible to develop estimates for which the social protection authorities can develop a contingency reserve and provide assistance to the people.

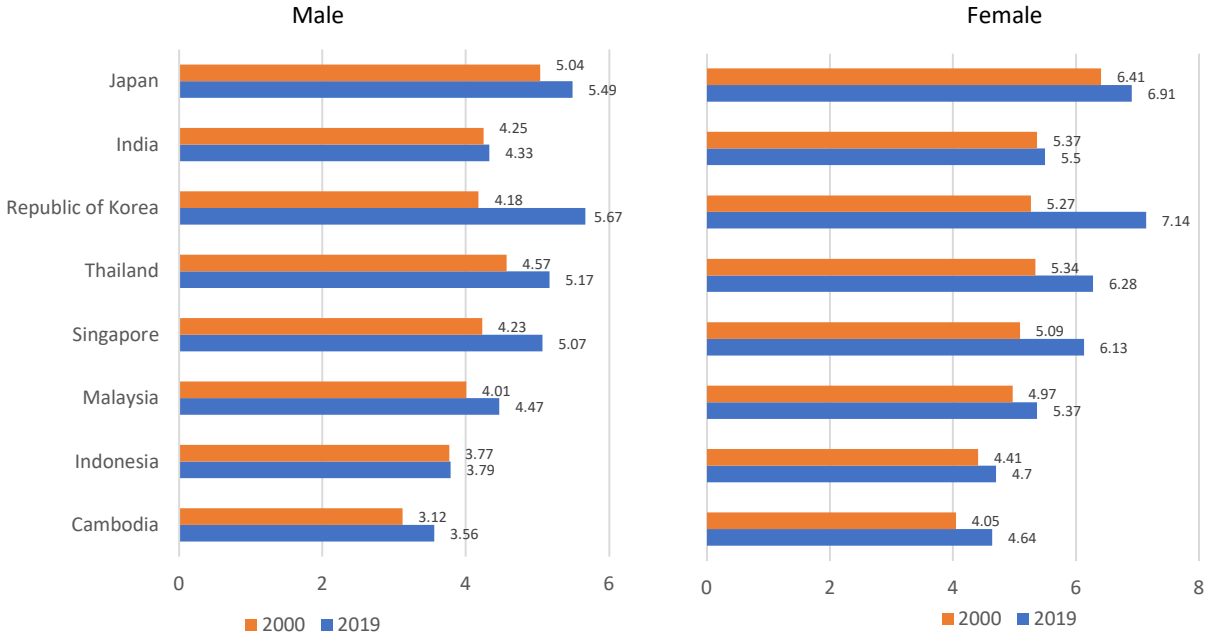
To understand the country's long-term care risks, this paper utilises two concepts: Healthy Life Expectancy and Years Lost to Disability. While there are other useful and more technical public health measures available, we find that the two are easy to understand and fit the conceptual purpose of this paper.

3.1 Healthy Life Expectancy

Life expectancy has risen, but the gap between average life expectancy (ALE) and healthy life expectancy (HALE),[9] has widened. In Malaysia, this difference increased from 4.01 years in 2000 to 4.47 years in 2019, suggesting longer periods of care needed in old age. The trend is not unique to Malaysia, almost all countries registered positive and increasingly longer ALE-HALE differences (Figure 9).

It is also worth noting that older women generally suffer ill-health or disability longer than men. Estimates for 2019 show that Malaysian females spent 5.37 years in less-than-full health, compared to 4.47 for males, i.e., showing almost a full year of difference.

Figure 10. Difference (in number of years) between Average Life Expectancy and Healthy Life Expectancy at Age 60 in 2000 and 2019, by sex



Source: Based on data from WHO's Global Health Observatory

[9] HALE represents the expected number of remaining years of life spent in good health from a particular age (typically birth or 60 years), assuming the rates of mortality and morbidity remain unchanged. It is used to indicate disability-free years of an average individual in the country.

3.2 Years Lost due to Disability

Years Lost due to Disability (YLD) is another concept that could be useful to understand the extent of old-age health challenges. It indicates the non-fatal burden of disease and injury, or in other words, the measure of healthy years lost due to ill health.[10,11] YLD is expressed per 100,000 people.

The chronic consequences of illnesses or injuries often account for a significant portion of YLD. Examples of disease, injuries, or medical treatments that can cause loss of BADL or IADL functionalities:

- Stroke that can lead to paralysis, speech difficulties, or cognitive impairment
- Diabetes, which can lead to vision loss, kidney failure, or neuropathy
- Traumatic Brain Injury (TBI), which can lead to memory loss, mood disorders, or motor dysfunction
- having multiple co-morbidities, which is often the case for older adults, affects various functional abilities and requires chronic disease management

The share of noncommunicable disease (NCD) burden on older people (for example, YLD from coronary heart disease, stroke, and diabetes) in Malaysia is already alarming - 91.2% of all YLD for males and 87.4% for females (latest estimate 2021), aged 55 and above.

