



MONASH University

Financial catastrophe from non-communicable diseases: a case study on the economic burden of diabetes on households in Malaysia

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Master of Science (Health Systems and Public Policy)
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Abstract

The need for large out-of-pocket (OOP) health care payments can lead to catastrophic healthcare expenditures (CHE) that could impoverish families, driving a vicious cycle that spirals families towards poverty, where poverty in turn exposes people to behavioural risk factors for non-communicable diseases (NCD). The aim of the study was to investigate the economic burden for households living with NCD, using diabetes as a tracer disease.

We used a mixed methods study design, with a quantitative cost-of-illness study to capture the costs incurred in the management of diabetes and estimate its poverty impacts, followed by qualitative in-depth interviews and focus group discussions to explore socioeconomic impacts, household financial coping strategies and resource allocation. Data was collected using electronic data capture (EDC) from all households with diabetes in Sungai Segamat and Bekok sub-districts under the SEACO health and demographic surveillance site.

We found that the largest cost component was direct medical cost (63.4%), followed by direct non-medical cost (20.6%) and indirect cost (16.1%). Monthly average OOP expenditure was RM93.1 (SD14.2). The lowest income group spent the least overall (mean RM48.6, SD 12.6) compared to the richest income group (mean RM214.5, SD 67.9), but with a higher proportion of OOP spending from total household income (12.1% vs. 5.5% from the highest quintile). Overall CHE prevalence was 19.9%, with the lower income group incurring less catastrophic spending than richer households. Determinants of CHE include age (OR=1.057, 95% CI: 1.015 – 1.105, p-value=0.008), area of residence (Rural, OR=0.234, 95% CI; 0.102-0.538, p-value=0.001), ethnicity (Orang Asli, OR=14.067, 95% CI; 0.823 – 240.415, p-value=0.068; Indian, OR=6.811, 95% CI; 2.065 – 22.460, p value=0.002; Malay, OR=5.651, 95% CI; 2.388– 13.369, p-value=0.0001), and also hospitalisation (OR=3.056, 95% CI; 0.857-10.897, p-value=0.085). In terms of impoverishment, 7.4% of households were pushed below the poverty line (with a poverty gap of RM93) after paying OOP for diabetes. Households coping strategies included reliance on public health services, personal savings, borrowing money, surrendering personal assets, and receiving social support. The family institution was found to provide crucial support (emotional, financial, physical) for patients to manage their chronic condition in the long-term.

Overall, despite having a UHC-based healthcare system in Malaysia, the economic burden from out-of-pocket payment for managing NCD is still substantial, as households incurred catastrophic spending and faced impoverishment from managing their conditions.

Catastrophic healthcare spending is also seen shifting to households in higher income quintile groups, who opted for private care to avoid crowdedness and service quality issues in public healthcare under UHC. With the common practice of medical pluralism that utilizes both traditional and modern medicines particularly in Asian, African, and Pacific nations, the sustainable management of chronic care should also look at policies to integrate the two more cohesively particularly at the primary care setting towards enhancing UHC. Our study may provide insights to develop cost interventions and healthcare financing systems with enhanced financial risk protection and social protection towards effectively managing NCDs in the long-term.

Declaration

This thesis is an original work of my research and contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

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Publications during enrolment

1. Cheah JCH, Reidpath DD, Jahan NK, Allotey PA. Collecting poverty impact-related cost data on diabetes: an experience in using health and demographic surveillance systems and electronic data capture in Malaysia. *Health Policy and Planning*. 2020. (Submitted).
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3. Cheah JCH, Reidpath DD, Jahan NK, Allotey PA. The economic burden of diabetes: impacts and consequences to families living with diabetes in Malaysia. *Malaysian Journal of Medical and Health Sciences*. 2020. (Submitted).

Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes three original papers submitted to peer-reviewed journals. The core theme of the thesis is the economic burden of non-communicable disease on households. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Global Public Health unit of the Jeffrey Cheah School of Medicine and Health Sciences, Monash University Malaysia, under the supervision of Professor Dr. Daniel Reidpath, Dr. Nowrozy Kamar Jahan, and Professor Dr. Pascale Allotey.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of chapter 3,4, and 5 my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status (published, in press, accepted or returned for revision, submitted)	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash staff/student Y/N*
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**If no co-authors, leave fields blank*

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I hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

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List of abbreviations

AUD	Australian Dollar
BMI	Body mass index
CCM	Chronic Care Model
CHD	Coronary heart disease
CHE	Catastrophic healthcare expenditure
CKD	Chronic kidney disease
COI	Cost-of-illness
COPD	Chronic obstructive pulmonary disease
CPG	Clinical Practice Guideline
CVD	Cardiovascular disease
DALY	Disability-adjusted life years
EDC	Electronic Data Capture
EU	European Union
EUR	European Union Euro
FELDA	Federal Land Development Authority
FGD	Focus group discussion
FSDP	Functional Service Delivery Point
HCA	Human Capital Approach
HDSS	Health and demographic surveillance system
HIV/AIDS	Human immunodeficiency virus infection and acquired immune deficiency syndrome
ICCC	Innovative Care for Chronic Conditions
ID	International Dollar
IDF	International Diabetes Federation
IDI	In-depth interview
LMIC	Lower and middle-income country
MUHREC	Monash University Human Research Ethics Committee
NCD	Non-communicable diseases
NCD-CCS	Non-communicable disease country capacity survey
NHMS	National Health and Morbidity Survey
OECD	Organisation for Economic Cooperation and Development
OOP	Out-of-pocket

PDPA	Personal Data Protection Act
PHC	Primary healthcare
PL	Poverty line
RM	Ringgit Malaysia
SDG	Sustainable Development Goals
SEACO	Southeast Asia Community Observatory
SES	Social economic status
SMBG	Self-monitoring of blood glucose
SOCSSO	Social Security Organisation
T1DM	Type 1 diabetes
T2DM	Type 2 diabetes
TBCTA	Tuberculosis Coalition for Technical Assistance
UHC	Universal Health Coverage
UN	United Nation
USAID	United States Agency International Development
USD	United States Dollar
WHO	World Health Organisation

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CHAPTER 1.0: INTRODUCTION AND BACKGROUND

1.1 The global epidemiologic transition

Global disease patterns are shifting, with new epidemiological trends emerging due to industrialisation and globalisation, giving rise to non-communicable diseases (NCD) (1). NCDs are now fast-growing epidemics responsible for over half of the global burden of disease, and accounting for over 70% of the global mortality with more than three-quarters of NCD deaths occur in low- and middle-income countries (LMIC) (2).

Amongst NCDs, type 2 diabetes is one of the most prevalent. Globally it affects 425 million people, most markedly increased in LMICs, which are becoming the epicentre of the diabetes epidemic and accounts for over 80% of the diabetes population. South-East Asia and Western Pacific regions are now the epicentre of the diabetes crisis: 121 million people in China have diabetes, and India's diabetes population totals 74 million. The World Health Organization's (WHO) African, Middle Eastern and Northern African and South-East Asian regions are expected to face the highest upsurge in diabetes prevalence over the next 30 years. People from these regions develop diabetes earlier, get sicker, and die sooner than their counterparts in wealthier nations (3). This rapid increase implies growing morbidity and premature mortality, alongside significant rises in healthcare expenditures associated with the chronic nature of diabetes and the range of macrovascular and microvascular complications (3,4).

NCDs threaten to impose high, avoidable costs in human, social, and economic terms that impoverishes families, inflicts high cost burdens to health systems, and weakens national economies (3,5). The global proliferation of NCDs has caused them to be viewed as more than just a healthcare issue but rather as a development issue highlighted at the High-level Meeting of the 66th General Assembly of the United Nations (6).

The NCD epidemic is undermining poverty reduction efforts and diverting national resources that could otherwise be channeled to social and economic development (5). The economic cost of diabetes can be enormous. Global healthcare expenditure for diabetes was estimated to have reached United States Dollar (USD)727 billion in 2017, with the North American and Caribbean region spending over USD377 billion, while developing regions such as Southern-Central America, Southeast Asia, and Africa accounted for over USD50 billion (3).

1.2 Challenges in NCD management

NCDs are chronic and oftentimes a lifelong condition. People living with NCDs have multiple interactions with the health system over their lives for long-term care, and may require disability management that includes rehabilitation and palliative care (2). Patients with type 2 diabetes, for example, require constant medication and daily monitoring of blood glucose levels typically for life, more so if they have developed further diabetes-related complications. Exposure to common risk factors for NCDs are also often seen in people living in poverty, who are limited in their ability to practice behaviours that promote health due to the environments in which they live. The increased exposure increases the chance they will develop an NCD, and often be diagnosed at a later stage of the disease (after more damage has been done) than their wealthier counterparts (7).

High-income countries faced the challenges of NCDs brought about by increasingly affluent lifestyle changes many decades ago. During that period, the slower pace of population growth and economic progress enabled a host of public health measures at various levels to be implemented to mitigate the impacts of NCDs. However, as economic development, globalisation, and urbanisation continue to expand in both high-income and LMIC countries, demands on healthcare also continue to grow exponentially in tandem. Healthcare systems, medical resources, and available healthcare infrastructure are increasingly strained and faced difficulties coping with rising population demands (8). This situation is more so in LMICs where the double burden of communicable and non-communicable diseases further exacerbates the problem (9). Among developing countries, even nations that embed universal healthcare systems such as Malaysia are facing new challenges in managing NCDs. The focus on a biomedical approach to the diagnosis and treatment of NCDs has mostly ignored the broader implications of the chronicity of the diseases, and lacks the integrated response to a continuum of poor health within a population (10). The situation of Malaysia also exemplifies the asymmetric transition of healthcare, where the rapid shifts (both economic development and epidemiological) in context have not been adequately matched with a corresponding transition in the health system to address the current and future needs of the population (11).

1.3 The economic burden and poverty impacts of living with NCDs

NCDs impose substantial financial costs on the individual and households. Long-term care is resource-intensive and requires access to a wide range of health services and a continuous supply of medicines. A substantial volume of literature exists on the economic impact of NCDs on households in high-income countries (12–14), and increasing studies are examining the implications of NCDs in LMIC settings (7,15). At the household and individual level, studies in LMICs have shown that both direct and indirect costs of chronic conditions can be high, imposing catastrophic healthcare spending on patients and families (16–18) and reducing their capacity to spend in other areas (19).

Households with members living with NCDs need to reallocate household resources to cater to their additional healthcare needs, which can quickly drain household resources. There is little financial risk protection from governments or health insurance schemes in many LMICs and thus financial costs are borne mainly out-of-pocket (OOP) by households themselves rather than by governments or insurance schemes (20). The long-term cost of NCD treatments and self-monitoring can impose access barriers to lower-income groups who may not have the capacity to pay OOP for healthcare, particularly in health emergencies and disease complications that require hospitalisation and secondary care services. This is exacerbated by the expansion of private healthcare services particularly in LMIC settings, that drives larger OOP healthcare payments that pose threats to healthcare affordability and access, and impacts household economic stability and well-being (10,21).

The economic consequences of illness and healthcare use vary across households with different socioeconomic status (SES), as do households' ability to cope with the costs. Such consequences have implications for the inter-relationship between illness and poverty. There is empirical evidence that some households (including those in middle-income countries) succumb to poverty when faced with health care payments, especially when combined with the loss of income due to ill-health (9,22,23). This “medical poverty trap” phenomenon (24) is further compounded with the unlikely chances of a poor household ever moving out of poverty diminishes once confronted with illness-related costs (25).

1.4 Problem statement and study rationale

Affordability and access to NCD treatments remain as one of the key challenges facing national governments achieving Universal Health Coverage (UHC), a key enabler for the

goal of achieving good health outcomes for all, and a crucial part of global and national health and development frameworks (2). One of the key elements of UHC is to put in place a health financing system that protects the population against the financial hardships when accessing healthcare, which can place households at risk of catastrophic health expenditure (CHE) and impoverishment from medical expenses (26). For countries with UHC-based healthcare financing to minimise out-of-pocket direct medical costs for treatments in healthcare facilities, there are still aspects of hidden indirect costs related to the social aspect of chronicity which are often overlooked. Indirect costs and its complications for the society include loss of productivity due to morbidity, disability and mortality (22).

Experiences from high-income countries have shown that even in health systems recognised for having achieved UHC, many households still incur heavy economic burdens. The phenomenon is more pronounced in households with chronic conditions and those in low socioeconomic groups (27). The worsening prevalence of NCDs in LMICs, coupled with associated high costs for treatment and long-term management (requiring preventive, curative, and supportive care) raises the critical issue of health equity and adequacy of financial risk protection. Even for health systems with universal coverage, efforts to address NCDs are hampered by developmental priorities inclined towards increasing marketization of health services and expansion of private care.

1.5 Research aim and objectives

Research aim: To investigate the economic burden of households in managing and living with diabetes.

Specific objectives:

1. To investigate the household cost burden of both direct and indirect costs in managing diabetes.
2. To assess the poverty impacts of the cost burden of living with diabetes in terms of catastrophic healthcare expenditure and impoverishment.
3. To explore household financial coping strategies and aspects of decision making over the allocation of household resources.

Diabetes mellitus was selected as the tracer condition for the study for several reasons. Firstly, diabetes is a well-defined condition that is relatively easy to diagnose (28). Secondly, it is one of the most common NCDs globally with widespread prevalence, and is a critical cause of morbidity and mortality in both developed and developing countries (3). It is also one of the leading chronic diseases in Malaysia that has been consistently rising over the years, from a national adult prevalence of 8.3% in 1996 to 17.5% in 2015 (29,30). Thirdly, as a life-long chronic disease that entails a host of serious complications, diabetes imposes not only a heavy disease burden but also a high economic burden to governments, healthcare systems, and the individual (3,31). Lastly, diabetes was also found to be a suitable tracer condition that can provide insights on how health systems can respond to chronic disorders (32). Diabetes is also typically used in Malaysia as a tracer condition to examine the management of common NCDs (11).

In this thesis, I interplay with the terms “non-communicable diseases”, “chronic diseases”, and “chronic illness”. “Catastrophic expenditure”, “catastrophic spending”, and “catastrophic payments” are also interchangeably used.

1.6 Overview of the thesis

Chapter One provides the introduction and background of the research topic and the problem statement. The overall research aim and specific objectives of the study are outlined.

Chapter Two provides a review of the literature and elaborates in more detail the rising global prevalence of NCD and its associated health challenges and consequences to health systems and populations. The chapter reviews the evidence on the socioeconomic burden of NCDs at the individual and household level, the underlying aspects of poverty and health, the magnitude and types of health spending on NCDs, and assessments of the poverty impact of illnesses. The literature on how health systems response to NCD and its impacts is also explored, including financial protection mechanisms, universal health coverage, and NCD management models. Critical gaps found in the literature are identified, which highlights the significance of the study in bringing about new knowledge on the economic burden of NCDs and its impacts on households in low and middle countries.

Chapter Three describes the methodology used to address the study's aim and specific objectives. It details the overall study approach, the study design, descriptions of the study

setting and respondents, and specifics on how data is collected, managed, and analysed in both Phase 1 (quantitative) and Phase 2 (qualitative) of the study. The underlying conceptual framework is on the economic burden of disease on households is also detailed.

The findings of the study are presented in Chapter Four, where the quantitative results of Phase 1 are featured, including socio-demographic characteristics, healthcare utilization, economic consequences of managing diabetes, and social predictors of catastrophic healthcare expenditure. Phase 2 entails a focus group discussion analysis on health-seeking behaviour of people with diabetes and in-depth interviews of the social impact of the economic burden of NCDs and coping strategies of households.

The principal findings from Chapter Four are discussed in detail in Chapter Five, which is organised into three interrelated themes corresponding to the study objectives. Research implications of the study, alongside strengths and limitations, are also deliberated.

Chapter Six outlined the study conclusions and provided suggested areas and topics for future research.

CHAPTER 2.0: LITERATURE REVIEW

2.1 The global epidemiological transition

2.1.1 The shifting disease burden

Patterns of disease and mortality across the world are shifting as communicable disease rates decline, with the major burden of disease transitioning to NCDs. Global trends in premature death and disability from 1990 to 2017 showed a 41% decrease in communicable diseases and neonatal disorders, while NCDs on the other hand, experienced a surge of 40%.

Disability caused by metabolic conditions, such as type 2 diabetes, is on the increase and large disparities were found to persist in health and disease burden by sex and across all levels of socio-economic development. Correspondingly, leading risk factors for premature death and disability have also changed; from child wasting, short gestation for birth weight, and low birth weight for gestation in the 1990s to high blood pressure, increase smoking, and high blood sugar today (33).

The epidemiological transition is also fuelled by demographic changes, where mortality levels are seen to be declining at the beginning of the demographic transition. The concurrent rise of fertility levels and falling rates of communicable diseases led to an increase in population size. Consequently, there are more elderly people in the population who are more susceptible to chronic illness, thus accelerating the epidemiological transition (34).

For a middle-income country like Malaysia which has been experiencing rapid economic growth since the 1980s, such economic developments have also accelerated its demographic transition. The UN Population Projections predicts Malaysia to be fast reaching an aging population, with 7% of those aged 65 years or older to progress rapidly in this demographic transition to an 'aged' society (14% population age >65 years) in a short period of just 20 years (35). Comparatively, a similar demographic transition took 115 years in France, 45 years in the United Kingdom, and 69 years in the United States (35). The working-age population (aged 15–64 years) in Malaysia comprised of 70% of the population in 2015, but is forecasted to gradually decrease to 64% by 2050 and 56% by 2100. In contrast, the elderly population (aged ≥65 years) is expected to double by the year 2020 (from the current 6%), and by another 2-fold in 2080 (11). The aging population is met with the epidemiological transition of rising NCDs – of which age is a risk factor. This includes a broad range of

diseases such as cancer, metabolic diseases (particularly diabetes mellitus), cardiovascular disease, and chronic respiratory diseases. The demographic transition of an aging society will impose major implications on the epidemiological patterns in Malaysia, with notable impacts to the general population, the healthcare system, and economic development (36).

2.1.2 The nature of NCD - characteristics and risk factors

The most prominent characteristic of NCD is its chronic nature, which inflicts a long-term and often life-long disease condition. People living with NCDs have numerous and extended interactions with the health system, and oftentimes require disability management. With aging societies and improvements in healthcare, multi-morbidity is increasingly becoming the norm as people are living longer with their illnesses, and this creates surmounting challenges for health systems that are commonly configured for individual and acute diseases. Aside from the disease burden, it can also generate disproportionate financial pressures both on health systems (healthcare financing) as well as on the individual (37).

NCD risk can begin as early as in-utero (e.g. genetic factors), and through risk behaviours such as patterns of unhealthy diets that could start from early years of childhood and adolescence. At the other end of the life-course, older people are at increased risk of developing both NCDs and NCD-related disabilities (2). Essentially, driving forces that lead to the increase in NCDs are high levels of common, preventable risk factors. The four major NCDs (cardiovascular disease, cancer, chronic respiratory disease, and diabetes) are causally linked with four corresponding behavioural risk factors, namely tobacco use, physical inactivity, unhealthy diet, and harmful use of alcohol. These behaviours consequently lead to four key physiological changes in the body in the form of raised blood pressure, being overweight/obese, elevated blood lipids, and raised blood glucose. These behavioural risk factors are the leading causes of death and disability burden in nearly all countries, regardless of the level of economic development (38).

The causes and consequences of NCDs are complex as these diseases have multi-factorial causalities that go beyond the health sector. The four major NCD behavioural risk factors noted above are driven by a wide spectrum of sectors including finance, agriculture, trade, education and transportation (2). Social determinants of health factors can also play a critical role in the vulnerability to the risks and consequences of NCDs, including the physical

environment (e.g., physical access and availability of health services, poor living conditions) and socioeconomic factors (e.g., poverty, low education). Together with behavioural risk factors, non-modifiable individual factors such as age, sex and genetics contribute holistically towards the vigorous development of NCDs (39).

2.1.3 The rise of non-communicable diseases

NCDs accounted for an estimated 41 million (71%) of the 57 million worldwide deaths in 2016, and an even higher proportion (75%) of premature adult deaths (occurring in those aged 30–69 years), highlighting the fact that NCDs are no longer a sole problem for older populations. Four key major NCDs were responsible for these deaths - cardiovascular diseases (17.9 million deaths, 44% of all NCD deaths and 31% of all global deaths), cancers (9 million deaths, 22% of all NCD deaths and 16% of all global deaths), chronic respiratory diseases (3.8 million deaths, 9% of all NCD deaths and 7% of all global deaths), and diabetes (1.6 million deaths, 4% of all NCD deaths and 3% of all global deaths) (38).

NCDs were responsible for a substantial share of deaths in people of all ages, except the very young, with at least 25% of all deaths in every age group above 10 years, and for more than half of deaths in those above 40 years of age (40). In terms of death risk, the global probability of dying from one of the four main NCDs in 2016 was 18%, with a slightly higher risk for males (22%) than for females (15%) (38), particularly men in Central Asia and Eastern Europe which have one of the highest risks of NCD-related mortality. Recent figures from the NCD Countdown 2030 research collaboration (40) also revealed that women in 164 countries (88% of all countries worldwide) and men in 165 (89%) countries have a higher chance of dying prematurely from NCDs than from communicable, maternal, perinatal, and nutritional conditions combined.

2.1.3.1 Non-communicable diseases in low and middle-income countries

There is also a clear relationship between premature NCD mortality and country income levels. Globally, the lowest risks of NCD mortality were witnessed in high-income countries in Asia-Pacific, Western Europe, Australasia, and Canada (40). The highest risks of death from NCDs on the other hand, were seen in low-and-middle-income countries with a greater probability observed in the African (22%), Eastern Mediterranean (24%) and South-East Asian (23%) regions (38), almost double the rate for adults in high-income countries (12%). In the 2018 WHO global report on the status of NCDs (38), it was reported that in 2016, 78%

of all NCD deaths, and 85% of premature adult NCD -related deaths, occurred in low- and middle-income countries. Similarly, in high-income countries, the proportion of all NCD deaths that were premature was almost half of that of low-income (43%) and lower-middle-income (47%) countries. Further compounding the disease burden in many low- and middle-income countries is also the coexistence of established infectious disease alongside emerging NCD epidemics (41).