While the most important NCD contributing to Malaysian elderly YLD is diabetes and kidney diseases, the burden is higher among females compared to males. Burden from cardiovascular diseases, on the other hand, is higher for males compared to females (Figures 11 and 12).

YLD associated with sense organ diseases, such as glaucoma, cataracts, macular degeneration, which affect vision or hearing, is higher in males, whereas musculoskeletal diseases, such as rheumatoid arthritis, osteoarthritis, back and neck pain, for instance, are higher in females.

In terms of communicable diseases, among older males, the highest number of YLD comes from chronic respiratory diseases (Figures 13 and 14). On the other hand, elderly females suffer from nutritional deficiencies more significantly than males. Female risks to malnutrition may be aggravated by her marital status and financial support, living arrangements, ability to purchase, cook or chew food, much needed for nutrition. The consequences of malnutrition include higher risks of frailty, cognitive decline, poor quality of life, and mortality.

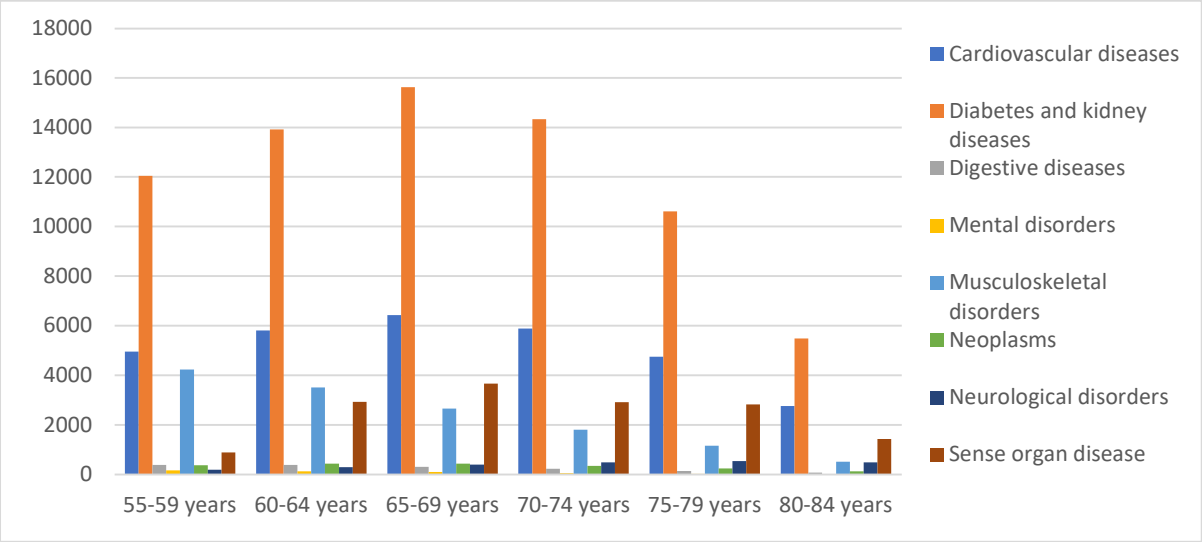
The risk of injuries from falls (lack of balance and poor sight) is also high amongst the elderly population. The most frequent cause of unintentional injury in older people is falling, from either a low level (i.e. from standing or a chair), or a higher level (such as falling from a ladder. For older people, even low-level falls can result in significant traumatic injury for example if it affects the head or causes broken (also known as fractured) bones, such as the hips or pelvis.

[10] Years Lost due to Disability (YLD) which is calculated by multiplying the prevalence of the disease' major sources of health loss (sequelae) to its disability weight by age group and sex. The total YLD for each disease and injury was obtained from the sum of YLD from all the sequelae of that disease. One YLD represents the equivalent of one full year of healthy life lost due to disability or ill-health

[11] The overall burden of disease, measured in DALY, combines the potential years of life lost (YLL) due to premature death and the years lost due to disability (YLD), an equivalent of potential healthy years lost due to poor health, illness or disability. It other words, DALY combines the impact of dying early and living with an illness.

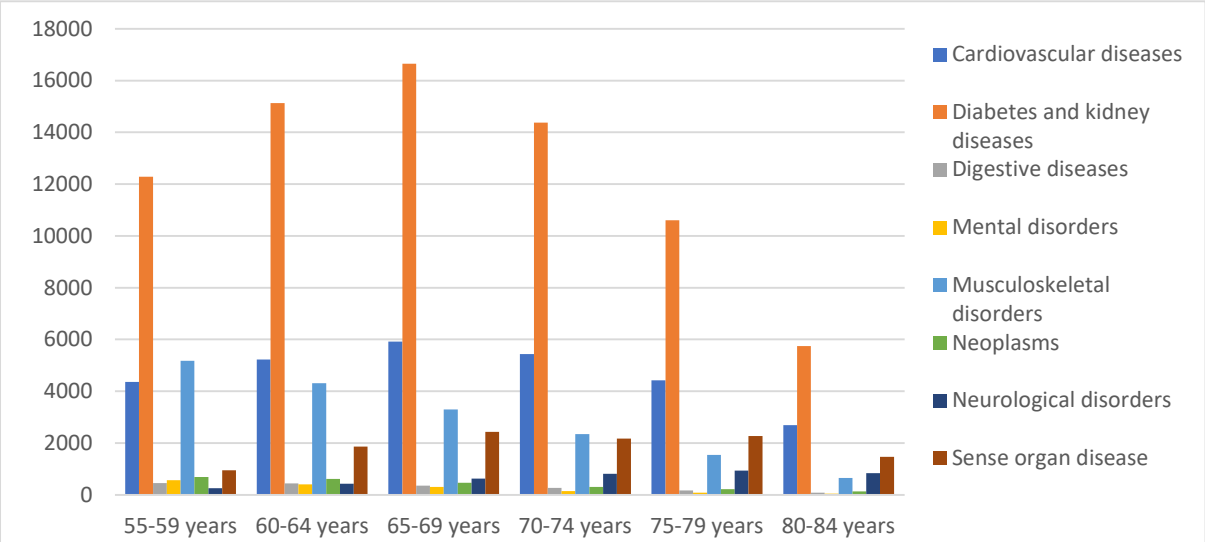
Age-related changes to the body and the presence of other diseases may delay healing and leave the older patient prone to other problems, such as infection or chronic pain. As a result of injury, older people may have to spend a considerable amount of time needing care and physio/occupational therapy compared to younger patients.

Figure 11. YLD per 100,000 population associated with different types of Non-communicable Diseases, 2021, Male



Source: World Health Organization. Global Health Estimates 2021[12]

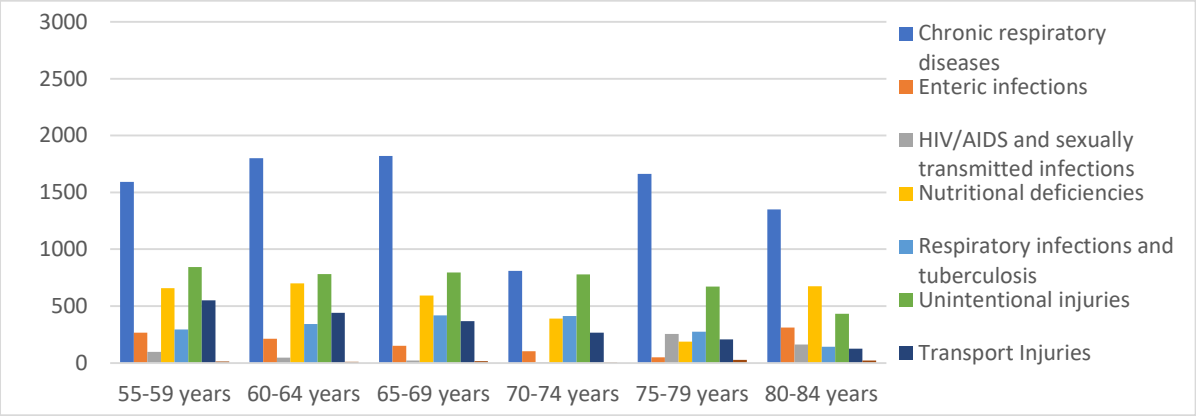
Figure 12. YLD per 100,000 population associated with different types of Non-communicable Diseases, 2021, Female



Source: World Health Organization. Global Health Estimates 2021

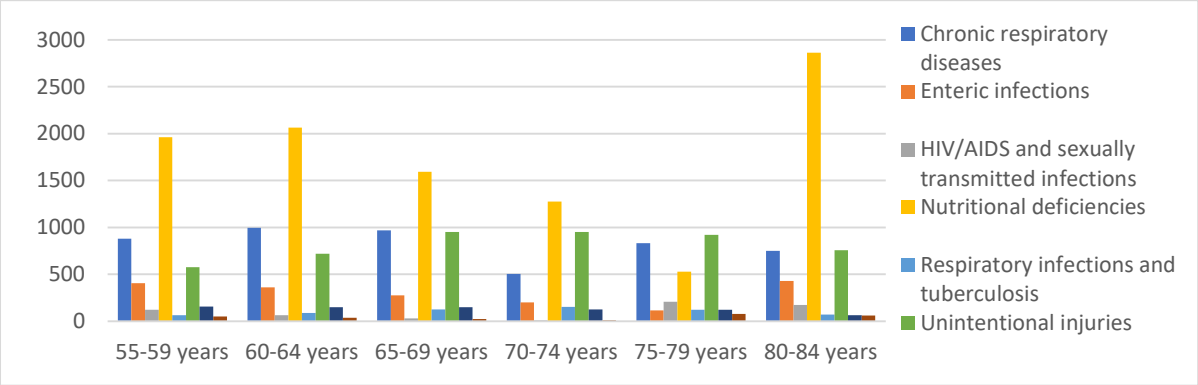
[12] Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2021 (GBD 2021). Seattle, United States: Institute for Health Metrics and Evaluation (IHME), 2024.