The fact that NCD mortality is higher in low-income and middle-income countries, and in people with lower socioeconomic status in high-income countries, (7,42,43) makes NCD an important obstacle to reducing global and national health inequalities (44). The four main behavioural risk factors are pervasive of economic transition, rapid urbanisation, and modern-day lifestyles, and they inflict the greatest impact on LMICs and the poor, mirroring the underlying socioeconomic determinants (5). When poverty exposes people to behavioural risk factors for NCDs, the economic burden of having chronic diseases in turn creates a downward spiral that also leads families towards poverty. Consequently, unless the NCD epidemic is aggressively tackled in the most heavily affected countries and communities, NCDs will continue to undermine the global goals to reduce poverty and providing universal health coverage to all.

2.1.3.2 Non-communicable diseases burden in Malaysia

The burden of disease in Malaysia has undergone a significant shift from communicable diseases and conditions affecting children and pregnant women to an epidemiological profile dominated by NCDs. In 1990s, 28.8% of disability-adjusted life years (DALYs) lost in Malaysia was due to communicable, maternal, neonatal, and nutritional diseases, but by 2017 this figure has fallen to more than half to 11.9%. On the other hand, the share of DALYs lost due to NCDs has increased from 60.2% to 88.8% (33). Data from the National Health and Morbidity Survey (NHMS) data from 1986, 1996, 2006, and 2015 showed that Malaysia's burden of NCDs is high and rapidly increasing. In the case of diabetes for example, both diagnosed and undiagnosed diabetes in adults aged 18 years or older, rose from 11.6% in 2006 to 17.5% in 2015 (36). These findings highlights the dual burden of disease in Malaysia.

The rapid economic and socio-cultural transitions in Malaysia, alongside aging and changing lifestyles, have also brought about increasing prevalence of NCD related health risks including dietary risks, physical inactivity, obesity, smoking, and heavy drinking. The NHMS

2015 reported that almost all (98.5%) adults aged 18 years and over in Malaysia have at least one of these five risks. Obesity and diabetes have grown to become inseparable where obesity is observed in 75% of Malaysians with type 2 diabetes (45). This high prevalence is a reflection of the low levels of physical activity (48% of Malaysian adults physically inactive) and unhealthy diets (90% of Malaysian adults have unhealthy diets) seen in the population. The prevalence of smoking among adults is 24%, which is comparable to that of the Organisation for Economic Co-operation and Development (OECD) countries. Nonetheless, studies based on NHMS data suggested that tobacco smoking is rising in children, especially among adolescent males. Heavy drinking has the lowest prevalence among health risks, with a relatively low 5% among Malaysian adults (36).

2.1.4 Non-communicable diseases in the global health agenda

With the growing awareness on NCD problems, the UN and WHO have been calling for action on the issue in several international fora. In the First Global Ministerial Conference on Healthy Lifestyles and Non-Communicable Disease Control (*Moscow Declaration 2011*) NCDs were highlighted as a major development challenge in the 21st century. Two high-level UN General Assembly meetings on NCDs were convened, which led to the UN Political Declaration. Multiple commitments were made under the UN declaration for NCD management and prevention amongst countries and donor agencies, which eventually led to the 25x25 commitment to adopt a set of risk factors and health system targets by WHO Member States to reduce 25% in premature NCD mortality by the year 2025 (46).

WHO Member States followed through on the global NCD commitments with tailored action plans for their own countries, most of which took guidance and support from global initiatives, particularly the Global Action Plan for Prevention and Control of NCDs (2013-2020). The Global Action Plan lays out comprehensive action strategies, proven interventions and health targets to guide Member States. It also consolidated existing policy instruments related to NCDs such as the Global Strategy on Diet Physical Activity and Health, the WHO Framework Convention on Tobacco Control, the Global Strategy to Reduce Harmful Use of Alcohol, and various WHO guidelines, including those on saturated and trans fats, sugars, and salt intake. The implementation progress of these instruments was then periodically reported to the United Nations General Assembly in 2010, 2011, and 2013, and 2017, together with individual country data published separately in the WHO NCD Progress Monitor (46).

The NCD agenda also made its way into the Sustainable Development Goals (SDG) in 2015. Under SDG target 3's call to "ensure healthy lives and promote well-being for all at all ages", a target to reduce one-third of premature NCD mortality by 2030 was specified. This is to be achieved through prevention and treatment of NCDs and the promotion of mental health and well-being (SDG target 3.4). SDG target 3.5 further bolsters the NCD reduction goal by calling for the strengthening of prevention and treatment of substance abuse and harmful use of alcohol". SDG target 3.a aims to "strengthen the implementation of the World Health Organization Framework Convention on Tobacco Control in all countries, as appropriate", whereas SDG target 3.b strives to "support for research and development of, and provide access to, vaccines and medicines, for the communicable and non-communicable diseases that primarily affect developing countries". Addition to the SDG goals is a further commitment pledged by countries to act on nutrition and unhealthy diet through the Decade of Action on Nutrition to reduce the consumption of sugars, sodium, and fats (47).

2.1.4.1 Challenges ahead

The abilities of countries to take action against NCDs vary widely. Despite the declarations and commitments made, progress has been limited and poor, even though many recommendations exist. Commitments pledged have failed to be translated into effective legislative measures, or in financing for NCD programmes, and this is consistent across the Member States. An example is the 2014 Outcome Document at the UN General Assembly which included four time-bound commitments to set up national NCD targets, strengthen health systems response, develop national plan, and reduce risk factors. A total of 83 countries had made poor or no progress even by 2017 (46). The lack of progress is also echoed and lamented by academics, who criticised the weak focus to mobilise real action to address NCDs (48).

Underlying reasons for the lack of action and implementation are varied and complex – ranging from the lack of political will and accountability, to unavailability of resources (workforce, funding) and technical capacity, and impacts of socioeconomic and market factors (46). Addressing these obstacles requires a holistic approach that encompasses the application of health-in-all-policies, whole-of-government approach, and cross-sectoral collaboration. Another essential component for the NCD agenda is the achievement of universal health coverage, whereby weak health systems, inadequate access, and lack of

prevention and health promotion services will further exacerbate the burden and impact of NCDs (46).

2.2 The economic burden of non-communicable diseases

2.2.1 The macroeconomic cost burden of non-communicable diseases

The impact of NCDs in populations extends beyond ill-health and mortality with large financial consequences. NCDs can dampen development and poverty reduction efforts in developing countries, as decreased labor force from short and long-term disabilities can reduce workforce productivity. Consequently, government revenues will fall in tandem and together with the rising needs of a disabled and aging population, with healthcare budgets and resources being pressed. Ultimately, this will escalate to a higher dependency ratio in the population that will lead to lower economic growth, deepening poverty, and greater inequity (49). In Sri Lanka, where life expectancy was found to increase at a faster rate than other developing countries, a World Bank study revealed that chronic illness causes workforce withdrawal from the labor market and lowers productivity (50).

Muka et al. (2015) (51) conducted an extensive systematic review on 153 studies that investigated the cost impact of six major NCDs – coronary heart disease (CHD), stroke, chronic obstructive pulmonary disease (COPD), major cancers, type 2 diabetes mellitus and chronic kidney disease (CKD) at the macroeconomic level (i.e., health-related costs, healthcare budgets and national income), and found that overall, there was a steady global increase in healthcare expenditure on NCDs over the years. In Germany for example, total health expenditure on major NCDs has been reported to have increased from 27% to 51 % (52). In the USA and Brazil, hospital expenditure on major NCDs doubled in a decade to an estimated USD200 billion (51). Cardiovascular diseases (including CHD) accounted for the highest expenditure level incurred in most countries, incurring 12% to 16.5% of the overall healthcare budget while the proportions spent on the other NCDs ranges from 0.7 to 7.4%. Cardiovascular diseases (CVD) accounted for 12% of all healthcare expenditures in the European Union (EU) with an estimated CVD-related hospital cost of USD151 billion in 2003 (53). CVD also imposed the highest NCDs cost in the USA, with annual CVD hospital costs reaching an estimated USD400 billion in 2008, doubling the USD195 billion in 1995 (54).

The International Diabetes Federation (IDF) estimation on the cost burden of diabetes is similarly profound. From 2007, total healthcare expenditure on diabetes for those aged 20-79 years has grown three times from USD232 billion to USD727 billion in 2017 (3). This burden is projected to grow and even under very conservative assumptions of only factoring the demographic changes alone, and the amount could reach USD776 billion by 2045, a further 7% growth. With regards to country-level estimates, and after adjusting for purchasing power differences, the highest expenditures on diabetes were observed in the United States with International Dollar (ID) 348 billion, followed by China, and Germany, with ID110 billion and ID42 billion respectively. In terms of region breakdowns, the North American and Caribbean region has the highest expenditure on diabetes of the seven IDF regions, with ID383 billion (52% of the total amount spent globally in 2017), followed by the European region with ID181 billion. Malaysia is a part of the Western Pacific group together with high population countries like China and Indonesia, which overall incurred an estimated expenditure of ID179 billion, 17% of the total global spending. The other four regions (Africa, South East Asia, Middle East and North Africa, South and Central America) spent significantly less on diabetes, despite being home to 27% of the cases, and were responsible only for 9% of the total spending (3).

NCDs have a large impact on national income, with estimated losses ranging from USD4.1 million due to cervical cancer in Malaysia, to USD71 billion in Germany and USD600 billion in the United States due to CHD (51). The enormity of the economic burden of NCD on macro-economic productivity was also explored by Chaker et al. (2015) (22), where productivity losses in high-income countries such as the United States ranged from USD88 million for COPD to upwards of USD20.9 billion for colon cancer. The team also found that people with diabetes, COPD, and survivors of breast and lung cancer faced a higher risk of reduced labor market participation, though in terms of NCD-related DALYs, large regional differences were found especially for cervical and lung cancer. Bradley et al. (2011) (55) demonstrated that, with the same level of colorectal cancer risk factors in the United States, the estimated economic losses due to colorectal cancer would rise from USD24.2 billion in 2011 to USD339 billion in 2020. A macro-economic simulation presented at the World Economic Forum in 2011 showed that over the next two decades, NCDs would lead to a staggering USD47 trillion cumulative output losses globally, representing 75% of global GDP (15).

Drivers of NCDs-related healthcare costs include the introduction of new technologies and changes in treatment practices (such as the volume of treatment services) that are found to be likely drivers of healthcare costs compared to aging or other factors (56). In the overall projected increase in health expenditure in Australia until 2032, the volume of treatment services had the largest contribution (Australian Dollar, AUD 81.3 billion), followed by population aging (AUD 37.8 billion) and population growth (AUD 34.4 billion). In a summary of evidence reporting the most of the anticipated increase in total health care spending in the USA, Aaron (2009) (57) attributed the cause to the growth of age-specific health care spending caused by population aging. However, although ageing may influence health care spending at a point in time, there is limited data available to project how the health care spending curve will evolve as life expectancy increases (57).

2.2.2 The cost burden of non-communicable diseases on households

Globally, an estimated 44 million households suffer severe financial hardship every year, and currently OOP healthcare payments are pushing 100 million people into poverty (58,59). Direct OOP represent more than 50% of total health expenditures in a large number of low and middle-income countries, but financial hardship is also experienced in richer OECD countries whereby approximately 4 million people in Greece, Hungary, Mexico, Poland, Portugal and the Republic of Korea reported different forms of financial hardship caused by OOP payment for healthcare (5). When households cannot pay for healthcare from their income, they will resort to utilise savings, borrow money, sell assets, cut food expenditures, take children out of school, or forego needed care - resulting in worse health, less productivity, and increased poverty due to loss of income (60).

The promulgation of NCDs further compounds the health-poverty predicament as long-term care is very resource-intensive, demanding access to a broad range of health services and continuous supply of drugs. Fundamentally both as a development and socioeconomic issue, NCD affects both rich and poor people but inflicting more ill-health and economic consequences on the poor in all countries. There has been an increasing focus to examine the implications of NCDs in low- and middle-income settings (7,15). In low-resource settings, families are driven to impoverishment due to treatments for NCDs such as cancer, diabetes, and cardiovascular disease. With low financial risk protection, financial costs are largely borne by households themselves rather than governments or insurance schemes (18,19).

The long-term cost of NCD treatments and self-monitoring can impose access barriers to lower-income groups who may not have the capacity to pay OOP for healthcare, particularly in health emergencies and secondary complications that require hospitalisation and secondary care services. Compounded by the growing rate of private healthcare particularly in LMIC settings (10,21), the need for large OOP health care payments becomes larger, threatening healthcare affordability and access, and impacts household economic stability and well-being.

In an extensive study by Wagner et al., (2011) (61) assessing the access to care and burden of healthcare expenditure of 286,803 households across 70 countries using the World Health Survey data, it was found that more than 90% of households had access to acute care, but less than half (41.9%) of the households with chronic condition reported to have healthcare access. Only 27% of households in low-income countries reported access to chronic care treatment, compared to 51% of households in high-income countries. Household healthcare expenditures were also reported to be lower in low-income countries, with median expenditure (tagged at 2002 US dollars) of USD5 as compared to USD69 in high-income countries. However, poor households in low-income countries with non-zero health care expenditures allocated 42% of overall expenditures to healthcare, in contrast to 11% in high-income countries. In addition, it was also found that one in four poor households in low-income countries incurred potentially catastrophic health care spending, with more than 40% of them used savings, borrowed money, or sold assets to pay for care. This could likely be linked to the weakness or non-existence of mechanisms to protect households financially from the burden of illness, particularly of NCDs, as highlighted in a review by Kankeu et al. (2013) (62). In relation, the findings by Xu et al. (2003) (63) also noted that increased availability of health services, while critical to improving health and healthcare access, also raised the proportion of households facing catastrophic expenditures. This scenario reflects the critical importance of having risk protection policies and mechanisms in place within health financing systems.

In terms of percentage of healthcare spending, households in LMICs on average spent within a range of 13%-32% out of total household expenditure in a month. A substantial portion of this expenditure was on medicine, with 41% of households in low-income countries and 61% of poor households in high middle-income countries devoted their entire healthcare spending to medicines (61). This finding is similar to those of van Doorslaer et al. (2006) (64), McIntyre et al. (2006) (17), and Saksena et al. (2010) (65), which further highlighted that

spending on medicines causes more households to face financial catastrophe. This is compounded in households with chronic illnesses where there is a long-term high reliance on pharmacotherapy to manage the disease (65).

2.2.2.1 Household direct and indirect costs on non-communicable diseases

Household OOP spending on health is typically categorised into direct and indirect costs, and the combination of both is used to estimate the economic burden of illness in cost-of-illness (COI) studies. Both costs may also vary considerably depending on the type of illness (17,66).

Direct costs

Direct costs are OOP expenditure incurred by individuals and households for the treatment, and are net of any reimbursement from insurance (62). They are further categorised into medical and non-medical costs, and the definition of these subcategories can vary in different studies. Direct medical costs are commonly associated with payments made for healthcare services, medicines (both western and traditional), laboratory services, medical supplies, and direct non-medical costs typically relate to the costs of transportation to healthcare facilities, accommodation for accompanying the household members, special diets (e.g., for people with diabetes), special foods linking to traditional medicine beliefs, as well as nutritional supplements (17,62,67).

Direct costs are known to impose catastrophic costs to households, largely through spending on medication (61,68) and inpatient care (65,69). In the study by McIntyre et al. (2006) (17) on the economic burden of health in LMICs, the authors found the direct costs for health ranged from 2.5%-16% of total household expenditure. For NCDs, this cost can be much more imposing due to the need for long-term medication, and frequent use of healthcare services such as dialysis or wound dressing for sores due to complications of diabetes (70). Muka et al.'s (2015) (51) review of the costs of major NCDs globally found that the highest direct attributable costs were observed for cancer (up to USD190,032 per patient/year (71)), followed by chronic kidney disease (CKD) (up to USD33,585 per patient/year (72)), chronic obstructive pulmonary disease (COPD) (up to USD22,183 per patient/year (73)), cardiovascular disease (CVD) (up to USD21,152 per patient/year (73)) and diabetes mellitus (up to USD12,246 per patient/year (73)). The authors also found that inpatient costs are the main source of direct costs for NCDs. Inpatient costs accounted for 47-58 % of total direct

costs of COPD (74) and 63 % of total direct costs for diabetes (75). Hospital costs represent the main driver of stroke expenditure, accounting for 90 % (76) of total direct costs. Hospitalization charges represented the greatest economic burden (55 %) for the management of colorectal cancer, followed by medical purchases (24 %) and outpatient care (18%) (77).

Indirect costs

Indirect costs mainly include time and productivity loss by patients and caregivers because of their illness as well as income lost by patients and family members. Although some studies also include intangible costs of pain and suffering, usually in the form of quality of life measures, this category of costs is often omitted because of the difficulty in accurately quantifying it in monetary terms. In such a case, studies typically note that intangible costs have been omitted (78). Nonetheless, indirect cost is recognised as a critical component to estimate the total economic burden of diseases given the significance of productivity and income loss both at the micro-and macroeconomic levels. Indirect costs usually account for a large proportion of total costs in most COI studies (79,80), and some have estimated indirect costs to exceed direct costs, which can range from 2 to 3.6 times in LMICs (81–83).

Available studies in Malaysia have focused on evaluating the costs of chronic diseases by measuring direct costs, with the emphasis on the cost burden on the government/provider and scarcely on indirect costs of household (84–88). Households that include people with chronic illness need to rebalance household contributions to account for illness-related changes in employment, and redistribute resources relative to increased needs of members with NCDs.

In terms of major NCDs, studies have found that mean annual estimated indirect costs for NCDs patients were highest for cancer and diabetes, with estimates up to USD24,740 (89) and USD23,418 (90) respectively. Mean annual indirect costs for breast cancer varied extensively, from USD2,109 (91) to USD24,740 (89), and similarly for diabetes, where estimated indirect annual costs ranged from as low as USD104 in Serbia (92) to USD7,797 in China (75). For COPD, the lowest indirect cost was reported in Japan with an average estimate of USD326 (93), and one of the highest was reported in the United States (USD3,393 (94)).

Nonetheless, measuring economic burden based on data on direct and indirect costs alone may not be sufficient to capture the full degree of household economic burden. This is notably so for the households in LMICs, where coping strategies to pay for OOP for

healthcare involve some form of borrowing or selling off assets. Adhikari et al. (2009) (95) measured the impact of health care payments incurred by households for an episode of visceral leishmaniasis (Kala-azar), the magnitude and distribution of health costs in terms of catastrophic and impoverishment impact, and the economic consequences of coping mechanisms. The authors found that aside from the direct and indirect costs of paying for treatments, coping mechanisms such as loans have a more severe impact on resource-poor households than the actual OOP payments they incur. Under the burden of loan repayments, a visceral leishmaniasis-affected household can easily fall into a poverty trap, escape from which is unlikely with the effort at the household level alone.

This finding resonates with the arguments raised by some authors (96) that the effect of mechanisms used to cope with health care payments is also important. Having a sustained state of indebtedness are likely to impoverish households, and this is very likely so for chronic conditions. Capturing data on household indebtedness is thus also an important aspect to take into consideration to assess the full impact of household economic burden.

2.2.2.2 Costs of non-communicable diseases according to disease severity and co-morbidity

Overall healthcare costs secondary to NCDs are found to increase in accordance to the severity of the disease, years lived with the condition, and co-morbidity (51). For example in patients with severe stroke, a 40 % greater increase in costs is seen compared to those with mild strokes (97). Among cancer patients, given the same stage of diagnosis, those with one, two or three co-morbidities experienced increased costs of USD3,737, USD4,188 and USD10,442 respectively (98). Costs for a patient with diabetes was also observed to have tripled between the first and seventh year after diagnosis (99). Increases in treatment costs of breast cancer by stage were also reported, with approximately 52 % higher treatment costs for stage II as compared to stage 0 (100). Similarly, a USD29,859 increase was seen with cancer progression from stages I to IV (77). Patients with co-existence of COPD and CVD reported having 135 % higher annual care costs compared with patients without CVD, whereas COPD related total costs were noted to be 38 % higher (101). Some studies reported lifetime healthcare costs of NCDs demonstrated that initial and terminal cares are the most costly (71,102,103).

In the cost estimation conducted by Cortaredona et al. (2017) (104), the authors demonstrated the pattern of super-additive costs in cases of disease interaction whereby the costs for ten selected chronic diseases were found to be substantially higher for individuals with co-morbidity (compared to similar groups without co-morbidity). They also conducted a simulation of a preventive action for diabetes (where prevalence is hypothetically set at 0%) and found that the health system as a whole can save up to EUR6 billion in direct effects and EUR1 billion in indirect effects if diabetes is eliminated. This also includes the extra costs that diabetes may generate through its interaction with other diseases, and represents more than 15% of the cost-of-diabetes valuation. The authors concluded that the potential benefits of any preventive action against chronic diseases are generally underestimated and that co-morbidities should be taken into account in cost-of-illness analyses (104).

2.2.2.3 Healthcare spending by demographic characteristics

Healthcare spending and the risk of CHE are also associated with demographic compositions of households. Certain types of households are known to be more vulnerable irrespective of the country they reside. These include households with members who are elderly, children under five years of age, disabled, and who are poor. These households are inherently disadvantaged in many systems as their health needs are likely to be the greatest, but living with the most constrained resources. This is illustrated in the study by Saksena et al. (2010) (65), where it was found that households with children or elderly members tend to face a slightly higher burden of total OOP though the difference is not very large in most countries. Elderly members also appeared to have a higher burden from spending on medicines. On the other hand, the authors also found that households with more educated heads were less likely to face catastrophic expenditures. This may be related to their higher levels of education and better job with high salary, hence more educated households tend to have better management of household budgets as well as better networks of accessing funds during the times of need.

Studies on economic burden of diseases in LMICs have devoted little attention to gender differences (17). Nonetheless, there is evidence that indirect costs are often greater when women are sick (105). For women, more hours of productive time are lost largely due to the longer hours they work relative to men, particularly when household maintenance activities are included (81). This is also echoed in the Saksena et al.'s (2010) (65) study, where the sex of the household head was found also to play a role. Households with female heads tend to

have a slightly higher overall burden, and this accounts for OOP for outpatient treatment, medicines, and also inpatient OOP spending.

For chronic diseases such as diabetes, the IDF Diabetes Atlas (2017) (3) reported that the age group with the largest expenditure (USD 127 billion) on people with diabetes was 60-69 years, with men being 7% higher than women in the same age group. This was followed by those age 70-79 years and 50-59 years, but in these age groups, women presented higher expenditure than men (USD86 vs. 78 billion, and USD84 vs.76 billion respectively). The underlying reasons noted by IDF for the large expenditure observed in the age group of 60-69 are costs associated with the frequency of diabetes-related complications in later stages of life. Nonetheless, IDF also noted that the observation of women in earlier stages of life experiencing higher healthcare expenditure than men is a pattern not exclusive to diabetes, but is also seen in healthcare in general.

2.3 The economic impact of illness

2.3.1 Household financial risk protection from the cost of illness

Equitable access to quality essential health and nutrition services allows the poor to protect and maintain their health, to work more and more productively, and to increase their earnings. It allows for family resources to be sufficiently allocated to enhance the cognitive capacities and educational attainment of children in lower-income families, to potentially improve their future income and close the income inequality gap over time (59). The economic effect of ill health, and more so of chronic conditions is evident at both the household and country levels, and will disproportionately affect the poor and vulnerable populations while slowing national development. With NCDs, escaping poverty will become more difficult for households due to the needs of long-term care, and poverty reduction efforts will be muted if NCDs are not effectively addressed (106).

Financial risk protection from the costs of illness is a major function of health care systems. It refers to the degree to which a health system enables the population to access all needed quality health services without financial hardship (107). OOP spending is often used as an indicator to measure financial protection (108), and it is widely acknowledged that OOP such as user fees, is the most regressive form of health sector financing that places a disproportionate burden on the poorest and most vulnerable communities (26). The element

of health inequality then rises as the rich to pay the same amount as the poor for any particular service. There are also many instances in LMICs where socioeconomic background is also not the only basis for inequality. Even when user fees are charged, patriarchal cultures of some communities dictate that women and girls often only receive healthcare treatment after the head of households (109).

Any rate or types of charges, even relatively low, can discourage households from using healthcare services or push people to impoverishment. Cohen and Dupas (2010) (110) conducted a study in Kenya that showed that even by introducing a USD0.75 charge for a previously free insecticide-treated bed net decreased demand by 75%, and imposing of a small charge for de-worming drugs has led to reductions in uptakes by 80% (111). Direct payments may also lead to the practice of inappropriate self-treatment and self-medication (e.g., use of expired drugs, self-prescribing partial doses) or postponing health visits and check ups. In addition, OOP may also cause inefficient and inequitable use of healthcare resources as those who can pay may overuse and those who cannot tend to underuse or avoid healthcare altogether (112). Direct payments also do not have to be official to restrict access. Informal payments are found in many countries around the world (113–115), and they prevent access to needed care as well as introducing additional anxiety for patients and their families given the unpredictable nature of unofficial rates. In Armenia, for example, only about 10% of direct payments at hospitals were official user charges levied by government facilities, while the remaining majority portion consists of unofficial or informal payments (116).

The 2010 World Health Report (26) documented the widespread and high reliance on direct payments to be due to several factors. Firstly, the reluctance of governments to allocate higher healthcare spending or unaware of their capacity to expand pooling systems leaves a gap between what services are necessary to cover against what the government can provide. Ultimately, health workers will try to provide services with limited medical supplies, which may lead to informal payments. In addressing this shortcoming, many governments have opted to implement formal user fees or co-payments to pay for health workers' salaries and buy more medicines and medical supplies.

The second factor is that direct payments provide a stable stream of funding in cases where government funding is irregular or non-existent. In the Democratic Republic of the Congo,

geographical remoteness and the occurrence of sporadic internal conflicts and natural disasters have known to isolate many parts of the country. The absence of government support and control, especially in the eastern provinces, have made direct payment from patients as the default method (aside from external aid) to keep the services running, at least at some level (117). In conflict zones, direct payments have evolved to become the fundamental method to finance healthcare in the aftermath of war crises.

Thirdly, during economic recessions, direct payments can seem to be an attractive option as part of structural adjustment policies recommended by international institutions such as the International Monetary Fund to restrict government spending (118). Charging fees were touted to be an effective solution to generate additional revenue, reduce overuse, and encourage low charges and costs. A prime example is The 1987 Bamako Initiative, whereby African health ministers agreed to the notion of imposing direct payments for chronically under-resourced public health sector to fund medical supplies and healthcare workers (119). While the availability of services and medicines have improved in some contexts, it was also found that direct payments have created barriers to access healthcare amongst the poor (120–122). Finally, many countries deliberately impose some form of direct payment or co-payment as part of its cost-containment strategies to curb the overuse of health services. This is considered by many as an ineffective cost-controlling mechanism that generates larger health inequities as it fundamentally deters the access of vulnerable populations who needed healthcare the most (26).

Expanding financial protection immediately reduces the chance that people will fall into poverty by paying for health services OOP (59). Scrutinising the distribution of the financial burden of healthcare costs – i.e. who is paying for healthcare – is noted to be critical to analyse the equity in financing and financial risk protection (123). In a study that disaggregated OOPs by socioeconomic status, it was found that in all 51 countries studied, the economic burden from healthcare payments falls disproportionately on the poorest communities (65). Thus, the swift implementation of any strategies that reduce out-of-pocket payments, especially among the poor and vulnerable stands to reap substantial benefits for poverty reduction. Positive externalities from having financial protection may also lead to reducing poverty and inequities while also spurring economic growth, as people would not tend to forego health care nor need to sell assets or borrow to meet health payments. When

healthcare costs are adequately covered, spending and investments can be allocated to other areas.

2.3.1.1 Financial risk protection - health system context

The concept of financial risk protection originated from economics and insurance theory (124–126), and these disciplines place importance on explicitly understanding the adverse impacts of uncertainty and its economic value. Current indicators used to measure financial risk protection (i.e., catastrophic healthcare expenditure and impoverishment) primarily capture the poverty impacts due to lack of financial protection, but may not adequately capture the adverse effects of uncertainty (127).

The tenet of universal health coverage on the other hand, emphasizes on the quality healthcare services made available and affordable for all. It also highlights concerns of the adverse impact of uncertainty, i.e. the risks of inaccessibility or unavailability in times of need. One key gap in the inter-linkages between financial risk protection and universal health coverage is whether non-use of health services (due to financial barriers) is sufficiently captured in current measures (127).

Nonetheless, the synergy of the concepts between financial risk protection and universal coverage is strong. The distinctive position of financial risk protection as an interface between health systems and other dimensions of health and well-being has rendered it a health system goal in itself. It also portrays an integral component of UHC to develop health systems that do not impinge on other social sectors, in that accessing healthcare does not result in forgoing other socioeconomic or health needs such as education opportunities or good nutrition (26).

2.3.1.2 Inequalities in financial risk protection

Equity is a pivotal concern of UHC, and thus there is an important consideration of those who are protected from financial distress from OOP and those who are not. Household income and expenditure are the key components for financial risk protection indicators (e.g., catastrophic healthcare expenditure), and hence are reflective of household inequalities (127,128).

Increasingly, more studies are now being conducted to further examine the economic hardship imposed on different sub-population groups (e.g. gender, age) by disaggregating indicators such as wealth and socioeconomic characteristics (127). Nonetheless, the

measurements of inequalities are not always so apparent; for example, income was also found to be negatively correlated with financial hardship (129,130), while there are also studies which showed the poorest quintile having the heaviest financial burden than the rest of the population. This is likely due to access barrier to healthcare or the fact that the household is already living in poverty (131). Moreover, incidences of financial catastrophe can sometimes be seen in higher income quintiles as they have higher spending power to access more expensive treatment options and private care (132).

Across different countries, the socioeconomic stratifiers used may vary based on the underlying causes of inequalities, but those based on wealth, socioeconomic status, education, ethnicity, and households composition will likely be similarly important (127). Multivariate analyses of these stratifiers have shown their association with increased incidence and severity of financial burden across different settings (65,129,133,134). For countries which are implementing changes to their healthcare financing mechanism and policies, understanding the distribution of the financial burden across different sub-population will be crucial, and issues related to the monitoring of inequalities in financial risk protection merit more attention.

2.3.2 Poverty impacts of out-of-pocket payment for health

In general, the higher OOPs share of total health expenditure in a country, the greater the incidence of catastrophic spending and consequent impoverishment (26). Incidences of financial catastrophe for direct healthcare payments can escalate to as high as 11% per year at a national level, and an average of more than 2% across low-income countries (26). In addition to higher incidences of catastrophic healthcare expenditure amongst the poor, bigger families with children or elderly and households with disabled members are also more likely to experience catastrophic health expenditures (135,136).

The WHO has estimated that a direct OOP limit of 15-20% of total health expenditures are likely to make incidences of financial catastrophe and impoverishment negligible, but suggested for lower-income countries to set a lower, more realistic goals (26). Countries in South East Asia for instance, have aimed for a target limit of 30-40% (137). Countries with particularly high OOP included Bangladesh, Cambodia, Vietnam, and even China (26). In the example of Cambodia, an average of 5.6% of the overall household budget was spent on

health monthly, pushing 4% of families below the poverty line (138). Countries with UHC-based systems have shown extraordinary resilience to financial hardship from healthcare OOP, with Sri Lanka, for example, maintaining OOPs below 50% of total health expenditures with minimal impact on catastrophic spending and poverty (139). Similarly, Thailand and Malaysia's capacity to contain the catastrophic and impoverishing consequences of OOPs is also notable, though vulnerable populations such as minority ethnic groups and non-citizen inhabitants (e.g., migrants, refugees) do not receive similar level of protection and fall through existing safety nets (140).

2.3.2.1 The economic burden and poverty impacts on households living with non-communicable diseases

Families with breadwinners who have NCDs are more susceptible to the poverty impacts of both short and long-term chronic disease management, particularly for single-income households or having to care for disabled family members. Disabilities caused by NCDs are known to impact women and children particularly, as it can result in lost opportunities for schooling and loss of main sustenance and income for the family (5).

Studies from India have shown that OOP spending for NCD contributed significantly to poverty (141,142). Neuhann et al. (2001) (142) estimated that the cost of caring for cancer and cardiovascular disease had caused catastrophic healthcare spending for 1.4 million to 2 million Indians, and pushed 600,000 to 800,000 people to impoverishment. The odds of incurring catastrophic hospitalization expenditures among households with affected individuals were also found to be nearly 160% greater for cancer and 30% greater for cardiovascular disease compared to admissions due to communicable diseases (143). In India, the duration for hospitalization ranged from 50 to 70 days for some NCDs, greater than other conditions. For outpatient illnesses, the days when people could not work were also greater for some NCDs than for other conditions (143).

A review of medicine prices in multi-country studies found that the purchase of one month's supply of at least one cardiovascular medicine in the public sector can cost an average of two to eight days of wages (144). In developing countries, a one-month combination treatment for coronary heart disease costs an average of 18.4 days wages in Malawi, 6.1 days wages in Nepal, and 5.1 days wages in Brazil. Costs for combination treatment for chronic respiratory conditions such as asthma are lower, but still amounted to an average of 9.2 days wages in

Malawi and 1.3 days wages in Bangladesh (145). For diabetes medicines, it cost an average of one day's wages for a month's supply for at least one type of medicine (146). In India, paying for diabetes care can cost low-income households up to one-third of their household incomes (147), while in Tanzania, the cost can escalate to a quarter of the national minimum wage (148).

Rijal et al. (2018) (149) reviewed the economic impact of diabetes in South Asia, and found that households with diabetes faced higher (more than twice) risk of spending, and have a 10% total expenditure on health more than households without diabetes. Distress financing was found to be the common financing mechanism for rural households, where the authors found that diabetes-affected households are 13 times more likely to sell assets and 21 times more likely to seek or received financial assistance from family or friends. In Bangladesh, 5.25% of households fell into poverty due to payment for diabetes care and poor households fall short of the poverty line by 1.1 cents (150). The cost of diabetic treatment can have significant variation between private and public hospitals in India (USD6,602 vs. USD1,320) (151), with inpatient diabetes care amounting to 17% of the household expenditure (151,152). In China, Gwatidzo et al. (2017) (153) found that almost 17% of people with diabetes experienced catastrophic healthcare expenditure on medications alone. Smith-spangler et al. (2012) (154) assessed the financial impact of diabetes on individuals in 35 countries using the World Health Survey data and estimated that people with diabetes have a 17.8% higher risk than those without diabetes in incurring catastrophic spending.

2.3.3 Assessing the poverty impacts of financial hardship

The considerable reliance on OOP payment to finance the healthcare system in many LMICs necessitates an accurate and reliable assessment of financial hardship imposed on households. Effective measurement and monitoring are therefore necessary to develop the proper design of health financing systems, and it has become an important issue for research across countries at all income levels (58,63,64,155,156). The numerous methods of measuring financial risk protection directly reflect the trade-offs people make between paying for the health services they need, and paying for other necessities such as food and basic education (157,158).

However, considerable debate has continuously been ongoing between capturing the value of financial risk protection in itself, and the impact of the lack of financial protection. Both concepts can be distinctive, but are commonly placed under the heading of financial risk protection (159). These discussions are particularly relevant as UHC gains prominence as an essential health systems' goal (2,46,160,161). Over the last decade, four indicators of financial risk protection have assumed prominence, and they are associated with the two concepts of financial hardship due to OOP payments; CHE and impoverishment (155).

2.3.3.1 Assessing catastrophic healthcare expenditure due to out-of-pocket healthcare payments

Proper measurement of CHE is crucial for identifying households experiencing financial catastrophe due to illness. Examining CHE to evaluate the health system records previously to Berki (1986) (126), who defined it as an expenditure which constitutes a large part of household budget that affects household's ability to maintain the minimum standard of living. The underlying notion is that if healthcare spending constitutes a large portion out the household budget, it will then invariably affect the consumption of other household items. Russell (1996) (162) also contextualised this as the opportunity cost of healthcare spending. Subsequent studies until today have maintained this view of CHE, with the additions of varying measures of catastrophic expenditure (127,129).

Catastrophic health expenditure occurs when a household's OOP payments are excessive relative to available household resources to the extent of foregoing the consumption of other necessary goods and services (63). The application of this concept though, varies based on how the available resources are calculated and how much of these are consumed to the point of reaching catastrophic expenditure. The former is defined as health spending exceeding a share of either total expenditure, or non-food expenditure, or expenditure net of basic food needs, while the latter relates to the threshold at which health payments become catastrophic, which commonly ranges from 10% to 40% (63,163).

There are two indicators that measure the concept of catastrophic expenditures. The first relates to the incidence of catastrophic health expenditures, i.e., a headcount indicator calculating the proportion of households in a population with health expenditures exceed the threshold point. The second indicator, catastrophic overshoot, which captures the extent of health expenditure exceeding the threshold, is lesser used (155). A key advantage of the

concept of catastrophe is that its measurement is across the entire population, reflecting the fact that financial hardship can occur in any population group. Furthermore, given that the concept is focused on health and based on a pre-established framework, the likelihood of political or societal manipulation of the thresholds or the denominator is arguably none (127).

CHE threshold level

Several important considerations need to be factored in when choosing the catastrophic expenditure threshold. For instance, a relatively high threshold such as 40% increases the likelihood that households incurring discretionary spending on health (e.g., private hospital admissions) are not classified as incurring catastrophic expenditures. Some studies have used a lower threshold (applied against total household consumption) and some assessed the sensitivity of financial catastrophe to several different threshold levels (164). There are also approaches that varied the threshold so that it increases as a function of income (165).

Various methods are found in the literature to quantify catastrophic payments. Some studies (67,127,163) noted that an OOP payment greater than 10% of total household consumption is catastrophic, while Xu et al. (2003) (63) defined the total OOP expenditure equalling or exceeding 40% of non-subsistence household expenditure (i.e. household capacity to pay) as catastrophic. The more widely used method for measuring the incidence and intensity of catastrophic payments is the methodology of Xu et al. (2006) (135) and van Doorslaer et al. (2006) (64), who used a threshold range from 5% to 25% of household income.

There is no consensus regarding the CHE threshold percentage, and it is recognized that the threshold is to some extent arbitrary, as a relatively wealthy household may be able to cope with health care costs exceeding 40% of non-food expenditure, whereas a poor household may face financial catastrophe (165). A key factor lies in the provision of a consistent basis for assessing the financial consequences for households' use of a health service relative to their resources. This standard measure is independent of any disease or local financial context, and therefore facilitates documentation, interpretation and comparison of findings across different diseases, settings and regions. Nonetheless, there are also arguments that any health expenditure that deters households from consumption of their basic needs is catastrophic and may not essentially amount to high healthcare payments in real terms (96).

Estimations of catastrophic payments found in the literature are based on medical costs (23,63). Because of this, such estimations tend to underestimate the magnitude of catastrophic payment. Adhikari et al.'s (2009) (95) study measured different levels of catastrophic incidences (5%, 10%, 15%, 25%) resulting from various cost components (total direct cost, total medical and travel cost, and only medical cost), and using these different components, the study has shown that the magnitude of underestimation and distribution of such payments would be in the order of 15–22% if medical costs alone were used.

Of equal importance to measuring the level of household OOP expenditure is the measurement of inequalities in facing such expenditures. The common approach to examine catastrophic expenditure is using the same threshold across all socioeconomic groups. Under this approach, poorer households would visibly have a greater need for financial protection compared to richer ones given the same threshold level. Undoubtedly, the most disastrous consequences of catastrophic healthcare expenditure occur for the poor, as they may be forced to sacrifice other living necessities to access healthcare (163). When some households spend a catastrophically high share of their capacity to pay on health care, an extreme horizontal inequality will occur (63). Similar to the vertical equity principle, a higher expenditure proportion would be required to designate richer households as having experienced a catastrophic event.

Expenditure on healthcare, even at low levels, can tip a household to poverty depending on the household's income (166). This risk rises in user fee/OOP-dominated settings (64,167), and highlights the need to identify context-specific levels of expenditure that can lead to financial catastrophe. In the study by Onoka et al. (2011) (168), the authors argued that a fixed threshold level are likely to underestimate the degree of inequality in the distribution of catastrophe between socioeconomic groups. The authors used a novel set of variable thresholds in their study, in which the levels for various socio-economic status (SES) groups were weighted by the ratio of household expenditure on food. The study population was divided into five quintiles and measured with different levels of threshold (10%, 20%, and 40%). Bhojani et al. (2012) (169) also used different threshold levels of 5%, 10%, 15%, and 20% to assess the severity of different quintiles of socioeconomic groups.

CHE denominators

Oftentimes a household's non-food expenditure is chosen as the denominator. While the choice for the denominator may be based on different assumptions and household priorities, the underlying notion for a non-food expenditure is the rationale that food is considered a critical basic need with a large expense that should not be part of the resources available for healthcare (128,168). The WHO has taken this concept in its standard methodology to estimate catastrophic health expenditure, which calculates a household's available resources as being expenditure net of basic food spending (i.e., household's capacity to pay) (63). With the limited economies of scale from its consumption, it would also mean that such expenditure is sensitive to household size and access to cash, and the level of consumption can also reflect the household's level of access to cash (168).

In developing countries, the use of household consumption expenditure is noted as the preferred measure of living standards (158,163), particularly in rural areas where subsistence economy made it difficult to determine the household income (170). In Bhojani et al.'s (2012) (169) study, the authors also argued that the use of household income instead of consumption expenditure for the calculation of catastrophic healthcare expenditure may lead to the overestimation of the household's capacity to pay and an underestimation of the true catastrophic incidence.

Some studies prefer to use a household's total expenditure as the denominator. While the calculations are more straightforward, economic theory suggests that richer households tend to spend more on health as they are able to. As such, the latter measure can be seen as pro-rich, particularly if the threshold for financial catastrophe is set relatively low (127).

2.3.3.2 Assessing impoverishment due to out-of-pocket healthcare payments

The second concept of financial risk protection relates to poverty, in that whether OOP payments are pushing households into and further below the poverty line - the threshold of monthly income for the most minimum and basic standard of living (171). Households are impoverished if they fall below the poverty line after incurring healthcare expenditures, and expenditure in this context can also include self-produced goods such as food. Similar the threshold level of measuring catastrophic healthcare expenditures, measurement of impoverishment also involved establishing a threshold, which in this case is the poverty line. The decision to use an absolute poverty line or a relative one is largely a value-based decision (127). An example of an absolute poverty line is the World Bank international poverty

threshold of USD 1.9 per day and national poverty lines, both of which are calculated based on basic subsistence needs. Relative poverty lines on the other hand, are based on the distribution of a specific measure of basic subsistence needs such as basic food expenditure.

A key advantage of using an absolute poverty line is the ease of monitoring the level of poverty over time, while an apparent disadvantage is its susceptibility to manipulation by political and societal agents. A relative poverty line does not have the same limitation and can account for different expenditure patterns, but it also moves in relation to the distribution of poverty in any country, making monitoring challenging (172). Countries assessing their own progress towards universal health coverage can use locally defined poverty lines, though for the purposes of international comparisons, it is also useful to have a common line such as the poverty threshold by the World Bank (128,173).