Figure 13. YLD per 100,000 population associated with different types of Communicable Diseases and Injuries, 2021, Male



Source: World Health Organization. Global Health Estimates 2021

Figure 14. YLD per 100,000 population associated with different types of Communicable Diseases and Injuries, 2021, Female



Source: World Health Organization. Global Health Estimates 2021

3.3 Depression and Dementia

Elderly depression can stem from intergenerational conflicts, elder abuse and neglect, lack of age-friendly infrastructure (for example barrier-free and universal design), chronic loneliness, low self-esteem and financial stress. However, the fear of drawing attention to oneself and burdening the family members, the community's stigma of mental illness, coupled with the lack of geriatric mental health professionals and adequate psychogeriatric services are factors that prevent access to mental health care.

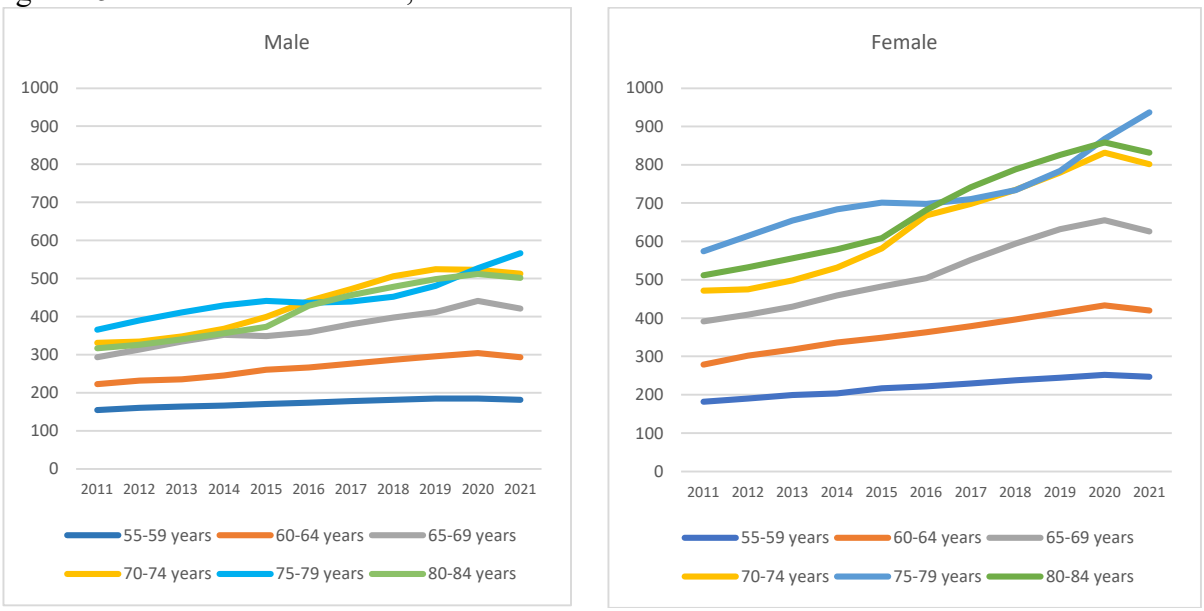
Dementia is today a major cause of disability and dependence in older persons.[13] In developing parts of Asia, dementia is the seventh most prevalent disease affecting older people (ADB, 2023). The Malaysian 2019 National Health Morbidity Survey (MOH) estimated that 8.5 per cent of the older adults in Malaysia potentially suffer from dementia (of which Alzheimer's disease will account for 60 percent to 70 percent of the dementia cases). Alzheimer's Disease

[13] Dementia is indicated by a group of symptoms related to cognitive decline. Dementia of Alzheimer's type is the most common, affecting memory, communication, and thinking. It worsens progressively and interferes with daily living.

Foundation, Malaysia (ADFM) estimated the number to grow to between 637,500 to 825,000 by the year 2050.[14]

Gender differences also prevail in respect to mental health care needs. YLD due to dementia amongst elderly females in Malaysia is higher than males across all elderly age groups, as shown in Figures 15. Important risk factors for women are depression or mood disorders, low education or low income, marital status, pregnancy and menopause and healthcare access. Men have a greater overall prevalence of sleep apnea, which together with poor sleep quality have been associated with cognitive decline and an increased risk of Alzheimer's disease dementia.