Saksena et al. (2014) (127) noted two indicators adapted from the general poverty literature to measure this concept. The first is a headcount measure that shows the proportion of households pushed below the poverty line because of OOP payments. The second indicator relate to the increase in depth of poverty - measuring the amount of OOP payments made that pushes a poor household further into poverty. An important advantage of measuring impoverishment due to OOP payments is that the concept resonates well with policymakers, as politicians and policymakers from almost all countries in the world are concerned with poverty alleviation (20,161). Nonetheless, a notable limitation of the headcount measure is that those who are currently living below the poverty line will not be counted, and capturing the burden of these households requires a measure of the depth of poverty.

2.4 Health systems response to the burden and impact of non-communicable diseases

2.4.1 Challenges of chronic disease management

The effective management of chronic diseases involves a complex process requiring a proactive team of healthcare professionals functioning in an integrated healthcare delivery system. However, the introduction of such an integrated care model to less developed countries have known to pose a number of implementation challenges. These relate to a number of factors from the general lack of resources, poorly functioning healthcare systems,

the rise of private healthcare financing and increasing out-of-pocket payments, to the overall lack of healthcare support services such as laboratory, waste management, and cleaning.

Health service approaches to managing NCDs explore challenges of access to screening for risk factors, regular monitoring and provision of expert care are mostly centred on acute care facilities (174). Ultimately, these approaches are based on an understanding of interventions at the level of the individual. With whole populations at risk, conceptualizing and addressing chronic diseases cannot merely focus on the current paradigms of illness and health seeking; a mind-set to think beyond individual care and implications for societies is needed (10).

A health system that relies largely on medical care for chronic disease management would be financially unsustainable. In the past years, various types of integrated care models have surfaced, but the majority of the models were designed for the health systems of high income countries as they primarily focused on improvement of quality of care rather to access or affordability. In the review by Wirtz et al. (2011) (68), the authors found little evaluation on integrated care models for LMICs, with the exceptions of the Innovative Care for Chronic Conditions (ICCC) Framework as well as the Functional Service Delivery Point (FSDP) framework which were particularly designed for LMICs. The ICCC framework emphasizes primary care integration as the focal point of managing and controlling NCDs. It highlights the importance of continuity and coordination, and the role of community leaders and caregivers that each member should be informed, motivated and prepared to manage chronic conditions. The FSDP model aims to define the roles of different stakeholders. It supports to identify the gaps in service delivery, and to evaluate the progress with detailed development of the demand side and each of its aspects. It emphasizes the critical importance of the communities in facilitating the access to health services where politicians, advocates, and grassroots organizations all mobilize the local groups to support health services and access to them.

Nonetheless, while both frameworks as well as other models provide strategies to reorganize chronic disease management, some have argued they have not explicitly address the challenges of access and affordability (175). An area of concern is access to essential medicines and routine care for chronic diseases; this includes some aspects which are unique to the pharmaceutical sector, such as the required coordination between medicine production, registration, procurement, prescribing, and dispensing to ensure that the medicine is made

available. Hence, it requires interventions such as health financing which are not included in already developed generic strategies to strengthen the health systems (68).

2.4.2 National health systems response to non-communicable diseases

Health systems that protect individuals and their households from the economic burden of NCDs are crucial for the UN's SDG of poverty reduction to be achieved. Health and economic outcomes are inextricably linked. Social disadvantages increase an individual's risk of chronic disease and predisposes them to illness-related poverty and economic hardship through loss of employment and OOP costs. This in turn affects the quality of life and potentially lead to depression, and even forgoing treatment (176). Human capital is also reduced when children are driven to provide home care or support the family, in which they lose education opportunities (177). This link between NCDs and poverty is evident in the SDGs, and there are goals that relate directly to measures that reduce the burden of NCDs (e.g., reducing premature deaths from NCDs by 30%, strengthening the implementation of the Framework Convention on Tobacco Control). Although the SDGs represent a great opportunity to channel global efforts to end poverty, illness-related poverty can potentially derail its success (20).

The response of national systems to NCDs is a critical component of the global response to NCD prevention and control. Due to gaps in the affordability and availability of basic health technologies and essential medicines, patients often delay seeking care and develop complications unnecessarily (38). Many NCDs and their complications are preventable, such as heart attacks and strokes if high-risk individuals are detected early and treated. However, poor access to primary health care services, affordability in laboratory tests and medicines; inappropriate patterns of clinical practice, and poor patient adherence to treatment have created gaps in the intervention coverage (38). The national system's response to NCDs is addressed through the global targets to ensure that those who require drug therapy and counselling receive them. Treating major NCDs in both public and private facilities requires up to an 80% availability of basic medical technologies and essential medicines (178). Without these minimum requirements in medicine and technology, even basic NCD interventions will be difficult to implement at the primary care level.

In assessing the capacity of countries to respond to NCDs, the WHO carries out periodic global NCD country capacity surveys (NCD CCS) for all its member states. Starting from the

year 2001, the surveys evaluated progress and trends over time, with the 7th survey recently completed in 2019 (to be published in 2020) covering over 194 countries. In NCD CCS surveys, countries submit detailed information on their capacity to address NCDs to map out current strengths and weaknesses in relation to their healthcare infrastructure, policy response and action, NCD surveillance, and health systems response (179).

In the 2017 NCD CCS report (179), it was highlighted that approximately one-third of countries had more than 50% of healthcare facilities with cardiovascular risk stratification to manage patients at high risk for heart attack and stroke. But this was only found most commonly among countries in Europe and the high-income group. On a worldwide basis, 18% had no healthcare facilities offering cardiovascular risk stratification, and only 50% reported having cardiovascular disease guidelines in at least half of the health facilities. Guidelines were much notably lesser available in the African Region (28% of countries) and the low-income group (23% of countries). Globally in 2017, nearly half of all countries reported having all ten essential NCD medicines in their public primary care facilities. The least available medical supply is steroid inhalers (58% of countries), while the most common being thiazide diuretics (in 90% of countries).

For essential NCD technologies, close to 50% of all countries reported having all six essential NCD technologies in their healthcare setting in 2017. Blood pressure measuring technologies were most commonly available (97%), while those measuring total cholesterol were the least common (in 59% of countries). Nonetheless, in terms of having both essential NCD medicine and technologies, the majority of countries are still considerably lacking with only 35% having access. More than half of the high-income group reported having access to all NCD medicine and technologies as “generally available”, and there were none from low-income groups.

Overall, the results of the NCD CCS indicated stark challenges in addressing NCDs both at the global and national scale. Poor policy implementation, inadequate action to address NCD risk factors, limited funding for NCD services and research, and lack of population surveillance are among the main challenges plaguing governments worldwide. While the global capacity to respond to NCDs has reported improvements over time, notable disparities remain visible among different regions and income groups. A number of recommendations were also raised by the 2017 NCD CCS report, particularly on the need for additional funding

for NCDs and a higher uptake of WHO's recommended "Best Buys" list (for reducing NCD risk factors and managing four major NCDs of cardiovascular disease, diabetes, cancer, and chronic respiratory disease). Developing cost-effective interventions were also mooted, in addition to having a broad, multi-sectoral, integrated NCD action plan, and the expansion of screening, diagnosis and treatment services (179).

2.4.2.1 Chronic disease management in Malaysia

In LMIC settings, even for countries that embed a near universal healthcare system such as Malaysia are facing new challenges in managing chronic diseases. The focus on a biomedical-centric approach of diagnosis and treatment has largely ignored the broader implications of chronicity and lacks the integrated response to a continuum of ill-health within a population (10). Under heavy state subsidy, direct medical costs for diagnosis and treatment in public health facilities are low, but hidden indirect costs related to the social aspect of chronicity are often overlooked. Indirect costs and its complications for the society include lost productivity due to morbidity, disability and mortality.

In Malaysia, public provision of healthcare and social care are isolated under different ministries and their functions are not streamlined. This creates a gap in the continuum of care needed for people with NCDs. The notable consequence of this shortcoming is a failure at the population level to effectively diagnose and manage NCDs in both public and private outpatient settings. The sub-optimal continuity of care between primary, secondary, and tertiary levels have contributed to high rates of admissions due to chronic conditions such as asthma and diabetes mellitus (11). Around 15–20% of hospital admissions are for conditions that should be effectively managed through ambulatory care, reflecting lower performance of the health system as a whole that affects health outcomes and resource use efficiency. The inadequate management of NCDs can be apparently seen at the population level – evident by the rising prevalence of NCDs, high share of the undiagnosed population with NCDs, and having 98% of the population with at least one risk factor for NCDs (11). The creation of a sustainable healthcare system that can manage and control NCDs hence requires developing strategies to better streamline healthcare and social care, as well as the potentials of integrating NCD management into communities.

2.4.2.2 Healthcare privatization - impact on chronic disease management

In the Southeast Asian region, respective governments to varying degrees respond to addressing emerging health challenges by privatizing healthcare with hopes of market competition to bring forth efficiency gains and private payments to alleviate fiscal burdens (180). With the growth of global trade, medical tourism, and private healthcare, key functions of the public sector including regulatory, financing, and provision are prompted to adapt accordingly to balance new supply and demand of equilibriums (181,182). Public hospitals went through restructuring and corporatization in Singapore and Indonesia (183); and countries such as the Philippines have radically decentralised healthcare services alongside wide-ranging of privatization and deregulation strategies (180). In Malaysia, the healthcare sector is viewed as a highly potential revenue generator, and policies are being rolled out to increase its marketization, promoting market growth of healthcare services through expansion in medical tourism and increasing private care (184).

The implications of the wide range of neoliberal development policies, while promising efficiency in gains and improved quality may also likely to undermine the tenets of health equity of the health system. The focus to intensify private healthcare expansion could potentially have an impact on population affordability and access to care. A study by Chee (2004) (185) in Malaysia found that although only 20% of hospital users utilise private facilities; they account for 86% of the total household expenditure for hospitalisation, with an average expenditure of RM1,955 (approximately USD488) for each episode of care compared to RM81 (approximately USD20) in the public sector. Chronic disease management often involves significant financial commitments and is likely to disadvantage those in lower income groups especially if they have to pay OOP for healthcare. This trend would also likely to increase the access differences between rural and urban communities (10).

Moving in tandem with private care expansion is the emergence of the medical tourism industry, as its potential economic benefits make it an attractive investment option for governments. Encouraging foreign direct investment in healthcare infrastructure and medical tourist inflows with correspondent revenue can create additional resources for investment in health care (186). In Singapore, Malaysia and Thailand alone, an estimated two million medical travellers visited in 2006-2007, which generated earnings over USD3 billion in treatment costs (187). Facilitating the growth of medical tourism is a wide array of healthcare infrastructure and more importantly, the health workforce. While some may argue that medical tourism may retain the international outmigration of doctors (188); others have

asserted that the private market has spurred the migration of doctors from the public to the private sector, hence straining public health provision especially in rural areas (187). This will have significant implications to NCD management, where there is a high reliance on the public health sector for access to treatment and long term pharmacotherapy. In addition, constraints in health workforce may also hamper health promotion and NCD prevention programs which are largely conducted by the Ministry of Health.

2.4.3 Non-communicable disease and Universal Health Coverage

Achieving UHC has been recognised as vital for the NCD agenda (26). For most, if not all countries, NCDs will need to be adequately addressed if UHC is to be achieved. Following several UN resolutions and declarations affirming UHC as a global health priority, many countries have progressively adopted legislation mandating universal access to services, regardless of level of income or ability to pay (189).

Global civil society movements such as the NCD Alliance have asserted that attaining UHC lies in placing focus on NCD prevention, and control in the design and implementation of UHC (189). When achieved, UHC presents a potentially powerful vehicle to accelerate progress on NCD outcomes, reducing inequalities, and improving socioeconomic impact which led to the call for action from the WHO Independent High-level Commission on NCDs to heads of States. The commission is pushing for multi-sectoral national action on NCDs to create an enabling environment (legislative, regulatory, economic) that can seamlessly integrate NCD into national universal health coverage agendas and health systems, alongside broader national development plans and social protection policies (46). Specific areas of focus include placing emphasis on health promotion and prevention, addressing social determinants of health, and creating domestic innovative financing mechanisms.

Various developing countries in Asia and Latin America have employed UHC in access to healthcare as both a means and an end (190,191). Among developing countries, Thailand and Malaysia are notable for having a public health system that provides comprehensive care with broad population access. While the system produces favourable vital health statistics such as maternal and child mortality comparable to those in developed countries (192,193), prevalence rates of NCDs on the other hand, have been rising dramatically over the last decade (30,69). The lack of effective responses in addressing NCDs reveals notable gaps even in health systems with UHC. Challenges are emerging with rapid socioeconomic

development, rising trade of health services, migration of the health workforce, and liberalisation policies espousing increasing privatisation of public services (180,192).

2.4.3.1 Scaling up financial protection for chronic diseases with UHC

In several LMICs such as Mexico (194), Thailand (190), and China (195), the substantial progress made in introducing UHC to scale up the level of financial protection will differ between countries due to differences in local cultures, governing institutions, and economic conditions. As highlighted in the 2000 World Health Report (107), without substantial domestic support such as taxation, it will be difficult to develop sustainable measures. Essential NCD services will remain difficult to access or unavailable, given the sizeable inequalities in NCD risk and health outcomes among the population.

The common challenges to implementing UHC include financial sustainability, maintaining equity of access, and adequate level of subsidies to ensure service coverage and meet the minimum standard quality of treatment (196). This is particularly because existing primary healthcare facilities tend to be curative in design and respond to manage acute conditions, rather than conducting early diagnosis and long-term disease management (197). This nature of NCD pose specific challenges to health financing, OOP spending, and service access that has implications on how UHC is achieved and placed within the broader health and social policy environment (20). Essentially, these challenges reflect the core UHC tenets of providing health services, covering populations, and covering costs.

Providing health services

The management of NCD patients necessarily required the combination of preventive, curative, and supportive care services, in which UHC policies can contribute to shaping health systems to deliver such services equitably. Having financial protection for a comprehensive range of services can potentially create important flow-on effects. For example, having effective population-based prevention strategies and timely access to diagnostic and health screening enables NCDs to be detected and managed early, thereby reducing the likelihood of hospital admissions for people with NCDs. This, in turn, can reduce the risk of patients incurring catastrophic spending (20).

UHC programs typically define a core package of health services which are most relevant to the country's health needs, health system, and broader context. For NCDs, it presents a good

opportunity to scale up quality NCD services to the whole population and transforms the health system to be more responsive to managing long-term chronic conditions. Several countries have taken the initiative to introduce NCD packages into their UHC programs, guided the WHO UHC framework that helped to shape the prioritization, structuring and costing of comprehensive NCD packages (44). The WHO estimated that if the NCD package is scaled up to 80% across all LMICs by 2025, it could potentially avert 37% of the global burden of cardiovascular disease and diabetes, and 6% of the global cancer burden (5). It is well-documented that the greatest impact will be achieved through delivery of the whole package, but acknowledging the inherent resource limitations of countries in lower-income groups, a progressive phased approach is warranted (189).

Nonetheless, the scaling up of health services should move in tandem with decent quality health services. The availability and access to safe, quality essential NCD medicines and technologies remain a key challenge in many low-income countries. Hypertensive medicines in Rwanda for example, were found to be of substandard content and 70% were of insufficient stability (198). One pragmatic approach to improving the quality is to draw upon the existing mechanisms of other health issues such as HIV/AIDS that already has an established quality assurance system. Integration of these health mechanisms and services are known solutions that can reduce cost, improve efficiency and achieve better health outcomes. The universal approach of UHC can help shift the focus away from vertical health programs (such as for HIV/AIDS, tuberculosis) towards an integrated horizontal health system-approach, particularly so at the primary care level which caters to the broad population access. This utilisation of existing service delivery platforms presents a variety of upgrades from risk assessment and early diagnosis to management of NCDs (199).

Covering populations

UHC embeds an intrinsic focus on health equity and universality, which strives to ensure the disparities and gaps in the access, coverage, and utilisation of health services are minimized across populations (26). With the prevalence of NCDs spreading across all levels of society, the vulnerable, marginalised, and underserved populations are facing devastating impacts both in terms of health outcomes and socioeconomic conditions. Evidence drawn from the Latin American and Caribbean region suggests there still exist considerable disparities in the use of NCD intervention services, such as access to diagnostic tests and procedures that tend to have higher uptake by higher-income groups (200). As such, targeted NCD interventions

need to necessarily complement a population-wide approach - with a specific focus for indigenous communities, women, children and the elderly to achieve both equitable and sizeable decreases in the total NCD burden (6).

On the outset, the health inequality gap can be narrowed through actions by the health system alongside cross-disciplinary sectors that address broader social, economic, and environmental issues. UHC policies need to be explicitly pro-poor to reach through to vulnerable communities to reduce health inequalities and flatten the social gradient (44). Governments embarking on the UHC agenda have been called upon to commit to “progressive universalism” — an approach to include people who are poor from the beginning, towards the aim for 100% health coverage (189).

Critical enabling factors to success will include having empowered communities and civil society. Exemplary role models from the HIV/AIDS response have shown that strengthening civil society is the crux to improving health equity, access and coverage. At the grass-root level, community-based approaches utilised in HIV/AIDS initiatives have reported a high level of success in efforts to mobilize the demand for quality services and increasing accountability from local healthcare providers. Thus, replicating this approach has strong potentials to provide a robust platform to support progress on UHC and NCDs (189).

Lastly, efforts to reduce inequalities are also reliant on the creation of a broader enabling environment in society. Multi-sectoral and “whole-of-society” approaches are espoused to coordinate the action across a wide array of sectors and different levels of stakeholders. To complement the health system response, there will need to be affirmative national policies and laws that can improve opportunities for economic productivity and social participation, in addition to facilitating healthy living lifestyles (42).

Covering costs

Health financing remains as an essential core component and enabler for healthcare service access and comprehensive coverage under UHC. Countries failing to strengthen and sustain health financing will likely lead to significant shortcomings in achieving not only UHC targets but also health- and poverty-related Sustainable Development Goals (59). Ultimately, it is envisioned for all countries to achieve a high-performance health financing system, defined by the World Bank and WHO as having adequate and sustainable funding levels;

sufficient risk pooling to spread financial risks of ill-health; and efficient and equitable spending for health service coverage, care quality and financial protection for all (26,59). The positive direct impacts of both UHC and its financing on the economy can be far-reaching. For example, with financial protection offered by UHC, poverty rates can be reduced and economic growth can be stimulated. Health financing structuring and arrangements can also drive improvements in sector efficiency and control cost escalation to optimise resource allocation and use (59).

While prepayment and risk-sharing through tax-based or obligatory health insurance are known to be efficient and equitable mechanisms to increase population health coverage and promote equitable care (26), the response to NCDs has also led to the use of innovative financing mechanisms to supplement financial resources. Taxation on the consumption of unhealthy products that lead to NCDs — namely tobacco, alcohol, and also sugar-sweetened beverages (sugar/soda tax), is of particular relevance to financing UHC. These sin taxes are prioritized in the WHO Global NCD Action Plan 2013–2020, and The Lancet Commission on Investing in Health identified tobacco taxation as “the single most important opportunity for national governments worldwide to curb NCDs” (44). Taxation on unhealthy products is highly advocated for its two-pronged benefits of improving population health while raising more funds.

Nonetheless, while the removal of financial barriers will help low-income groups to access NCD care, it will not guarantee it. Indirect costs related to healthcare access such as transport costs and loss of income can be, if not more prohibitive than the cost for treatment itself. Social protection schemes then play a key role in overcoming these cost barriers. Many countries are exploring ways to overcome these barriers by expanding social protection schemes to support NCDs, which included conditional cash transfers for actions to improve health, microcredit schemes, and vouchers or rebates to cover the cost of travel to healthcare facilities. In the case of Rwanda, funding from HIV programs has been used to expand health insurance coverage for poor sections of the population to improve access to health services, including those for NCDs (201).

Pressing limitations on resources denote that achieving UHC to be a long-term endeavour in many settings. While moving towards the UHC goal, cost-effective services that benefit lower-income groups must be prioritised while maintaining progressive financing systems

(202). Given the multi-sectoral nature of NCDs and the increasing role of the private sector in global health and human development, there is also a push for governments embarking on UHC pathways to consider mixed financing models that draw upon the strengths of both the public and private sectors (189). Mechanisms such as public-private partnerships (PPPs) have the potentials to develop and deliver innovations and solutions to support the attainment of UHC in LMICs, but caution was also drawn for the state to safeguard the health of its citizens at its utmost priority.

One critical enabling step is the strengthening of governance structures and establishing local institutions for public investment decision making to be transparent and objective. As espoused by the WHO in their Best-Buy recommendations, achieving value-for-money is imperative when determining the services to include in the benefit packages. This is particularly critical in resource-poor settings where cost-effectiveness is an important starting point in guiding financial protection and health financing measures (20).

2.5 Research gap and significance of study

In summary, the literature review informed of the enormity of NCD's growing burden of disease and its impacts to health and socioeconomy, both at the national and household level. NCDs are also not being effectively addressed in many aspects, from policy commitments to strategy implementation. The severity is more pronounced in LMIC that lacks of numerous resources, from healthcare financing to service delivery, leading to worsening financial risk protection.

Our review uncovered a number of studies on cost of illness (69,177,203), poverty impacts of healthcare payments (12,130,204), and household coping from healthcare financial burden (205,206). However, these aspects were explored independently, which may not provide the full picture of a household's economic burden due to living with chronic diseases. In addition, very few studies were conducted to estimate the long-term costs associated with chronic diseases. In this respect, a longitudinal community cohort such as those in health and demographic surveillance sites presents a strong potential to capture these long-term cost prospectively. A broad range of indicators of household economic outcomes can be included in the routine demographic surveys conducted to longitudinally capture the important dimensions of the economic burden on households (20).

The review of literature also indicated a need for more microlevel data on the overall cost of chronic illness shouldered by households in developing countries, particularly middle-income countries. Most studies used macrolevel expenditure data that presents limitations to accurately assess whether households are at risk of catastrophic healthcare expenditure. They also face challenges in evaluating factors affecting the level of risk, given that the aggregated data which lacks details on the types and quantum of cost components. In the case of Malaysia for example, estimates for the prevalence of catastrophic healthcare expenditures are measured through national household expenditure surveys that measure direct household spending on healthcare (207). This will bias the results because indirect costs will not be captured, resulting in the underestimation of the total cost of healthcare to the household. Furthermore, cost items are not disaggregated by disease so that one could not estimate the separate healthcare cost of, for instance, diabetes.

Examining the level of catastrophic spending and impoverishing effects of household health spending on NCDs will reflect how well the healthcare system responds to NCDs, particularly in terms of household financial risk protection and adequacy of healthcare service provision. It also provides the opportunity to reveal possible gaps in the system, paving the way for future research to explore new strategies and solutions to effective NCD management. In addition, our study explores the underlying risk factors for catastrophic healthcare expenditure, as well as the survival strategies that households employ to cope with the possibility. This provides an avenue to explore not only the resources and decision-making processes of households but also the potentials of the community to play a larger role in the healthcare system to supplement the existing primary healthcare structures. The leverage on the potentials of the community in NCD management is crucial for LMICs as financial resources both nationally and individually are often constrained, in addition to having fragmented healthcare services.

An understanding of the economic burden and its impacts on households living with NCDs is particularly relevant in LMIC settings where the challenges are complex and many. Filling the evidence gap from the demand side will have significant implications on the design of healthcare systems. Policies and strategies can be better designed, aligned and targeted to better reflect the financial risk protection needs of the population, towards creating a sustainable healthcare system that can respond effectively to NCDs.

CHAPTER 3: METHODOLOGY

3.1 Research setting

3.1.1 Study site

The study was conducted in the South East Asia Community Observatory (SEACO), a Health and Demographic Surveillance System (HDSS) established as a sentinel surveillance research platform in 2011. SEACO is managed by Monash University Malaysia and collects longitudinal data on fully enumerated populations in five selected sub-districts (mukims) in the district of Segamat of Johor, the southern state of Peninsular Malaysia. The sub-districts vary in terms of geographical size, population density, ethnic mix, and level of social-economic development, and they consist of Sungai Segamat, Bekok, Chaah, Jabi, and Gemereh which cover an area of approximately 1,250km².

3.1.2 Background of Segamat district

Segamat is a semi-rural district that covers an area size of 2,825 km² divided into 11 sub-districts with an estimated population of 170,000 people. It has an ethnic mix consisting of 50% Malay, 36% Chinese, 9% Indians, with the remaining comprising of Orang Asli and foreigners (plantation workers from Indonesia and Bangladesh). Mukim Sungai Segamat, as the district capital, is the most populous in the district. Mukim Gemereh has the highest population density while the lowest population density is in mukim Bekok which is also the most remote and rural. Agriculture is the main contributor to Segamat's economy, with extensive palm oil and rubber plantations as well as fruit orchards (208).

Hospital Segamat is the only district hospital in the area. It has over 300 beds and is equipped with acute and emergency care, though patients requiring specialist care such as ophthalmology are often referred to other district or state hospitals for treatment. Supporting the district hospital at the primary care level are ten health clinics and 25 community clinics that are strategically located within various sub-districts to provide access to care (208). Private care in Segamat is mainly available in Sungai Segamat town, and consists of only outpatient treatments with general practitioners and dental clinics.

3.1.3 The SEACO population

SEACO enumerates the population of five sub-districts in Segamat and enrolled approximately 38,000 people who consented to join the dynamic cohort. This constituted 85% of the total population. The ethnic composition of these populations according to the baseline SEACO enumeration (2012–13) was 62% Malay, 18% Chinese and 10% Indian, with 2% indigenous groups (Orang Asli). The remaining 8% consists of other ethnicity and foreign nationals, who are predominantly plantation workers. Compared to the national population spread statistics, SEACO sub-districts recorded almost twice the aged national age dependency ratio (0.078 versus 0.147) with its low young adult population and high numbers of children and the elderly. This is due to the rural-urban migration of young working force, leaving the elderly and children behind-due to either employment or education (209).

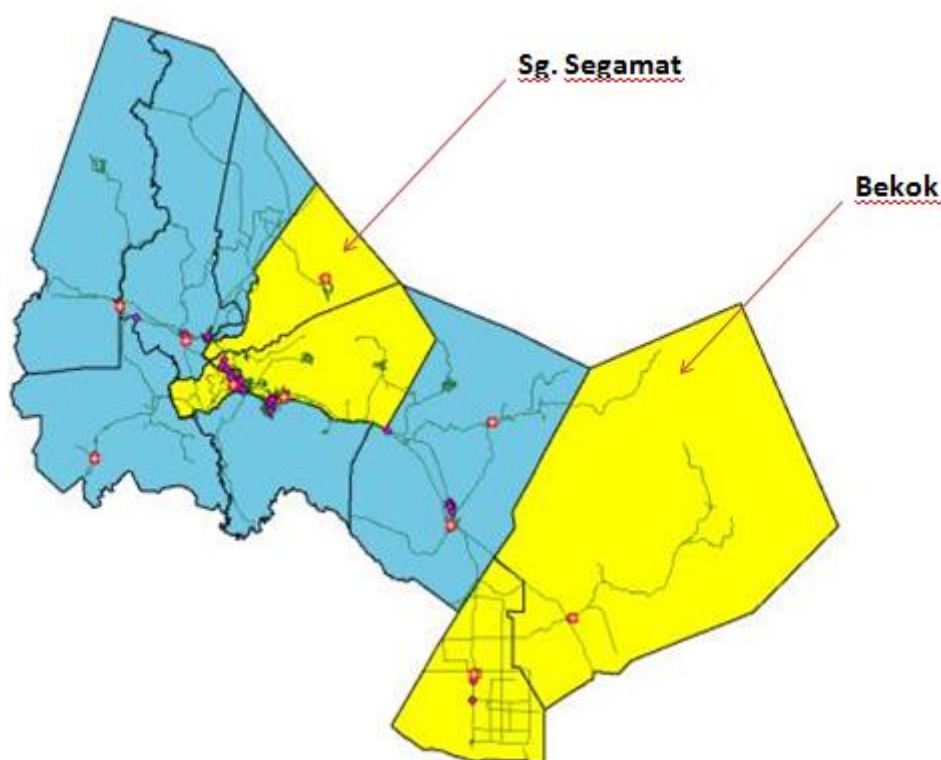


Figure 3.1: Map of Segamat district with the study sites in yellow

3.1.4 Selection of study site

Collecting data from households requires substantial resources, particularly for conducting fieldwork, getting access to households, obtaining quality data, and having structured and secured data management. As a community research platform, SEACO provides several key research advantages and research support including:

- A ready sample population of households with diabetes identified in the SEACO database, with a population mix similar to the national ratio of the three main ethnic groups in Malaysia. Being an HDSS, SEACO enumerates all households in its sites and produces annual longitudinal cohort data.
- Extensive community engagement has been carried out to build a strong sense of trust and rapport between the Segamat community and SEACO. Together with an established infrastructure of well-trained local data collectors, this enabled better access to households, higher quality data (i.e., more accurate responses), and lower attrition rates.
- A database of baseline household data (e.g., demographics, health status) is readily available. Data is also electronically collected through a tablet computer that uploads data directly to the database server, providing enhanced efficiency and data quality, better data protection, and ease of data analysis.

3.2 Research approach

This study aims to investigate the economic burden for individuals managing and living with diabetes in the household. Addressing this involves exploring three key aspects: 1) mapping out diabetes-related OOP spending to estimate the cost of illness, 2) assessing the poverty impacts of the cost burden, including its socioeconomic repercussions, and implications to disease management and healthcare usage, and 3) exploring the contextual factors and circumstances of how households in a LMIC living in a multi-ethnic community mobilize their resources to cope with OOP health expenses.

Considering the broad range of data required, several research approaches were explored and considered. Ultimately, the mixed methods approach was found to be the most feasible methodology as it combines both qualitative and quantitative components that enable us to explore a better understanding of the research problem that either quantitative or qualitative research cannot provide (210). Mixed-methods has emerged as a practical approach to address a research problem which needs to solve, combining both inductive and deductive thinking (211). In epidemiology and public health, it has been increasingly being used, and underpinning its popularity is the paradigm of pragmatism. Rather than being methods-

centric, researchers focus on the research problem and strive to exhaust all available approaches to understand the problem (212).

Fundamentally, the mixed methods research is a research design with philosophical assumptions as well as methods of inquiry. As a philosophical underpinning, Morgan (2007) (213), Patton (2002) (214), and Tashakkori and Teddie (2010) (215) conveyed its importance that places focus on the research problem, and apply pluralistic approaches to derive knowledge about the problem. As a method, mixed-methods focus on collecting, analysing, and combining both quantitative and qualitative data in a single or a series of studies.

3.3 Study design

Under mixed methods research, we selected the explanatory sequential mixed methods design to frame the study. Explanatory sequential mixed method has two variants: the follow-up explanation model (quantitative emphasized) and the participant selection model (qualitative emphasized) (211). We selected the former variant to align with the sequential order of the study objectives, where the mapping of cost items and the cost of illness are more feasibly conducted quantitatively via household surveys (66,79,216). Utilizing the follow-up explanation model, we structured the study into two phases. Phase 1 comprised of a quantitative survey that focused on investigating two key aspects: 1) mapping out both direct and indirect cost of diabetes-related OOP spending, and 2) estimating the poverty impacts of the household cost burden of living with diabetes. Phase 2 consists of the qualitative component that explored household financial coping strategies and aspects of decision making over the allocation of household resources.

The use of the follow-up explanation model commonly presents two key methodological challenges: 1) difficulty in identifying the quantitative results to further explore the qualitative aspect, and 2) sample sizes for each phase of the study were unequal (210). In this study, these challenges were acknowledged and addressed by firstly, standardizing the method to identify households experiencing catastrophic healthcare expenditure, and secondly by using the purposive sampling method to systematically identify the sample size for Phase 2.

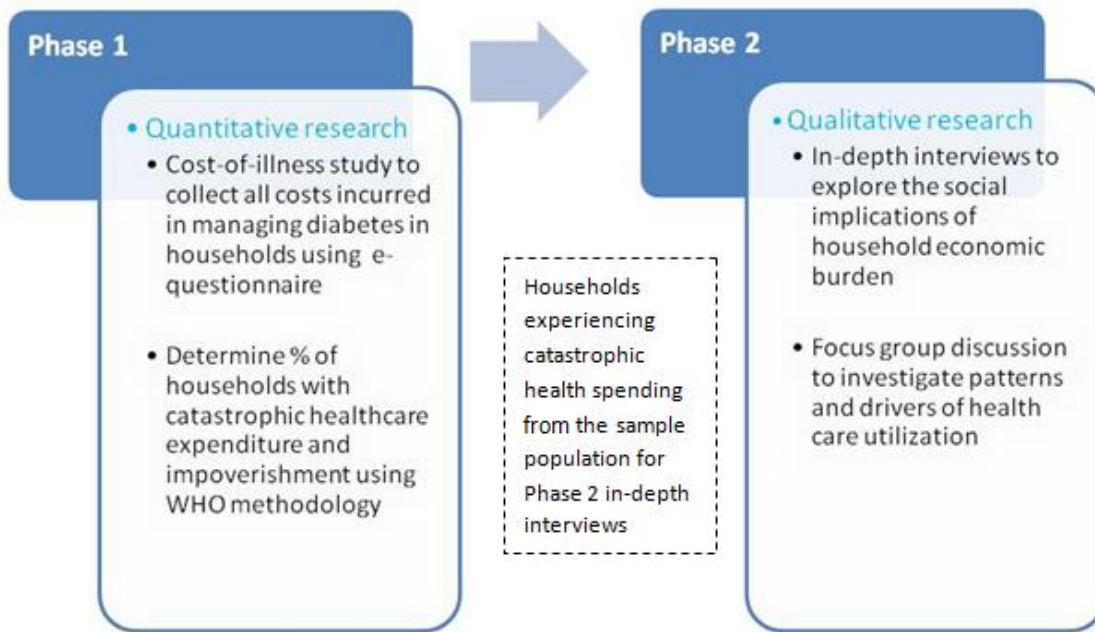


Figure 3.2 : Study design

3.4 Phase 1 – Quantitative research

Phase 1 is a cross-sectional cost-of-illness (COI) study aimed to map out disaggregated cost items incurred by households in diabetes management. The OOP identified cost items were subsequently assessed to estimate the economic burden that imposes on the household, in terms of catastrophic healthcare expenditure and household impoverishment.

The rationale for the selection of COI analysis was due to its suitability to identify and quantify all costs of a particular disease which include direct, indirect, and intangible costs. The output is then presented in monetary terms of the estimation of the total economic burden of a specific disease (217). COI studies include the impact of a disease on individuals, community, and the country as a whole from various aspects. Estimating the total cost of an illness was known to be a useful tool in national and international health policy decision making (66,218). In a recent systematic review by Mutyambizi et al. (2018) (219), the researchers also found that COI studies have been conducted across a broad range of diseases, and they continue to play important roles in conducting full economic evaluations of treatments and other healthcare interventions (220,221).

The type of COI study design used was prevalence-based from a household/patient perspective, using a bottom-up approach to collect cost data which is the most widely used globally (203). We opted for this design as it generates an overall picture of the economic burden as well as component costs (216), as compared to the second type of COI design which is the incidence-based approach. Incidence-based COI studies are often cited as being more appropriate for evaluating disease prevention strategies, and these types of studies are relatively rare in the diabetes area (222).

3.4.1 Study respondents

Study respondents comprised of adults over 18 years old with diabetes in households identified in the SEACO first health round household survey. The status of diabetes was self-reported and through random blood sugar test conducted by the SEACO data collection team. Study respondents came from two sub-districts of SEACO, which were selected based on aspects related to healthcare access and usage of healthcare services: 1) the social-economic status of the residents, and 2) the accessibility to healthcare services. Based on these criteria, from the five sub-districts, Sungai Segamat (comparatively most urban and closest to the district hospital) and Bekok (most rural and furthest from the district hospital) were selected.

Data was collected from members of the household who have information on the household expenditure on diabetes and overall household expenditure. This included the individual with diabetes, the household caregiver(s), and the head of household. In SEACO, household members are defined as individuals who are living under the same house for at least three months, not on a visiting basis, and collectively share household resources. Households in this study were defined as those with at least one member who has diabetes as identified in the SEACO first health round survey.

We have established a set of screening criteria (Table 3.1) based on similar approaches in existing cost-of-illness studies (66,203) and widely used patient cost data toolkits (WHO/TBCTA/USAID) to capture cost data, as well as considerations of the disease nature of diabetes.

Criteria	Rationale
Individual with diabetes who have been diagnosed with Type 2 diabetes before January 2013	The management of NCDs requires a continuum of care for the long term, and having respondents who have been diagnosed and living with diabetes for at least 12 months is designed to capture the continuous and recurrent cost of NCDs.
Individuals with diabetes aged 18 years old and above, who are not pregnant at the time of recruitment	Adults can provide consent for the study and also better understand the nature of the study as well as their medical condition. The implications of diseased adults to the burden of the household are more severe, e.g., working adults who lost productivity and the ability to contribute and support the household. People with diabetes who are pregnant may likely be the cases of gestational diabetes, which are usually temporary and recovers after pregnancy.
Key informant: Person in the household who knows the information on household income and expenditure	Information on the status of household resources and the ways they are mobilised including income, expenses, and assets, are critical data for assessing the magnitude of the economic burden placed on households due to healthcare spending.

Table 3.1: Respondent screening criteria

3.4.2 Data collection

The data collection period for Phase 1 began in March 2015 and ended in July 2015. There were several revisits to a number of households between August – December 2015 for data validation after discrepancies were found during data set checks. The list of households with diabetes was obtained from the SEACO's database (first health round survey), which contained 275 households with diabetes in Sungai Segamat and 178 households in Bekok in total. Data was collected through electronic data capture (EDC) using an electronic questionnaire in a handheld tablet computer by trained data collectors.

3.4.2.1 Data collection team

In addition to the student researcher, data collection was supported by a team from SEACO. Three local data collectors were engaged and were from Chinese and Malay ethnicity to minimize language barrier and facilitate ease of access during fieldwork. Having a similar ethnic background provides the benefits of cultural and language familiarity which is advantageous in engaging with the local community (208).

Data quality control was monitored through two field supervisors and a field coordinator from the SEACO office who provided weekly field reports to the student researcher during the data collection period. The field supervisors also functioned to support the data collectors by providing a list of addresses of households with diabetes, a physical map of the houses, and performing weekly data uploading after collecting the tablet computer from the data collectors. Data collectors also correspond directly with the student researcher to report and troubleshoot field issues which they encountered.

All data collectors underwent training sessions conducted by the student researcher before conducting fieldwork. The training contents included;

1. Explanation of study concept and background.
2. Briefing on strategies to approach households.
3. Walkthrough of the e-questionnaire, i.e., types of data collected in different sections, types of data to input, skip logics, and completing the questionnaire for data upload.
4. Conducting simulation exercise with each data collector to ensure they are familiar in the flow of the questionnaire. The usage of the field notes booklet was also detailed.
5. Field testing of the questionnaire with a few selected households.
6. Discussion and feedback from data collectors for questionnaire revisions and fine-tuning.

3.4.2.2 Data collection kit

A standardized data collection kit was prepared, containing;

- Approval letters from community leaders and the Segamat district health office to conduct the study.
- List of addresses for households with diabetes in Sungai Segamat and Bekok.
- Physical maps with marked locations of households with diabetes.
- Tablet computer with pre-loaded study questionnaire.

- Token of appreciation (SEACO hand towel) for participating households
- Field notes booklet
- SEACO name tag and designated uniform (SEACO shirt)

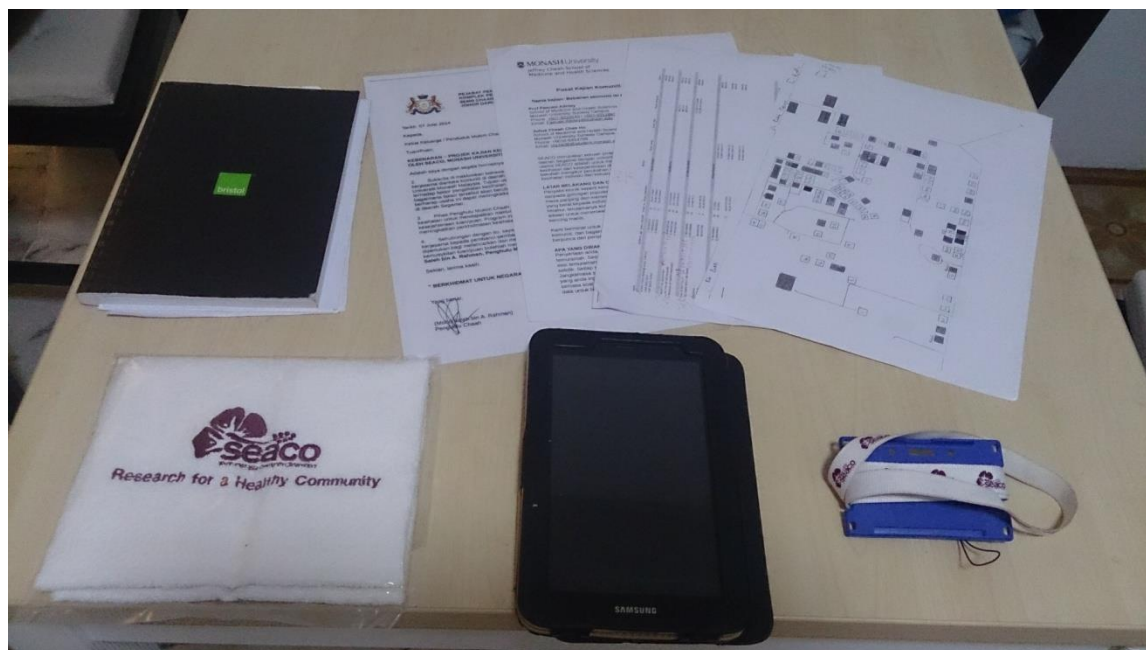


Image 3.1: Data collection kit

3.4.3 Data collection tool

3.4.3.1 Development of data collection tool

The data collection tool is a household survey questionnaire adapted primary from the two sources below. Further revisions were made after conducting pre-testing and content validity.

Tools	Source	Description
1. SEACO social demographic survey questionnaires (first round health survey)	Southeast Asia Community Observatory, Monash University Malaysia	SEACO's first health round survey (2010) collected data specific to the health status of every individual in the household.
2. Tools to estimate patient's cost for Tuberculosis	WHO Tuberculosis Coalition for Technical Assistance, KNCV	A manual developed to assist TB programs to estimate the costs of TB patients before and during diagnosis and during treatment by the National Tuberculosis Program. The

	Tuberculosis Foundation, and the Japan Anti-Tuberculosis Association	questionnaire used different contains sections evaluating economic constraints on individuals and households with TB, and also on assessing the impoverishing impact of TB on patients and their families.
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Table 3.2: Reference source for questionnaire development

3.4.3.2 Development of e-questionnaire

The questionnaire was administered in digital form and data was collected electronically through a tablet computer. The development of the e-questionnaire utilized an open-source mobile data collection application, *FormHub* (Modi Research Group, Colombia University). The questionnaire contents alongside the consent form were restructured into an XLS spreadsheet using *FormHub*'s XLSform syntax (Appendix 1). The XLS-form was uploaded into the tablet computer (Samsung Galaxy Tab 7.0) through the Open Data Kit (ODK) mobile application for the Android (Google Inc.) operating system. The ODK application can also be used offline and this provided the advantage of data collection in more remote areas where mobile phone signal is weak or the internet is unavailable. The collected data was encrypted and subsequently uploaded to a secured server in SEACO's office and a backup server at Monash University Malaysia's IT Department.

The XLSform developed for the study was pre-tested extensively with the SEACO field team and data collectors before fieldwork, and the contents were translated into both Malay and Chinese language to facilitate the data collection.