Figure 15.YLD due to Dementia, Male and Female



Source: World Health Organization. Global Health Estimates 2021

4. Social Protection for Older People with Long-term Care Needs

4.1 Long-term Care as a Separate Element from Healthcare

Social protection with respect to long-term care can be easily distinguished from universal health coverage (UHC), which Malaysia already enjoys. This is because, despite several overlapping elements, they essentially serve different needs and have different costs, scope, and policy challenges, which are discussed below:

- Different focus: While UHC aims to ensure all people have access to essential health services (e.g., doctor visits, hospital care, medications) without financial hardship, long-term care addresses "custodial care". This includes daily living assistance and support for chronic conditions, which are often seen as social or personal care, not strictly "medical".
- Funding and cost challenges: Long-term care is expensive and requires sustained funding for years or decades. Most UHC systems (in Malaysia, as well as Medicare in

[14] News Strait Times, Dementia cases set to rise 312 percent by 2050: Is Malaysia prepared? Tharanya Arumugam - June 6, 2022 https://www.nst.com.my/news/online-special/2022/06/802683/dementia-cases-set-rise-312-cent-2050-malaysia-prepared%C2%A0

the U.S., the National Health Services (NHS) in the U.K.) are not structured to cover these costs indefinitely. Including long-term care in UHC could strain public budgets, especially with rapidly ageing populations.

- Separation of health and social care systems: Many countries treat long-term care as part of social welfare (like housing or disability support) rather than healthcare. For example, while the NHS provides medical care, long-term care is managed by local authorities and means-tested. In Malaysia, government's long-term care facilities are managed by the Department of Social Welfare, rather than the Ministry of Health.
- Cultural and policy priorities: Society views caregiving responsibility to be with the family, especially in the local context, where multigenerational care is the norm. On the other hand, a few countries (e.g., Japan, Germany, the Netherlands) have integrated long-term care into public safety nets through dedicated social insurance systems.

Healthcare and social care are distinct yet interdependent. Effective integration of both systems is crucial for comprehensive care, particularly for ageing populations and those with complex health conditions.

4.2 Long-term Care as Part of a Life-cycle-Based Social Protection System

Long-term care is increasingly recognised as an emerging risk that people may face in the course of life, where due to its multifaceted effect on family wellbeing, is subsumed under many of the Social Security (Minimum Standards) Convention, 1952 (No. 102) contingencies, namely: sickness, old age, family responsibilities, and invalidity.

In December 2020, the United Nations General Assembly adopted the UN Decade of Healthy Ageing (2021-2030) through Resolution A/RES/75/131 which calls on Member States, among others, to focus on "delivering person-centred integrated care and primary health services responsive to older people; and providing older people who need it with access to long-term care.". In June 2021, the International Labour Conference (ILC) called on Member States and the International Labour Organization (ILO) to consider long-term care as an integral part of social protection systems, to invest in the care economy and support workers with care responsibilities (ILO, 2021a).[15] Cognizant of the growing scale of long-term care needs in the country, the Malaysian Ministry of Human Resources (KESUMA) has reportedly commissioned a study to introduce a 24-hour social security protection scheme and LCTI for the elderly.[16]

Policy responses to long-term care risks can be grouped into two. Firstly, policies that reduce socio-economic, gender and health inequities, coupled with programmes that promote healthy living (directed at particular stages of the life cycle) form the fundamental elements of a social protection system for the elderly. Why? Because prevention of illness and disability in old age requires that healthy behaviours, good nutrition, early detection and rehabilitation or management by professionals are embedded into people's lives from a very young age.

[15] ILO, 2021. Resolution and conclusions concerning the second recurrent discussion on social protection (social security), 109th Session of the International Labour Conference.

[16] The Star, "HR Ministry mulls 24-hour social protection scheme, long-term care insurance for seniors, says minister". 14 March 2024

Second, policies that provide effective protection against the financial risks associated with long-term care costs. Contingency social insurance, such as long-term care benefits, serves to cover the risks that old-age savings or transfers are insufficient to meet long-term care expenses. A social insurance model provides a proactive, solidarity-based approach to managing ageing societies' needs. By pooling risks and resources, it ensures dignity and care for vulnerable populations while mitigating economic inequality.

4.3 Determining Coverage

A country's overall demand for long-term care will depend on the number of people in need of care (since not all elderly individuals will need long-term care). This demand should dictate how the country sets policies, incentives, public spending and how it can put in place relevant social safety nets adequately.

While the number of people needing long-term care (magnitude of **demand**) can be estimated using the population's demographic and health data, the national **cost** of providing long-term care is more difficult to determine. This is simply because even if only a minority of the elderly population face catastrophic expenses for care, care needs and the length of the period for which care is necessary differ from one individual to another.

The majority of countries that have incorporated public provision of long-term care benefits or services have done so with some form of means-testing. (Addati et al., 2022).[17] While the rationale is often to contain public expenditure on long-term care (ILO, 2017a), the approach's scalability and desirability are limited by a number of factors.