3.4.3.3 Pre-testing survey questionnaire

The questionnaire went through pre-testing to establish content and face validity by identifying the questions that are poorly understood, ambiguous, or evoke hostile or other undesirable responses. The questionnaire was translated into the Malay and Chinese language, and tested out in the field among Malay, Indian, and Chinese households. Indian households in Malaysia are conversant in both Malay and English, and thus Tamil translation wasn't required. The following aspects were evaluated in the pre-testing:

- Are all words and sentences understood?
- Are the questions interpreted similarly by all respondents?

- Do the closed-ended questions have similar meanings that apply to each respondent?
- Is there any questions that are difficult for the respondents to answer?

Pre-testing process for content validity:

1. Internal review of the draft questionnaire (Duke and Fudan research partners, Ph.D. supervisors).
2. Questionnaire review with the SEACO field coordinators.
3. First round of questionnaire pre-testing (by student researcher) in households with diabetes (covering Malay, Indian, Chinese houses) on a sample of respondents outside of the targeted sub-districts. Mukim Chaah and Gemereh were selected for the questionnaire testing for logistic practicality, ease of travel, and having a feasible population size.
4. Second round of questionnaire pre-testing in the community with dedicated SEACO data collectors trained for the study in Chaah and Gemereh.
5. Final revisions of the questionnaire content and *FormHub* XLSform programming syntax before starting the fieldwork.

3.4.4 Data collection process

A standardised work flow was developed to ensure that data were collected efficiently and ethically and also to ensure that respondents are well-informed about the study, especially how their personal information is being treated. The process consisted of;

1. Data collectors introduce themselves to the respondents
2. Briefing on the study - its aim and objective, and how the study will be conducted.
3. If the household agrees, proceed to go through the Personal Data Protection Act (PDPA) requirements.
4. Proceed to ask the screening questions to confirm eligibility for the study.
5. If the household is eligible, proceed to obtain the informed consent.
6. If household consents, proceed with data collection.
7. If the household declines, thank the household and move to the next house on the list.

Individuals living in the household who met the recruitment criteria but are not part of the household family members (i.e., tenants) were considered as a separate household on its own.

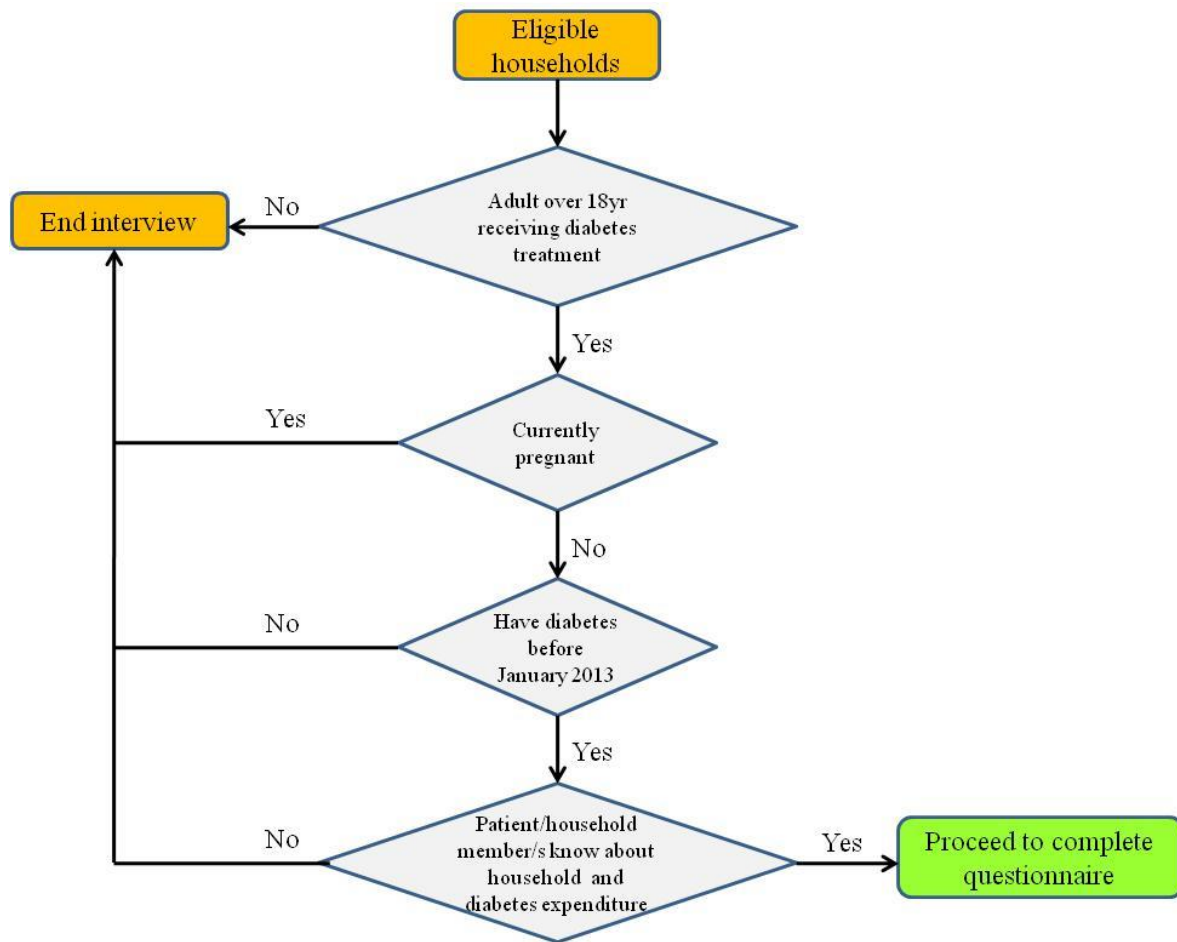


Figure 3.3: Flow chart for Phase 1 respondent screening

The person with diabetes was first approached as the primary respondent. If the person with diabetes has difficulties answering parts of the questionnaire, the questionnaire was then administered to the caregiver. The questionnaire consisted of two sections: Section A contained questions related to the cost of managing diabetes, while Section B captured the overall household income and expenditure. The questionnaire is considered complete only when both sections A and B are completed.

In terms of expenditure recall period, a 1-month recall was used for recurrent costs (general household expenses), 3-month recall on diabetes outpatient treatments (based on the recommended outpatient clinic follow-up period in the Malaysian Clinical Practice Guidelines for Diabetes management) (223) and a 12-month recall for major health events such as hospitalisation and inpatient cost (224).

The estimated time of engagement ranged between 30mins to 60mins, and the duration primarily depended on disease status (e.g., longer survey time for those with more severe conditions), and familiarity with OOP spending on diabetes as well as household finances. On occasions where the data collection process was disrupted or incomplete, data collectors scheduled revisits to the household to an alternative day and time convenient to the household.

3.4.5 Data management

3.4.5.1 Data storage, monitoring and quality control

The tablet computers used by the data collectors were collected weekly by the field supervisor for data upload into the SEACO database, and were returned to the data collectors on the following day. This ensured that the most recent data was stored to minimize the risk of data loss. Collected data was also periodically (weekly) checked for discrepancies. Any irregularities found were immediately informed to the data collector responsible for further clarification, and revisits were made to households requiring further inputs or corrections. Quality assurance was initiated from the planning stage of the study, with established and standardised workflow models integrated into the activities of data collectors, field supervisors, and field coordinators to implement the study. SEACO is accredited by ISO 2000 for data quality management on collecting, cleaning, storage, monitoring, reviewing, and security of research data.

3.4.5.2 Data backup

Data was encrypted and uploaded from the tablet computers to dedicated physical servers at the SEACO research office in Segamat. Automated data backups of the database were completed weekly into a backup server of Monash University Malaysia's IT Department.

3.4.6 Data analysis

3.4.6.1 Conceptual framework on household economic burden of illness

NCDs are often accompanied by long-standing disabilities and have a direct economic impact on households through the use of health services and goods and also on the levels of income or reduced labour productivity (5,69). Health services can impose regressive cost burdens, with poor households spending more of their income on health care in proportion to better-off households. The experiences in LMICs have demonstrated that a health care financing

strategy that places considerable emphasis on OOP payments, whether to public or private health service providers, can have serious economic consequences for households. There is substantial evidence of households being pushed into poverty when faced with substantial medical expenses, which is compounded with the loss of income due to ill-health (17,20,51).

Figure 3.4 below presents the conceptual framework for analysing the economic burden of non-communicable diseases for households. We highlighted vital components including resources (i.e., healthcare system, out-of-pocket payment, social resources), types of costs (direct and indirect), types of cost drivers (type and severity of illness, health service characteristics), financial coping strategies, and implications of illness costs and coping strategies. These elements are also similarly highlighted in the analytic frameworks in other economic burden of illness studies (17,62,67,225,226) which reviewed and investigated the economic consequences for households of illness and health care use in LMICs. These studies explored household-level impacts of direct costs (medical and non-medical), indirect costs (productivity and income loss from illness), and subsequent household coping responses. Our conceptual framework encapsulated the cost-of-illness approach that we utilised to analyse the results of the economic burden of diabetes, which aimed to identify and measure all the costs of a particular disease, including both the direct and indirect. The output (in monetary terms) is an estimate of the total burden of a particular disease to society (217,227).

An important point to note with regards to the framework was the fact that it was premised on households who have utilised healthcare for their conditions. An individual may choose or forced to ignore an illness due to a lack of access from economic or social factors. Thus, purely considering those costs that do arise relative to available household resources does not necessarily provide a full picture of economic access. It may also show that a health care financing mechanism is progressive or equitable if health care expenditure is relatively low in poorer households, whereas this only relates to those who have found a way to access and use health services.

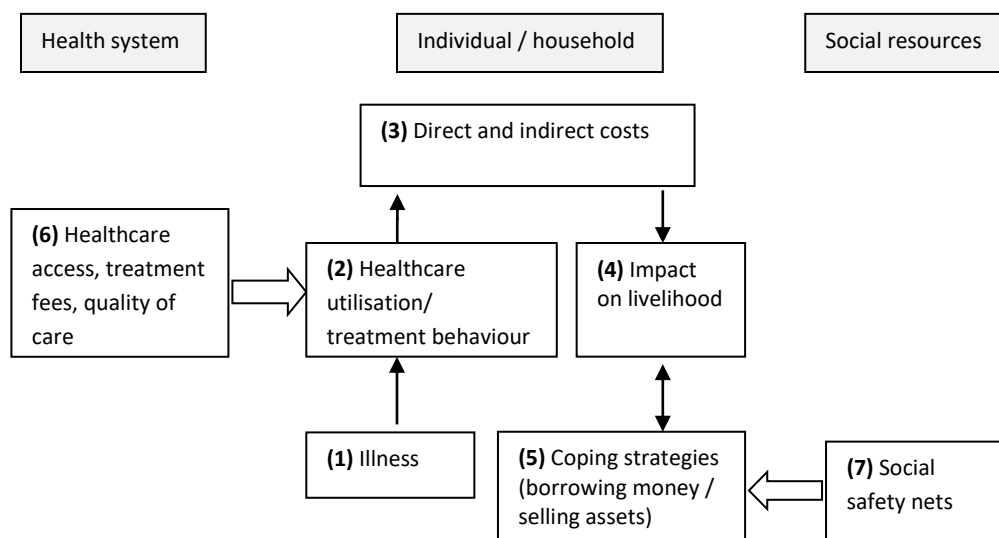


Figure 3.4: Conceptual framework for analysing the economic burden of illness for households

In response to having a chronic illness (Figure 1, Box 1), decisions are made on whether to seek treatment and from which source (Figure 1, Box 2). Accessing healthcare will impose both direct and indirect costs (Figure 1, Box 3), which refer to the treatment cost and non-medical expenses such as transport or special foods, and the loss of household productivity for patients and caregivers respectively.

Direct and indirect costs will be influenced by the type and severity of illness and health service characteristics (Figure 1, Box 6) that influence access and choice of providers. The costs incurred for seeking treatment will have both financial and social impact on their livelihood (Figure 1, Box 4), and illness costs going beyond the household's daily or monthly budget may trigger coping strategies such as borrowing or asset sales (Figure 1, Box 5). In situations of poverty whereby households struggle to meet daily needs, the loss of a daily wage due to illness is likely to trigger such strategies, which in turn could exacerbate their livelihood and living conditions. The household economic burden could be mitigated through social safety nets, such as formal social assistance or informal social networks or local organizations (Figure 1, Box 7). Households may also be protected from the cost of healthcare by the health system, shown as a secure source outside the household on which members can depend (Figure 1, Box 6).

3.4.6.2 Data variables

The household is the unit of analysis for assessing the costs of illness. In managing diseases from a household perspective, decisions about treatment and coping are often based on negotiations within the household. Both direct and indirect illness costs may be incurred by caregivers as well as the sick, which may likely to impact the overall household resources (67). Studies on the cost of illness and the economic burden of disease of households take into account the overall total cost the households incurred with living with the disease. The total cost is captured, and specific variations, such as co-morbidities were analysed in the findings.

The data for phase 1 were tabulated in comma separated values format and analysed using the *R* software for statistical analysis. The statistical analysis consisted of two parts, i.e., descriptive statistics of key variables measured, and regression analysis to examine the relationships between variables to identify potential determinants of catastrophic healthcare expenditure. Key variables included:

1. Social demographic characteristics
2. Diabetes disease burden
3. Utilisation of health service
4. Economic burden
 - Cost of illness
 - Direct medical costs
 - Direct non-medical costs
 - Indirect costs
 - Catastrophic health expenditure
 - Impoverishment

3.4.6.3 Indicators for estimating direct cost

Direct cost consists of any amount paid out of pocket for treatment and management of diabetes, which includes both direct medical and non-medical costs.

- Direct medical costs
 - Outpatient treatment (modern and traditional)
 - Inpatient treatment

- Self-monitoring (i.e., glucometer)
- Self-care items (e.g., bandages, antiseptics, gauze pads for wound care)
- Direct non-medical costs
 - Hiring of caregiver (formal care)
 - Food costs during visit to a medical facility
 - Transportation/travel cost to a medical facility
 - Special foods/diet or supplement consumed
 - Informal payments (if any listed under ‘others’)

Recall periods for outpatient and inpatient cost items were three months and twelve months respectively. Spending for TCM care (e.g., nutritional supplements, traditional and complementary medicine, spiritual healing), self-monitoring of blood glucose (SMBG) and self-care supplies (e.g., bandages, antiseptics), and formal caregivers were on a monthly basis. Respondents were asked to provide the total costs they paid OOP during these periods, irrespective of the frequency of visits or usage. All variables related to expenditure were converted to monthly figures following the methodology prescribed by the World Health Organization on measuring catastrophic healthcare expenditure (128).

3.4.6.4 Indicators for estimating indirect cost

The Human Capital Approach (HCA) was used for estimating indirect costs. Forgone income due to managing diabetes for the household was captured by estimating the time absent from work times the average personal take home earning per day. The national minimum wage of RM960 per month (228) was used as the standardised proxy measurement. We did not use reported income due to reasons of incomplete data, as we have had difficulties obtaining personal income data from a number of respondents with employment. Additionally, in LMICs and rural settings, informal employment is also known to be common, and income can often be seasonal (229). Indirect costs were measured for two categories of respondents;

1. Loss of income of the person(s) with diabetes due to diabetes (for those who are still working)
2. Loss of income of household members providing care for the person with diabetes (informal care)

The HCA is one of the most widely used approaches compared to other methods, (i.e., willingness-to-pay and friction cost) (230–233) to measure the monetary value of lost productivity. The willingness-to-pay approach attempts to address the underestimations of the HCA with higher estimates of the value of life, but this approach is often challenging to implement in cost-of-illness studies. For specific diseases, extensive surveys of people's preferences are needed. However, the results rely heavily on people's responses to very specific hypothetical questions about their willingness to avoid certain illnesses. These responses are also subjected to personal interpretations and social desirability bias in answering (78).

Proponents of the friction cost method on the other hand, criticize the HCA for overvaluing the indirect costs, postulating that productivity losses are often eliminated after a new employee is trained to replace the former employee. Nonetheless, the friction cost method is rarely used due to its extensive data requirement for estimating only the losses in the friction period. Valuation of the productivity losses is complicated further by the use of internal reserves of labor during the friction period, which lowers the estimates of losses even more but can be difficult to calculate (234).

Ultimately, our decision to use HCA in the study was due to its predominant use in COI studies, its simplicity and reliability (235), as well as considerations of the feasibility to collect cost data within the time and resource limitations of this study.

3.4.6.5 Measuring catastrophic health expenditure

Data collected through the questionnaire were used to estimate the CHE of households with diabetes. We follow the WHO guidelines on using a 40% threshold (128). Data requirements for CHE assessment are household surveys that include:

- Individual-level:
 - Socio-economic information (age, gender, education, urban/rural location)
 - Health service utilization
- Household-level:
 - Household size
 - Total household consumption expenditure
 - Total household food expenditure

- OOP health expenditure
- Household expenditure on diabetes management

The formula for calculating CHE was based on WHO's methodology on the distribution of health payments and catastrophic expenditures (128). First, the household subsistence spending (se_h) was calculated by multiplying the poverty line, (PL, national poverty line of RM960 was used) with the household equivalent scale ($EQSIZE_h$). The $EQSIZE_h$ was derived from the household size squared by the beta of 0.56 (β value is established as a standard based on household data of 59 countries) (128).

$$eqsize_h = hsize_h^{0.56}$$

$$se_h = pl * eqsize_h$$

Subsequently was to calculate the household capacity to pay (CTP_h) which was defined as the non-subsistence effective income of the household. CTP_h is the total household expenditure (exp_h) after deducting for household subsistence spending (se_h) or household food expenditure ($FOOD_h$).

$$ctp_h = exp_h - se_h \quad \text{if } se_h \leq food_h$$

$$ctp_h = exp_h - food_h \quad \text{if } se_h > food_h$$

There may be households which report food expenditure that is lower than subsistence spending ($se_h > FOOD_h$). This indicates that the household's food expenditure is less than the estimated poverty standard. All the households in this study have a higher subsistence spending than food, and hence non-food expenditure is used as the household capacity to pay (CTP_h).

Finally, CHE ($cata_h$) can be determined by measuring the out-of-pocket payments (OOPh, i.e., diabetes spending) as a percentage of a household's capacity to pay. CHE occurs when a household's total OOP health payments equal or exceed 40% of the household's capacity to pay. The variable on CHE is constructed as a dummy variable with value 1 indicating a household with catastrophic expenditure, and 0 without CHE.

$$cata_h = 1 \text{ if } ^{oop}p_h / ctp_h \geq 0.4$$

$$cata_h = 0 \text{ if } ^{oop}p_h / ctp_h < 0.4$$

In developing countries, the use of household consumption expenditure is noted as the preferred measure of living standards (158,163), particularly in rural areas where subsistence economy made it difficult to determine household income (170). Also, the use of household income instead of consumption expenditure may lead to the overestimation of the household's capacity to pay and an underestimation of the true catastrophic healthcare expenditure incidence (169).

Among household expenditure items, food consumption expenditure is typically used as a standard weight for the threshold level for assessing catastrophe (135,168) as it accounts for a large proportion of household expenditure. The limited economies of scale from its consumption meant that such expenditure will likely be sensitive to household size and access to financial resources. The level of consumption can reflect the level of access to cash for the household (168).

3.4.6.6 Measuring impoverishment

The impoverishment impact of OOP was estimated by comparing the difference between the average level of headcount poverty (H) and poverty gap (G, which is the intensity of poverty or poverty deepening) with and without OOP. This followed the widely used methods as in earlier studies (64,155). Headcount poverty is designed to measure the percentage of individuals or households living below the poverty line. The poverty gap on the other hand, measures the intensity of poverty (the amount by which the poor households fall short of the poverty line).

Pre-payment headcount poverty ($H^{\text{pre-payment}}$) was calculated by comparing per capita household expenditure (including OOP payments for health care) with a poverty line estimated by the authors. Similarly, the post-payment headcount poverty ($H^{\text{post-payment}}$) was measured by comparing per capita household expenditure (excluding direct OOP payments for health care) with the poverty line. We used the poverty threshold based on the Malaysian national poverty line of RM 960 per household per month (228).

Assume z_i to be per month per household expenditure (including OOP payments for health care), y_i is per month per household OOP payments, P_L is the poverty line and n is the number of households. Pre-payment and post-payment headcount poverty measures can be expressed, respectively, as:

$$H^{pre-payment} = 1/n \sum_{i=1}^n \alpha_i, \text{ such that } \alpha_i = 0$$

$$\text{If } z_i \geq P_L \text{ and } \alpha_i = 1, \text{ if } z_i < P_L \quad (1)$$

$$H^{post-payment} = 1/n \sum_{i=1}^n \beta_i, \text{ such that } \beta_i = 0$$

$$\text{If } (z_i - y_i) \geq P_L \text{ and } \beta_i = 1 \text{ otherwise} \quad (2)$$

Similarly, the pre-payment and post-payment poverty gap can be defined, respectively, as:

$$G^{pre-payment} = 1/n \sum_{i=1}^n \gamma_i (P_L - z_i); \quad (3)$$

$$G^{post-payment} = 1/n \sum_{i=1}^n \gamma_i \{P_L - (z_i - y_i)\}, \quad (4)$$

where, $\gamma_i = 1$ (i.e. the household is poor) if $z_i < P_L$ and $\gamma_i = 0$ (i.e. the household is non-poor) if $z_i \geq P_L$. The headcount poverty is higher in Eq. (2) compared with Eq. (1) if OOP payments are positive. Similarly, the poverty gap is higher in Eq. (4) compared with Eq. (3). Thus, the difference between Eq. (2) and Eq. (1) depicts the headcount impoverishment impact of OOP payments. Similarly, the difference between Eq. (4) and Eq. (3) illustrates the intensity of poverty on account of OOP payments. More precisely, the headcount and poverty gap impoverishment impact of OOP payments can be expressed, respectively, as: $(H^{post-payment} - H^{pre-payment})$ and $(G^{post-payment} - G^{pre-payment})$.

3.4.7 Statistical analysis

All statistical analyses were performed by using *R statistical package* version 3.5.1 (The R Foundation for Statistical Computing). Univariate analyses of all variables were calculated and graphed to examine the distribution of the data and check for outliers. Descriptive statistics such as frequencies, percentages, means, ranges and standard deviation (SD) were used to describe socio-demographic and healthcare utilisation data. The bootstrap was used to estimate the standard deviation to adjust for positively skewed cost data. Categorical variables are expressed in absolute numbers and percentages. We calculated the interclass

correlation of patient clustering in households, and found that the statistical impact was small and non-significant, indicating that the analyses could be conducted without adjusting for a clustering effect.

For comparing baseline characteristics between CHE and non-CHE groups, independent sample t-test was used to estimate the significance difference between the two groups. The variables tested included socio-demographic (age, gender, education level, place of residence, number of household members), household economy (employment, household income, household expenditure), and disease condition (duration of diabetes, level of diabetes care, having co-morbidities, having diabetes-related complications). For non-normal distribution, the Kruskal-Wallis test was used, and the median and inter-quartile range was reported. Chi-square test was conducted to test the significance in the difference in proportions between the two sub-districts across income quintiles.

A p-value of ≤ 0.05 was regarded as statistically significant for the rejection of the null hypothesis. The variables tested were identified from the literature as statistically significant variables that are likely to have an impact on catastrophic healthcare expenditure. In reporting and interpreting studies, apart from the statistical significance, the substantive significance (effect size), i.e., the magnitude of the difference between CHE and non-CHE respondents were also reported. Regression analyses were conducted using binary logistic regression to calculate odds ratios (ORs) and their 95% confidence intervals (CIs).

3.4.7.1 Cost of illness

The cost of illness was calculated based on the reported cost items incurred in the survey in terms of direct medical cost, direct non-medical cost, and indirect cost. The mean cost for each cost item was estimated based on the overall respondent population. All cost items were adjusted to a monthly figure following the WHO methodology for estimating the catastrophic healthcare expenditure (128). Adjustment for positively skewed cost data was done through statistical bootstrapping on the mean. The distribution of diabetes-related out-of-pocket expenditure between quintile groups was mapped out based on the household income of the study population. For comparison, cost data is also expressed in US Dollars, using the currency exchange rate for Ringgit Malaysia 1 to USD0.235 (Central Bank of Malaysia, 11 June 2020).

3.4.7.2 Social predictors of catastrophic healthcare expenditure

The indicators of financial risk protection are derived from a household's expenditure, which reflects the existing inequalities in income and wealth. These indicators are increasingly being disaggregated in recent studies to examine the hardship imposed on different sub-population groups based on income, wealth, or other socioeconomic characteristics (127). Known socioeconomic predictors or determinants from related studies include sex, ethnicity, education of the household, residence (rural/urban), household size or composition, and the presence of chronic illnesses. These predictors have been associated with increased incidence and/or severity of financial hardship in different settings (129,133,134). Bivariate and multivariate regressions were conducted to identify the social predictors of household catastrophic healthcare expenditure through logistic regression.

3.4.8 Measurement validity

The questionnaire was pretested with a sub-set of household and focus group discussions were held with the field team to ensure the content and face validity of the measurement items in the questionnaire. All the items were adapted from previously validated measures (i.e., SEACO first round health survey questionnaires).

3.5 Phase 2 – qualitative research

Phase 2 explored the various contextual factors relating to household economic burden (objective 3). Two types of qualitative methods were used: in-depth interviews (IDI) and focus group discussion (FGD). The former was used to investigate how households cope with the economic burden, the decision-making process on household resource allocation, and the role of gender and cultural distinctions. The latter, on the other hand, was used to explore how households with diabetes in the two sub-districts utilized healthcare services.

3.5.1 Study respondents

3.5.1.1 In-depth interview

The pool of respondents for the IDI consisted of households who CHE, which was derived from the findings of Phase 1. With the specific pool of respondents identified in Phase 1, purposive sampling was conducted with research-based recruitment. This type of recruitment is known to be very practical when seeking greater depth of information from participants already involved in the study (236).

IDI is preferred over other methods as it provides detailed insights into the research issues from the emic perspective, specifically regarding;

- How they make household financial decisions
- Motivations behind their behaviour in managing diabetes and coping with cost burdens
- Beliefs and perceptions of managing diabetes
- Feelings and emotions of living with diabetes
- Social and environmental context surrounding their lives

In addition, issues surrounding personal financial status and money are often regarded as sensitive (237), where information on income and expenditure are oftentimes considered as very private information. In-depth interviews provided privacy for respondents as the interaction is one-to-one or amongst the respondents' household members. In finalising the list of households with diabetes to approach, some related socio-demographic key factors corresponding to the measured indicators in Phase 1 were taken into consideration:

- Gender
- Ethnicity
- Living location (rural vs. urban)
- Employment status
- Household size
- Years living with diabetes
- Having diabetes-related complications
- Having other chronic illness

A total of 15 respondents were identified and allocated into three groups based on the catastrophic healthcare expenditure severity level, i.e., borderline ($>0.4, <0.5$), mid ($>0.5, <0.8$), high (>0.8). The severity levels were derived based on the minimum and maximum value of catastrophic healthcare expenditure found in the study. Ultimately, 13 respondents were interviewed and two were unavailable. We did not conduct any further interviews after the 13th respondent as we found that the interview contents were becoming repetitive with no new information surfacing, which we subsequently concluded to have reached saturation point.

3.5.1.2 Focus group discussion

Two focus group discussions were conducted with individuals with diabetes identified by SEACO (in the first health round survey) in Sungai Segamat and Bekok. Similar to the in-depth interviews, purposive sampling was used and the respondents range of characteristic include;

- Aged 18 and above
- Male and female
- Mix ethnicity
- Varying severity of diabetes
- Understanding of own diabetes and its management
- Conversant in Malay language (discussion was carried out in Malay)

The FGD was conducted in Sungai Segamat with a group of five respondents, while the group in Bekok was larger with 11 respondents (Appendix 5).

3.5.2 Data collection method and tools

All qualitative interviews were conducted by the student researcher with the support of a SEACO data collector to identify houses and facilitate access to households. A copy of the “Study Information Sheet and Personal Data Protection Act” was provided and briefed to the respondents. Consent for the interview was sought earlier in the Phase 1 survey. Interviews were conducted primarily with the person with diabetes and also in some cases together with their caregivers. All sessions were audio-recorded conducted in either Chinese, Malay, or English, depending on the preference of the respondent after providing their consent. The time taken to complete one interview ranged from 30mins to 60mins. In ensuring consistency and data accuracy with the context and content, all transcriptions and translations were completed by the student researcher.

For the IDIs, a semi-structured interview guide (Appendix 2) was used as a memory aid to guide the interview session. A list of open-ended questions was developed and structured into four parts;

1. Opening questions
2. Questions on the economic impact on individual and family
3. Questions on coping with diabetes and its related economic burden
4. Closing questions

For the FGDs, a semi-structured discussion guide was used (Appendix 3). The questions in the guide were structured into two parts;

1. The range of health care providers sought and underlying reasons
2. Factors that constitute satisfaction and dissatisfaction with each health care provider

The two subtopics included key questions asking respondents about how, why and where they seek treatment for diabetes, their daily management regime, and experiences with the healthcare service.

3.5.3 Data management

Qualitative research data was stored in an online cloud system with restricted file sharing set up between research team members. The data was only accessible by the research team (i.e., student researcher and study supervisors). Coding was done manually and also through the *QSR Nvivo Software* for qualitative research.

3.5.4 Data analysis

Data was analysed through thematic analysis to identify the patterned meaning across the dataset. Thematic analysis was selected as the method of analysis to further connect and explain the quantitative results in Phase 1. The choice of thematic analysis was also due to its advantages of being theoretically-flexible for use within different frameworks to answer different types of research questions, and also suits questions related to people's experiences, views and perceptions (238).

The approach used for thematic analysis followed the process developed by Braun and Clarke (2006) (238) that involves six-phases:

- 1) Familiarising the transcript content
- 2) Generating codes from data extracts
- 3) Theme searching to identify broader patterns of meaning
- 4) Reviewing themes to ensure alignment with the research objectives
- 5) Defining themes and develop a scope and focus for each theme
- 6) Writing up an analytic narrative

While the phases are sequential, the analysis conducted was also a recursive process, with movement back and forth between different phases. Codes and themes were developed inductively as directed by the data, as also deductively from the conceptual framework of the study and the topics from the interview guides. These were subsequently structured into thematic frameworks for each subsection of the findings.

3.5.5 Data validity

Data validity of the findings in Phase 2 was established through several strategies as outlined by Creswell (2014) (211):

- Triangulation of different data sources of information by examining evidence from the sources and using it to build a coherent justification for themes. Themes were established by converging several sources of data and perspectives from participants.
- Use of rich description such as detailed description of the setting to convey findings.
- Clarifying bias of the researcher in the study to create an open and honest narrative of how the interpretation of the findings was shaped by personal background (e.g. gender, culture, history, socioeconomic origin) to embed a good sense of reflectivity.
- Discussing possible negative or discrepant information that runs counter to the themes to present a more realistic and valid sense of real life scenarios.

In terms of data reliability, the recommendations from Gibbs (2007) (239) qualitative reliability procedures were referred to;

- Transcripts were checked to ensure no apparent mistakes made during transcription.
- Data was constantly compared with the codes, alongside writing down memos on code definitions to ensure no shifting in the meaning of the codes during the coding process.

3.6 Ethical considerations

The study was approved by the Monash University Human Research Ethics Committee (MUHREC) (CF14/2053 – 2014001075). The study was embedded as a research project in the SEACO platform, which has obtained ethical clearance from MUHREC in how households in Segamat could be engaged and approach for data collection. Informed consent was sought from participants in both the qualitative and quantitative interviews in their

preferred languages. The purpose of the study, the procedures involved, as well as the risks and benefits of participating were explained. Respondents were aware that their participation was voluntary and that they were able to withdraw at any point during the study.

For qualitative interviews, there were ethical challenges specific to focus groups, in terms of the difficulty in controlling disclosure outside the group and ensuring that group dynamics did not hinder or encourage too little or excessive disclosure. To minimize these potential problems, ground rules were informed at the beginning of each session to provide confidentiality, respect of other's opinions, and fairness in expressing personal views and experiences. Unique ID's (e.g. IDI-xx or FGD-xx respectively for in-depth interviews and focus group discussion respondents) have been used to replace identifying details and protect the respondents' autonomy.

3.7 Personal reflections on the methodological approach in collecting household OOP cost items for evaluating the economic impact of chronic illness

(This section has been developed into a journal paper submitted to the Health Policy and Planning journal)

Concerns on the level of OOP have shaped emerging universal healthcare policies to prioritize reducing poverty impacts of catastrophic and impoverishing healthcare expenditure. In line with the changing policy priority, poverty impact is increasingly evaluated alongside and within economic evaluations to estimate the impact of health services as well as health interventions on poverty. However, the collection of data collection for metrics of catastrophic and impoverishing healthcare expenditure can be challenging in LMICs due to study design and practical limitations (240).

Studies that reported on the poverty impact of health expenditure are known to draw from data from large cross-sectional surveys such as the Living Standards Measurement Survey or the World Health Survey (240). These datasets are useful to facilitate equity analyses at the national level to evaluate the distribution of health impacts or the analysis of financial pooling mechanisms across socioeconomic status (63,241). However, unfortunately they cannot be easily used to capture the impact on poverty, and they may not always include the level of detail on indirect costs, which can be a critical cost component (16,127). Data on

indirect costs are more often collected within a smaller-scale study setting, despite challenges of increased time needed and cost of data collection (240).

Poverty impact data that are collected as part of intervention evaluations (e.g., an extension of a clinical) has notable inconsistencies in data collection methods. Despite using the same measure of poverty impact, systematic reviews of existing patient cost studies in LMICs highlighted a lack of standard approaches across cost components, data sources, sampling methodologies, and recall periods (17,62,242–244). The lack of standardised data collection can lead to challenges in assessing the comparability, quality, and accuracy of findings (240). Such a mix of approaches may stem from limited practical guidance or standards for collecting patient-incurred cost data.

In economic evaluations, reporting guidelines tend to address provider perspectives and are missing poverty impact metrics. They placed considerable emphasis on measuring outcomes and the policy implications, and lack guidance when it comes to data collection constraints that require compromise, such sample size limitations or shortening questionnaire length (245–248). Consequently, the choice for a collection method for resource use cost data is often a matter of discretion based on convenience and practicality instead of structured methodological considerations.

Attempting to fill the gap on the lack of standard reporting methods for measuring the impact of illness on economic vulnerability, Sweeney et al. (2016) (240) developed a framework of methodological choices in planning research on poverty impact metrics to encourage a standardized and transparent way of reporting. The framework also prompts consideration on the potential implications of varying approaches in data collection, and it consists of four key components;

1. Comprehensiveness of survey design
2. Timeframe and recall period
3. Sample size
4. Data source and administration

Drawing from these four key elements, we retrospectively reviewed how our study design and data collection processes compare with the theoretical framework. We also highlight the

potential advantages and limitations to guide future studies on collecting and reporting of poverty impact-related cost data.

Comprehensiveness of survey design

A notable challenge in survey design is the representation of complex patient experiences within a manageable survey length. When a patient cost questionnaire investigates a wide range of cost items alongside other aspects such as disease status and healthcare access, it increases the risk of survey fatigue, participation refusal, and requires more resources to conduct the survey (240).

In terms of the questionnaire content, available studies have known limitations with regards to the spectrum of cost ingredients collected. The focus was centred on direct medical-related costs, and other cost components such as indirect costs and loss of income were primarily neglected due to time constraints and the resource-intensive nature of data collection (240,249,250). Household coping with health shocks is also another layer of complexity that is scarcely explored in household expenditure surveys (127). Questions on healthcare utilisation were also typically not covered in the same study, though given the increasing focus on universal health coverage (UHC), healthcare utilisation has been suggested to be included to explore the linkage between health services and financial risk protection (127).

Our study attempted to capture the various aspects above (i.e., indirect cost, household coping, and healthcare utilisation) in a single survey. To address the problem of likely survey fatigue, we selected the mixed-methods approach that divided the cost component and household consumption questions in the Phase 1 survey questionnaire, and details on healthcare utilisation and household coping mechanisms were covered in a series of qualitative interviews in Phase 2. Similar mixed-methods approach, though in different variants, have been tried by Minh and Tran (2012) (251) and also Haque et al. (2013) (252).

Patient cost drivers are known to vary by setting and across income quintile groups (65,243), which makes it difficult to make generalised assumptions on any exclusions on each aspect of expenditure or income measured. In our study, to determine the full effect of managing diabetes on the entire household, we asked respondents to detail all direct medical and non-medical expenditures incurred for the management or treatment of diabetes. The cost we sought included costs associated with access to both formal (i.e., through clinics and

hospitals) and informal care (i.e., traditional and complementary medicine), as well as health supplement use. Respondents were also asked to list out the cost for buying medical devices related to diabetes, such as glucometers and glucose test strips, diabetic health shoes, bandages and antiseptics, and insulin pen needles, all of which required spending out-of-pocket. Direct non-medical costs included items such as transport fares, meals, and also the cost of caregivers. Indirect costs accounted for the foregone income of the person with diabetes or their household caregiver due to managing diabetes.

Another widely recognized challenge in designing surveys collecting household income is the measurement of income itself, which is made more difficult in LMICs whereby informal employment is common, and income is often seasonal (229,253). Income data is known to be difficult to collect as interviews in an intervention evaluation are often conducted with one household member (usually the head of household). This may have miscalculated the economic burden on the family, given that household members may be sharing income within the household (237). Hence, an appropriate proxy for household income relevant to the study context is critical, and the limitations of such a decision should be clear.

In our study population, a majority of the respondents were retirees who have no formal income sources. We sought data from the head of household or any household members who knew the overall household income and expenses, but this information may be over or underestimated in the absence of other household members when the survey was conducted due to proxy reporting. We tried to validate income data by cross-referencing it with expenditure data, which are considered more reliable (128,237) by observing any instances where expenses were reported to be higher than income. This process was greatly facilitated through the use of electronic data collection, where data can quickly be viewed and checked in the server database. Households with discrepancies in income data were identified, and the data collection team made a revisit to the particular household to do a follow-up interview and any data correction. In addition, we also opted to use the WHO method (63) for measuring catastrophic healthcare expenditure, which uses household expenditure data as a proxy rather than income data.

Sample size and representativeness

Sample size considerations are critical in the planning stages of a study and will depend on the aims, nature, scope of the study, and the appropriate degree of precision (254). The

United Nations guidelines of a 5–10% margin of error at the 95% confidence interval are usually followed, with further adjustment to account for clustering and non-response (255). But this degree of precision may be difficult to achieve, and researchers need to be pragmatic with some trade-off in error margin in the interests of the practicality of the survey. Furthermore, there are also considerations in deciding survey related uncertainties, such as conducting longer interviews to avoid recall bias may generate more reliable results than seeking to interview more respondents (240).

In our study, the respondents were not part of a sample, but the whole population of households with diabetes enumerated by SEACO. We were able to obtain a comprehensive list of households with diabetes of the study sites (sub-district Sungai Segamat and Bekok) identified from SEACO's health survey round in 2014). While this has addressed coverage error, non-sampling errors remained an issue that affected data quality, particularly in terms of non-response error. Possible non-response errors in the study included failure to obtain the intended information from respondents (due to household inaccessibility), refusal or inability to respond, and the clarity of the way questions were asked and to whom they are being asked.

Time frame and recall

The appropriate timing to conduct the survey is also an important aspect affecting data quality. One of the key factors lies in the circumstances around the living environment of the respondents, which can be social (e.g., certain events such as the Ramadan fasting month, or a post-election) or economic, such as crop harvesting periods. These two aspects can significantly affect the response rate as well as recall bias, leading to missing values and measurement errors (256). The former was demonstrated in the study by Wiseman et al. (2005) (257) on the usage of patient cost diary, where 38% of their respondents preferred to keep their cost diaries for less than six months, citing disruptions during farming seasons. The issue of recall bias was also evident in the study by Beegle et al. (2012) (258) where the time difference between cropping period and interview sessions was a key factor leading to recall bias. Thus the interviews about health care costs should be near contemporaneous to avoid the problem of recall bias but timed appropriately so as not to clash with other commitments.

Due to time and resource constraints, part of our questionnaire survey was inevitably conducted during the fasting month of Ramadan, and this has affected the availability and

response of Muslim respondents, who are the majority population. Data collectors had to make follow-up visits in some Muslim households to complete the survey as respondents were noted they were tired due to fasting or occupied in preparing for prayers and meals for breaking the Ramadan fast.

Data source

Identifying data sources and plan for survey administration, such as data collection tools, location, and the person conducting the survey, and medium of recording, are key factors to ensure accurate and effective capturing of data on patient costs and income (240). In terms of data collection tools for costing studies, the use of cost diary is known to be the gold standard in patient cost collection for its advantage in terms of minimising recall errors and better completion of data reporting (257,259). However, in low-income or rural settings where the illiteracy rate is likely to be high, training respondents to be able to fill up diary entries accurately and consistently on their own presented a notable challenge (247,257). In addition, in situations where respondents may feel that the information being gathered could incriminate them, for example, in recording undeclared income, using cost diaries may not be feasible (260). Due to these reasons, and also that diaries are time and cost-intensive to implement for researchers, we have opted for a cross-sectional household survey, which is more commonly used in LMIC settings (258).

Survey administration

Survey setting

Data quality is also dependent on where data collection is conducted. Administering the survey in a formal setup such as a health facility or research office may invoke potential non-response or inaccurate answers due to pressure or stigma and lack perceived privacy to disclose details on income and spending (240). In our study, we tried to minimize non-response associated with the interview location by surveying a private setting at the respondent's home or at community centers where respondents would feel most comfortable. Interviews were also conducted in the SEACO office, where regular community meetings and engagement activities take place. The respondents' comfort and needs determined the choice of location.

Quality of data collectors

It has been demonstrated that the competency of data collectors can substantially affect data quality (240). Information on personal income and expenditure is commonly considered as sensitive, and the ability of data collectors effectively communicate the interview purpose, and survey questions are critical to avoid under or over-reporting of cost data.

When conducting our study, SEACO provided us access to a highly experienced team of local data collectors who have strong engagement with the community and experienced in conducting interviews with electronic tablets. SEACO's data collection processes also conformed to ISO 9001 certification (261). The data collection team also reviewed the questionnaire and field-tested it to prove community feedback before commencing the fieldwork. The strategy helped to improve the content and the flow of the questionnaire. Our experience of the process was consistent with the study by Kufa et al. (2014) (262), which showed that using trained interviewers who understand the principles and rationale for collecting patient costs improved the quality of the data that are elicited. Similarly, Lievesley (1986) (263) and Couper and Groves (1992) (264) have also found that interviewers' survey experience is positively correlated with response rate.

Data collection tool

We employed Electronic Data Capture (EDC) as our primary tool for the Phase 1 data collection for its ability to enter, review and analyse data in real-time. Additionally, EDC also enabled online data validation checks to assure data quality at the point of entry. Known issues in LMIC settings on the usage of EDC mainly operational feasibility in the field, such as availability of infrastructures for internet connectivity and the more technical training required for data collectors (265).

We have had a positive experience of using EDC in our household survey. Without having to manually write down survey responses and embedding skip logics in the questionnaire, our data collection process was expedited. This led to a shorter survey length, which could minimise survey fatigue (240). The collected data was uploaded weekly at the SEACO office where internet is available, omitting the need for manual data entry from paper to the database, and lowering the risk of missing data due to missing questionnaire forms. Besides, the short data entry period from the time of the survey to the database was also found to improve data quality (266).

Internet connectivity did not pose a significant challenge, as the e-questionnaire can be conducted offline without interruption. Also, once the data has been uploaded, data checks can be immediately performed to check for completeness and detect data entry errors. If discrepancies were found, data collectors were prompted to revisit the affected households to update or redo the survey.