1. The means-testing approach goes against the intention to pool the risk of needing long-term care amongst all members of society, because it gives rise to the development of a two-tiered system; public provision ends-up catering to the poorest, while the more affluent acquires long-term care services from markets that tend to remain poorly regulated, hence largely resulting in segmentation and cream-skimming.
2. Implementation of means-tests, in particular with proxy means tests, necessitates that exclusion errors to be minimal. This affects the desirability of adopting the social protection measure as a society if seen to be poorly managed and delivered.
3. With the chronic shortage of health and personal care workers in the long-term care sector, there is every possibility that the two-tiered system will create larger inequities in access and quality of the benefits provided, since the long-term care sector for the rich would be more able to attract a supply of personnel and expertise.

Even now in Malaysia, where medical care is state-guaranteed, support for home-based care (such as *Bantuan Pesakit Terlantar* or *Bantuan Warga Emas*) is means-tested, 'social hospitalisation' cases keep on occurring. The term refers to families delaying an older person's hospital discharge due to a lack of options for care, being either very scarce, overwhelming or expensive. MOH reports that between 2018 and June 2022, as many as 2,144 elderly persons were abandoned at various hospitals nationwide.[18]

[17] Addati, L., Cattaneo, U., Esquivel, V., & Valarino, I. (2018). Care work and care job for the future of decent work. International Labour Organization

[18] New Strait Times, "2,144 senior citizens abandoned at hospitals over last five years", 21st July 2022

4.4 Ensuring Adequacy

To apply the rights-based approach to universal coverage in long-term care, it means that the country is committed to ensuring universal access to long-term care services without hardship. ILO recommends that entitlement is materialised through a clear definition of:

1. the **contingency** covered – types of functional impairments and indicators on ADLs and mental capacity
2. a package of **benefits** corresponding to the contingency – whether entirely cash to cover costs of accessing goods and services needed, or mixed with in-kind benefits such as health care and social care services provided in the home, in the community or in institutions, as well as access to house equipment/adaptations and assistive medical devices.
3. **delivery** of care – depending on the package of benefits, care is delivered either through a dedicated network of service providers (public or private) or through distribution of cash, which beneficiaries are free to use in the care market
4. the level of **financial protection** provided to cover the costs of the benefit package- including avoidance or minimization of co-payments so as not to impoverish the families affected

For instance, in Japan, health and social care can be accessed through services that are facility-, home- or community-based, depending on the level of care needed. For the same system to work here in Malaysia, a harmonised quality standards for long-term service providers must be established, beyond establishing legal frameworks, to include enforcement, grievance mechanisms, care workers' rights and so on.

In determining which care providers are included in the network approved for the social protection programme, numerous conditions must be met (for example, quality of physical infrastructure, quality of care services, accessibility, governance).

The delivery network model also requires that there is a continuum of well-coordinated care services available along family, home-based social and health care, and residential care lines. This is a particularly arduous task when different care categories are governed by different government agencies or laws. Diversity of provider payment methods must also be taken into account, for example, home-based care providers versus institution-based care providers.

Singapore's long-term care social insurance programme, ElderShield, provides benefits in cash in the form of monthly payments, while the Republic of Korea provides benefits both in-kind and cash benefits. The advantage of cash is the flexibility of use. Beneficiaries can use the money to pay family caregivers, or pay for home care services, such as bathing, day and night care and nursing for older family members. The Republic of Korea also gives financial support for the purchase of assistive devices. Cash 'vouchers' method is used in specific regions in Italy and in France, where beneficiaries are given vouchers to purchase services, using providers approved by the government or directly from the market.

4.5 Sustainability

Northern European countries such as Sweden and Denmark employ the traditional tax-funded model to finance a universal system of long-term care for their elderly citizens (see Box 1), whereas Japan is a well-known example of the long-term care social insurance model (see Box 2). A **social insurance** programme for long-term care, for instance, can be instituted, where virtually everyone contributes to a national insurance plan (typically a fixed percentage of their earnings), and everyone who contributes is eligible for benefits.

Traditional social insurance differs from private insurance in that there is no individual underwriting necessary - no one can be excluded from the programme because they have a high risk of needing the benefits provided. Furthermore, social insurance is community rated i.e. everyone contributes at the same rate or level. The social insurance programmes allow the elderly to access a wide range of institutional and community-based services. Also, since eligibility is universal and in the case of Japan, premiums are compulsory for all, there is also less stigma involved for the elderly in seeking long-term care assistance.

The rest of the section looks at examples from four countries: Sweden, Japan, Singapore and the United States, to illustrate the diversity in approaches to public provision of long-term care.

Box 1. Sweden's Tax-funded Long-term Care System

The long-term care system in Sweden is widely regarded as one of the most comprehensive and well-developed in the world. The system is designed to support older adults who have lost the ability to perform ADLs due to ageing, illness, or disability, ensuring they can live with dignity and independence. Principles underlying the design of Sweden's long-term care system:

- Universal Access: All elderly citizens are entitled to long-term care services, regardless of income or social status.
- Benefits Package: Home-Based Care (*Hemservice*), Assisted Living Facilities (*Servicehus*), Nursing Homes (*Särskilda Boenden*), Respite Care (*Anhörigomsorg*), and Day Care Centers (*Dagverksamhet*).
- Decentralization: Municipalities (local governments) are responsible for organising and delivering care services, ensuring they are tailored to local needs. There is a high emphasis on quality care, with strict regulations and oversight mechanisms in place.
- Ageing-in-Place: The system prioritises allowing elderly individuals to remain in their homes for as long as possible, with support from community-based services.

Long-term care in Sweden is primarily funded through municipal taxes and government subsidies, ensuring universal access. However, while the system is heavily subsidised, users may pay a small fee based on their income and the type of service received. These fees are capped to ensure affordability. At the same time, the government regulates costs to maintain the sustainability of the funding mechanism. In 2014, Sweden dedicated 2.9 per cent of GDP to its long-term care system, 90 per cent of which was covered by county councils and municipalities and 5 per cent by the Government, leaving only 5 per cent to be borne by users (Schön and Heap, 2018).

Box 2. Japan's Mandatory Medical and Long-Term Care Insurance

The principles underlying Japan's statutory health insurance system programme are universality of coverage, financing through social insurance, freedom of choice by service users, and reliance on a private-sector driven market. In 2000, the government introduced a national compulsory Long-term Care Insurance (LCTI) administered by municipalities to provide care to those aged 65 and above, based on their respective care needs.

The system is part-funded by insurance premiums (mandatory for everyone aged 40 years and above), and part-funded by national and local taxation. Benefits cover services such as home care, respite care and domiciliary care. At points of service, users are expected to contribute a 10% co-payment towards the cost of care received.

A person's eligibility to claim the benefits is assessed based on their current cognitive, physical and mental status. Care needs assessment is done at home and/or at the facility where the elderly person is staying. To illustrate, an individual is classified as Level 1 if needing partial care for ADLs, where as a Level 5 individual are those who cannot perform any ADL without extensive assistance. Financial assessment is also carried out in parallel, where the elderly are divided into six income categories. Monthly benefits range from ¥49,700 ($340) to ¥358,400 ($2,440) of services from accredited providers to cover most items in an assisted living facility. Room and board costs must be paid by the residents themselves.

Box 3. Singapore's Elder Shield and CareShield Life

ElderShield is a long-term care insurance targeted at severe disability. It provides cash payouts for up to 72 months to help cover OOP expenses. Premiums are determined upon entrance to the scheme and remain fixed, payable annually until the policy anniversary following the insured's 65th birthday or upon a successful claim. Until 2019, all Singapore Citizens and Permanent Residents with MediSave Accounts were enrolled in ElderShield at the age of 40, unless they opted out. Auto-enrolments into ElderShield were discontinued in 2020, replaced by CareShield Life.

The Central Provident Fund's (CPF) MediSave balances can be used to pay ElderShield premiums. The system also allows family members to help pay the premium from their own MediSave account or to top up the account with cash. ElderShield payouts are approved via an MOH-accredited assessor, where the person must be verified to have lost his or her ability to carry out a minimum of three out of six of the BADLs.

CareShield Life automatically covers CPF members upon turning 30 years old, or from 1 October 2020, whichever is later, regardless of any pre-existing medical conditions and/or disability. Coverage is for life once the person completes paying all the premiums at age 67 (or 10 years after joining, whichever is later). Similar to Eldershield, family members can help pay premiums on a person's behalf. In addition, the government offers means-tested subsidies up to 30% of the premium, Participation Incentives and Additional Premium Support (APS) for eligible members.

On the other hand, a person can purchase supplement plans through one of three approved private insurers by paying an extra premium in cash or through their Medisave account. Additional benefits can take the form of higher monthly payouts, death benefit during claims period, rehabilitation benefit, dependant benefit, caregiver relief benefit and lower claims eligibility (for example, only two out of six ADLs).

Box 4. US Medicare and Long-term Care taxes

The US has a more complicated long-term care social protection framework, mainly represented by the Medicare programme. It is a health insurance programme for people 65 or older. However, exceptions are made for younger individuals with disability, End-Stage Renal Disease (ESRD), or ALS (also called Lou Gehrig's disease). The original Medicare programme consists of:

- Part A (Hospital Insurance), which helps cover inpatient care in hospitals, skilled nursing facility care, hospice care and home health care.
- Part B (Medical Insurance) which helps cover: services from doctors and other health care providers, outpatient care, home health care, durable medical equipment (like wheelchairs, walkers, hospital beds, and other equipment), many preventive services (like screenings, shots or vaccines, and yearly "wellness" visits).

Nearly everyone who works in the U.S. is required to pay Medicare taxes. In 2024, the Medicare tax rate is 1.45% for an employee and 1.45% for an employer, for a total of 2.9%. Under the Federal Insurance Contributions Act (FICA), employers withhold Medicare and Social Security taxes from employees' salaries. The Self-Employed Contributions Act (SECA) mandates that self-employed workers pay Medicare and Social Security tax as part of their self-employment tax. Medicare Parts B and the optional Part D (Drug Coverage) are funded by a combination of premiums (25 per cent of programme cost) and general revenues (75 per cent). These parts of Medicare also charge higher premiums to those with higher incomes, so that contributions are progressive.

To complement the Medicare benefits for long-term care, states can separately establish additional social insurance protection. Washington State enacted the Long-term Care Trust Act in 2019, which provides front-end coverage based on contributory social insurance (payroll tax). The programme pays beneficiaries assessed as needing functional supports, up to a fixed maximum amount over a beneficiary's lifetime. The programme which covers long-term care received at home, in the community, or in a facility, is funded by an employee contribution of 0.58 per cent of wages (without a cap). Independent contractors can opt into the programme by paying the same contribution rate on their earnings. Workers become eligible for benefits after a vesting period of a total of 10 years (without any interruption lasting five or more consecutive years) or three of the past six years.

Even in the US, Medicare covers minimal in-home care costs, with high bars for eligibility that are also subject to a fixed period of 'coverage' time. It also only pays for a limited number of medical or assistive devices, such as a wheelchair or home hospital bed, and this is a one-off allocation in the system. Medicaid and the Affordable Care Act provide some funds for in-home care for people at or near poverty, but eligibility and benefits are very restricted.

4.6 Prefunding

Funded social insurance systems must accumulate sufficient reserves before they can begin paying benefits. Prefunding through reserve funds can smooth out the effects of demographic ageing by limiting the amount of implicit debt that is passed on to future generations in the context of a pay-as-you-go (PAYGO) system. Other possible advantages of having pre-funded elements built into long-term care financing systems include smoothing over possible changes to benefits or contributory rates to meet the costs of care over time.

A number of countries that have implemented PAYGO-type social insurance-based systems to finance long-term care also have pre-funding mechanisms in place, although the amounts accumulated are equivalent to only a very limited fraction of expenditure. In Germany, the recent long-term care insurance reforms introduced an increase in the contribution rate. The resulting funds will be set aside in a buffer fund that will only be spent from 2035 onward, in order to level the effects of the country's demographic transition. Pre-funding options and reserve funds also offer ways to strengthen the intergenerational balance in financing long-term care. This is because current generations build up assets for future generations, while using revenue from taxes on consumption ensures that older people also contribute to the financing of long-term care needs.

5. Lessons for Malaysia

In designing a policy intervention, the central objective must be to guarantee the fundamental right to dignified care in old age through a combination of public provisioning, regulated private sector participation, and community-based support systems. Specifically, the social protection intervention should lead to:

- Improved access to long-term care services for those who need them
- Improved key outcomes (health and wellbeing) without destabilizing family finances
- Reduced public health services spending pressures by ensuring that elderly individuals receive the support they need to stay healthy and avoid costly medical crises

The proposed intervention must address both objective barriers (e.g., complex procedures) and subjective motives (e.g., lack of awareness) for non-participation. For older populations, simplified application processes are critical. Digital systems should account for low tech literacy among elderly users.

In the case of countries with limited resources, it is important to consider solutions for assessment of loss of function that will be implementable within the context of existing health and social care structures. Any social protection intervention must be financially sustainable, efficient to run and be structured in a manner that will garner broad public support, not just at the beginning of its implementation but over the long term.

The model calls for an integrated and multi-agency approach, leveraging the specific strengths of national institutions and existing infrastructure available. For example, EPF and *Kumpulan Wang Persaraan's (Diperbadankan)* (KWAP) well-respected effective management of beneficiaries, and assets, liquidity and long-term value of retiree's savings are critical to ensure the sustainability of proposed social insurance programme.

At the same time, Social Security Organisation's (SOCSO) coordination system and existing networks (for example approved clinics, Medical Board or Special Medical Board or the Appellate Medical Board) used in determining eligibility for Permanent Invalidity grants/pension and Constant Attendance Allowance, lends itself easily to the objective of the new elderly long-term care social insurance programme and spares the government from creating a separate network of facilities and assessment systems, which will be costly and redundant.

A tripartite institutional arrangement, which is founded on thorough considerations of operational and delivery efficiency, can serve as a viable path forward. This approach paves the way for adopting a sustainable long-term care social insurance model that reflects our society's commitment to intergenerational equity and human rights, ensuring that ageing populations can live with dignity and security.

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