One notable issue we encountered using EDC was the longer preparation time needed for designing and testing the questionnaire as compared to conventional manual forms. Similar challenges are noted in other studies, in addition to the need for technical expertise in programming and database development, which may not be readily available in low-income settings (265). Nonetheless, a well-designed EDC has the potential to be more time-effective and accurate compared to conventional paper-based data collection.

Relationship with respondents

A critical factor in the success of collecting accurate cost data is the level of trust between the researchers and data collectors, and the community (257). Trust is an essential element in HDSS sites generally because they conduct longitudinal studies over many years. This requires consistent community engagement to build the levels of trust, which also facilitates a consistent, high response rate (above 80%) (208). Through SEACO's extensive community engagement program, which involves community members as part of their research projects (208,261), SEACO has established a long-term presence and familiarity within the Segamat community. This supports household access and the collection of data with minimal issues.

Conclusion and recommendations

From our field experience, we found that collecting household cost data through DHSS sites may improve the data collection process and data quality. With the availability of census data, households with diabetes can be quickly and easily identified for researchers to interview whole populations or samples. With a stable longitudinal cohort and an experienced team of local data collectors, HDSS sites can also potentially provide advantages in reducing non-response and non-sampling errors in terms of coverage error and responder bias as whole populations are mapped, and households are regularly engaged.

Data quality can be improved with the use of EDC, where data can be entered, reviewed, and analysed in real-time. Immediate access to the database enables households with data

discrepancies to be identified and revisits to be done quickly to clarify possible data errors, in addition to providing time and cost-savings as compared to paper surveys.

The fact that HDSS sites regularly collect socioeconomic data of income and expenditure makes it an ideal data foundation to conduct cost-of-illness or economic burden studies and poverty impact evaluations. Having a community cohort also enables cost data to be collected prospectively (such as using patient/cost diary) to minimize recall bias. Challenges of respondent training and information disclosure can also be mitigated by a trained data collection team and the high level of community engagement and trust built in an HDSS platform. A longitudinal cohort in HDSS sites can also assist in observing and exploring the effect seasonality has on expenditure, particularly in rural communities.

While our study provides a snapshot of costs incurred in a particular year, a more detail and accurate estimation of lifetime costs may require incidence-based studies coupled with modelling techniques. Such studies will give a more accurate understanding of the lifetime costs of diabetes, and the savings accrued from intervening at different stages of the disease. Demographic and health surveillance systems sites could act as platforms to implement such studies, as systems for following up individuals are already in place.

CHAPTER 4.0: STUDY FINDINGS

4.0 Introduction

This chapter presents the findings of the study, which consolidated the results from both the Phase 1 household survey and the Phase 2 qualitative studies. Incorporating the key elements in the conceptual framework described in chapter 3, this chapter is structured into three subsections which are also mapped to the study objectives;

- 1) household cost burden from managing diabetes (*objective 1*),
- 2) poverty impacts of living with diabetes (*objective 2*), and
- 3) household financial coping strategies and resource allocation (*objective 3*).

For purposes of anonymity codes and numbers were used for each respondent in the qualitative interviews (Appendix 4 and 5).

4.1 Background characteristics

This section provides a background of the respondents that included social and demographic characteristics, the disease burden of diabetes, and also insights on how respondents are living with diabetes.

4.1.1 Socio-demographic characteristics

The social-demographic characteristics of the study respondents are presented in Table 4.1. The mean age of the respondents was 63.4 (SD 11.1, min 29, max 87), with a majority (67%) of them over 60 years old, and a relatively few (1.8%) in the younger age category (age 18-39). Females with diabetes are more prevalent, accounting for 66%, and the population consisted mainly of Chinese and Malays (42.5% and 45.9% respectively), together with a smaller community of Indians (9.8%) and the Orang Asli (1.5%). In terms of place of residence, it was almost equally spread between rural (Bekok, 50.8%) and urban (Sg. Segamat, 49.2%). In terms of education level, most of the respondents in Sg. Segamat and Bekok (52.3%) only attended primary school, 14.7% of them reported having no formal education, and less than 3% of them attended university or obtained a professional certification. In terms of employment, slightly more than one-fifth (22.3%) reported having current employment. The median monthly household income reported was RM1,500 (USD352.5). Comparatively, the national household monthly median income is RM3,000

(USD705) (267). The median household spending found in the study was RM1,000 (USD235) per month.

Table 4.1 – Socio-demographic characteristics of study respondents

SOCIO-DEMOGRAPHIC CHARACTERISTICS	
Total population size, n(%)	327
Sungai Segamat	161 (49.2%)
Bekok	166 (50.8%)
Mean age of respondents	63.4 (SD 11.1, min 29, max 87)
Ages 18 – 39	6 (1.8%)
Ages 40 – 59	102 (31.2%)
Ages > 60	219 (67%)
Gender, n(%)	
Male	112 (34.3%)
Female	215 (65.7%)
Ethnicity, n(%)	
Malay	150 (45.9%)
Chinese	139 (42.5%)
Indian	32 (9.8%)
Orang asli	5 (1.5%)
Education level, n(%)	
No formal education	48 (14.7%)
Primary	171 (52.3%)
Secondary	99 (30.3%)
Tertiary	6 (1.8%)
Professional certification	3 (0.9%)
Employed/working, n(%)	73 (22.3%)
Household income (median)	RM1,500
Household expenditure (median)	RM1,000

4.1.2 Disease status

In terms of disease status, respondents in the two sub-districts have been living with diabetes for an average of 99 months (min 10, max 444). A total of 77 (23.5%) respondents reported having at least one diabetes-related complication. Seven (9.1%) respondents from those who reported complications have one complication, five reported to have two complications (6.5%), two reported to have three or more complications (2.6%). The remaining 63 (81.8%) mentioned they have some type of diabetes-related complications but could not specify the complications they have.

A total of 22 (6.7%) respondents in the study recorded seeking secondary care treatment for diabetes-related complications. These include microvascular (diabetic foot from neuropathy, retinopathy, and nephropathy) and macrovascular (cardiovascular issues) complications, as well as syncope due to hypoglycaemia. The average hospital length of stay was 5.7 days, and visits to health clinics took up an average of 112 minutes. With only one district hospital available in the whole of Segamat, apart from those living close to the hospital, travelling time evidently took a longer time than to clinics, averaging 53.5 mins vs. 26.6 mins. A majority of the respondents (79.3%) also reported a wide range of chronic co-morbidities, with the top three most common being hypertension (90%), vision problems (43.1%), and joint pain (34.6%). Out of those having co-morbidities, 80.3% of them have between one and three other chronic diseases, while the remaining 19.7% have more than three chronic diseases (Table 4.2).

Table 4.2 – Disease status of respondents

DISEASE STATUS	
Average duration of diabetes (mean, range)	99 months (10-444)
Reported to have diabetes-related complications, n(%)	77 (23.5)
1 complication	7 (9.1)
2 complications	5 (6.5)
3 complications	2 (2.6)
Don't know*	63 (81.8)
Secondary care treatment n(%)	22 (6.7)
Having co-morbidities n(%)	259 (79.3)

Types of co-morbidities** n(%)	
Hypertension	233 (90)
Vision problems	112 (43.1)
Joint pain	90 (34.6)
Heart disease	56 (21.5)
Physical mobility problems	40 (15.4)
Stroke	38 (14.6)
Other pain	31 (12.3)
Hearing problems	15 (5.8)
Asthma	10 (3.8)
1-3 co-morbidities	208 (80.3)
> 3 co-morbidities	51 (19.7)
Average travel time to healthcare facilities (mean)	
Outpatient	26.6 mins (min 2, max 240)
Inpatient	53.6 mins (min 2, max 180)
Average time spent in healthcare facilities (mean)	
Outpatient	112 mins (min 10, max 600)
Inpatient (days stayed)	5.7 days (min 1, max 20)

**unable to specify type of diabetes-related complications*

***multiple-choice responses*

4.1.3 Living with diabetes

Respondents experienced various challenges living with diabetes. These included both internal/personal (home diabetes management, emotions, daily lifestyle) and external (treatments received, support structure) that affected the optimal long-term management of the disease, quality of life, and the burden placed on caregivers. The internal and external challenges are presented below, with the specific items visualised in a thematic framework (Figure 4.1):

4.1.3.1 Internal

Personal barriers to diabetes management

One of the reported personal barriers was the fear of injection, which stopped them from initiating insulin therapy that could enable them to better control their glucose levels despite the doctor's recommendation.

"Yes, I know, but I'm scared of injection. A lot of people here also say no to injection. 2-3 people I know were asked to start on insulin, but we keep pleading the doctor no. In the next check-up, when the doctor sees the (glucose) level is lower, then we're safe, haha. It's been a year since and we keep saying this." [IDI-07]

Respondents also reported being fearful to see the doctor and are anxious about medical appointments, to the point of 'preparing' themselves to be in good glycaemic control as much as possible prior to the clinic appointment.

"I'm scared to go for clinic checkups. My check up is tomorrow, but I was scared for the past week so I went to buy meds from the pharmacy and take them before I go for check up...I see how it is, wait for 2-3 days then I go. So in the meantime I will keep a strict diet". – [IDI-07]

"That's why when it's almost time for a check up we will make sure to fast (to present low sugar levels". - [FGD-BK05]

In a multiethnic setting such as Malaysia, language can often be considered as a barrier in accessing healthcare, especially in the public sector, where the majority of healthcare professionals are Malays, and the medium of communication is typically Bahasa Melayu.

"For Malays it's not a problem, but for other races like Chinese sometimes they don't understand Malay. There are those who understand and those who don't." [FGD-BK01]

"The Chinese tend to be less proficient in Malay. Sometimes when we ask them things in Malay, they say they don't know anything." [FGD-BK02]

Some individuals felt ashamed of having diabetes and kept their conditions very private from the community, leading to undertreatment or even no treatment out of fear of stigmatization.

“Some people are ashamed of having diabetes and don’t want anyone else to know. Only until they cannot bear it, then we know.” [FGD-BK11]

Nonetheless, some of the participants have been living with diabetes for a long time, and have developed a sense of acceptance for the disease as part of their lives;

“When I first know I have diabetes, my reaction was we just need to accept it as our age is old. When we reach above 60, many illnesses will come to the body. Many of my friends are like that. I had it when I was 60, and now I’m 66. Old people will have it; there’s nothing much to do about it.”[FGD-SG01]

“Sometimes we see people who go to clinics to check. We ask if they have diabetes, and they say they’re just there for a check-up. They’re scared. Why are they scared? It’s a common disease these days. Women who are pregnant also get it.”[FGD-BK06]

Impact of diabetes on daily lives and activities

Diabetes has also affected the quality of life of respondents, particularly in terms of daily activities and productivity. Diabetes-related complications, ranging from poor wound healing, foot amputation, fatigue, and dizziness (due to hypoglycaemia), caused disruptions to daily activities and work.

“No, my leg is in pain. I haven't been working in the past three years. This part of the foot I have problems, and then this part, and this (pointing to ankle wound).” [IDI-06]

“Yes, of course. I can work a lot more last time. Now I can't. I do a little bit of work, and then I got tired. I have not worked for a long time.” [IDI-07]

“It didn't happen last time (affecting work) before I start on insulin. The doctor told me now I might get some dizziness.” [IDI-02]

Respondents were frustrated with how diabetes restricts their lifestyle, particularly in terms of diet.

“My diabetes has more or less burdened me. For example, eating is already giving me pressure. I have to choose carefully and avoid sweet and high carb (carbohydrate) foods.” [IDI-10]

Lifestyle disruptions caused by the additional need to manage diabetes at home have led to issues of self-medication. Respondents noted that they either deliberately missing their prescribed doses or adjusting the doses by themselves based on how they feel rather than following the proper regimen.

“Insulin yes, at 1030pm or 11pm. I don’t eat medicines consistently. It’s inconvenient, and there are many to take. If its insulin, I just adjust it to 16 and inject, wait for a few seconds, and it’s in.”[FGD-SG01]

“Insulin. I take it every day. In the morning, the doctor told me to inject 40 IU/ml, but I don’t want to, I’ll sweat a lot, so I reduce to 30 IU/ml. 30 in the morning, 30 in the evening. But this is good because if you eat medicine, it will affect the kidney. If it’s this (insulin), it goes direct to blood.”[FGD-SG04]

In addition, it was also found that having awareness and knowledge on how to optimally manage diabetes does not necessarily translate into action to improve disease management. Despite being advised and guided by their doctor to change to a healthier diet, the respondents noted that they don’t practice healthy lifestyle management despite being aware of its benefits and importance.

“Everything I will eat. A diet book was given to me but I don’t really look at it and just eat.”[FGD-SG01]

“I don’t control my diet at all.” [IDI-07]

4.1.3.2 External

Experiences with healthcare providers

There were mixed responses with regards to the access and use of healthcare services. Some respondents were favourable and satisfied with the healthcare providers, particularly at public health clinics.

“The service is very good. The nurses are very good. When you were sleeping, they will wake you up when it’s time for medication. They will say sorry for disturbing and then help you with your medication. When I hear this, I also feel happy.”[FGD-BK11]

“Ok, it’s clean and has ample space for seating” [FGD-SG01]

There was also an established sense of trust for the public healthcare service.

“I’m worried that taking anything aside from KK (government health clinic) medicines may cause problems. In that case, it’s not compatible (contraindication).” [FGD-BK05]

“Because we believe in the medicines provided.”[FGD-BK01]

“I don’t dare to (take traditional medicine). What if something happens? I’d just take the meds the government clinic gives.” [IDI-06]

“I just get my meds from the public clinic, my wife also goes there. I go to the clinics nearby here and also in Labis (nearest and one of the largest sub-districts).” [IDI-08]

“I only believe in medicines provided by the KK (government health clinic), that’s all I consume. Other things I don’t have the money to buy even if I want to.” [FGD-BK02]

However, frustrations and anger were also noted by some respondents who encountered negative experiences in public healthcare services.

“The public sector is full of people and not enough doctors. What can they do? The nurses just keep postponing appointment dates. For my condition, if I go to the government hospital, I think I would have been long gone (dead) already.” [IDI-11]

“When they inserted the needle, it was so painful for almost an hour. I told them I had enough and then went home. I cannot take the pain anymore. They are not making people better but giving pain to people, what is this??? I told the doctor I don’t want it (treatment) anymore and I want to go back.” [IDI-06]

“He (husband with diabetes) was in a lot of pain, and then we went to the hospital. The doctor kept asking me when did he get the wound, and I got angry. I just took him (husband with diabetes) to see him the other day, and he still doesn't know when. And then he (doctor) just kept quiet.” [IDI-08]

Fear of low-quality treatment was also talked about by respondents, particularly those who accessed hospital care in the public sector.

“Luckily, my son brought me to a private hospital. If I go to the government, they will surely have amputated my toe. I’m scared of public healthcare.” [IDI-10]

“When I was leaving the Segamat Hospital, the doctor actually asked me am I leaving and forgot that he had signed the discharge papers for me. You see, this also they don't remember. What kind of work are they doing there? That's why I'm scared.” [IDI-11]

Respondents tend to be passive when interacting with healthcare personnel, particularly the consulting doctor. Some of them described a sense of fear; *“That’s why when it’s almost time for a check-up, we will make sure to fast.”*(to get lower blood glucose readings during checkup) [FGD-BK05], and some were docile and preferred to remain passive despite having concerns on their condition;

“There’s a time when I went for a check, and they told me my readings were 5 (blood glucose reading). I asked them, are you sure it’s 5? Because if it’s 5, I tend to get tired easily. Then I just go home.”[FGD-BK07]

“I bought the equipment for diabetes (home screening). Before I go to the clinic, I checked at home, and it was low. When I checked at the clinic afterward, the reading was high...I didn’t say anything, I just observed.”[FGD-BK03]

There were even respondents who were skeptical and showed a sense of mistrust towards doctors;

“The sugar level will go down, the medicine is good but he doesn’t give to everyone. The insulin they use in the ward is different. A friend of mine went for eye surgery and has a sugar level of 17, the next morning when he was discharged it was 8. The best

insulin they keep and don't simply give out. For us, they (clinic doctors) give like the second one (second best)."[FGD-SG04]

Supportive environments

Disappointment was felt by some respondents, particularly concerning the lack of formal and informal support by their surrounding community.

"If they want to help, I mean, I'm not begging. People know my situation is difficult. So I won't go for begging; just let it be. If they come, then I receive it. If not, people will talk about it...I'm very tired of asking for help here and there. We never get any formal welfare support, like from the village chief or anything." [IDI-01]

Now BRIM (national financial aid program for the poor) is getting hard to get, not like previously. Now you have to fill forms, they will check your details, and then 2-3 months still, you will get nothing. [IDI-04]

We're tired of that...we will never get that...we are permanent residents and not citizens, so we are shut off from a lot of things. – [IDI-01]

"No, no one came, and no one will come. I've been sick for so long, no one there (MIC, Malaysian Indian Congress, political party representing the Indian Community) ever comes...I'm telling you, these politicians are really useless. Like my hospital fees for this while they (MIC) never offered any help. They know about my condition, but they didn't do anything." [IDI-11]

They seldom come back. Last time, I gave one of children about RM50,000-70,000. They are working now, but they do not give me money though they can afford to...I do not depend on my children. I gave RM40,000 to my son when he has mortgaged off his house. I cannot see my child living on the street. – [IDI-12]

Figure 4.1: Thematic framework of experiences living with diabetes



4.2 Cost of illness of diabetes

Cost data were collected from the patient's perspective, mapping out the various types of expenditure incurred in managing diabetes as well as the overall cost burden to the household. The mean cost for direct medical and direct non-medical items was estimated based on those respondents who had reported spending. Indirect costs were estimated for respondents with employment using the Human Capital Approach, with the national monthly wage of RM960 as the proxy measurement. Cost findings are presented in adjusted values where statistical bootstrap was used to estimate the standard deviation for positively skewed cost data. The currency exchange rate for Ringgit Malaysia to US Dollar is RM1 to USD0.235 (Central Bank of Malaysia, 11 June 2020).

4.2.1 Cost burden of diabetes

4.2.1.1 Direct medical cost

Outpatient care

The average outpatient cost for households with diabetes was found to be RM12.7 (SD 1.7) (USD3.0) per month. Given that outpatient treatment cost in public clinics is nominal

(registration fee of RM1 (USD0.235), consultation and medications are free thereafter) for Malaysian citizens. The overall outpatient OOP spending incurred by respondents in the study was related to visits to private clinics and the purchase of medical devices such as needles for insulin pens, alcohol swabs, bandages, and antiseptics. Visits to private clinics were mainly driven by convenience and time-saving, as public clinics are known to be crowded, and working individuals are not keen to spend the time waiting for care.

“I heard about it, but I don’t go there (public clinic). All my check-ups were done in the private clinic... I’m already used to it.... for me. I just want it to be easy and fast. I don’t have time as I have to work.” [FGD-SG05]

We also found that private care was preferred for acute conditions such as fever or flu, whereas public clinics were frequented for chronic illnesses. This showed a reliance on the public health service for the continuous provision of drugs and regular check-ups for long-term chronic care. The private sector is preferred for faster access (i.e., shorter waiting times) and treatment of acute medical conditions and symptoms.

“For diabetes medication and check-up, we go to KK Bekok (public clinic). We go to Batu 8 (private clinic) when we have other illnesses like stomach ache, fever, etc.” [FGD-BK05]

The quality of care was also an important aspect that drives respondents to seek private care.

“I am used to Dr. X (private GP). Treatment from government clinic here is not as good”. [IDI-12]

“Erm, I don't really quite like how they work. When we go and want a check-up on the same day they say cannot, and ask us to come back on another day. How can we wait until then? That's why my son says, don't go there (public care) and just go to private care. The money is fine.” [IDI-11]

Long waiting time in public clinics was one of the notable complaints highlighted. Respondents waited an average of 112 minutes at government clinics for each visit for a diabetes check-up.

“The biggest problem is we have to wait (in public clinics). The rest is like normal, they only give medicines, and there is no big difference.” [FGD-SG01]

“When doctors come in, they don’t see you immediately. When they do see you, it could sometimes be in the afternoon, and you could have fainted.” [FGD-BK06]

Depending on the condition of the diabetes patient, a clinic visit could take a full day.

“If your readings (blood glucose) are high, sometimes they (clinic doctors) will call you and give you a drip, and that can take up a whole day.” [FGD-SG04]

In comparison, waiting times at private clinics were noted to be much shorter.

“I go there (private clinic) early in the morning around 9am, then complete within 20mins.” [FGD-SG05]

While treatment and medication are provided free in government clinics, the associated supplies required for long-term management and homecare of chronic disease are not. People with diabetes on insulin therapy require insulin pen needles for their injections, which they have to buy OOP. Similarly, for patients requiring regular wound cleaning due to diabetes, essential items such as bandages and antiseptics need to be purchased.

“The needles are expensive. One piece is already 60 cents. The most you use it two times then you throw, but we use up to 5-6 times because it’s expensive. In total, it costs around RM100 (USD23.5) per month.” [FGD-SG01]

“I clean my wound two times a day. It used to be three times but now reduced. The pharmacy told me now the items are getting more expensive. I used to buy this bandage for RM8 (USD1.9, and now it’s RM10.50 (USD2.5). The medicine, plasters, everything increased”. – [IDI-06]

“Treatment at the hospital there in Johor Bahru is free, but the wound cleaning the cost for it is a lot, and I’ve been doing cleaning for 40 days”. – [IDI-02]

The availability of many healthcare facilities is also an important factor for access. Currently, there is only one public and two private clinics in Bekok, while more government and private clinics are spread out in Sg Segamat town providing more access options.

“We want to complain but can’t because there’s only one clinic (public) and have to take it.”[FGD-BK07]

Public clinics and the district hospital both face shortages of medical supplies and equipment, which forces people with diabetes to seek either private care or travel far to adjacent districts for care.

“I buy bandages and wound cleaner because I clean my wounds at home. Sometimes I go to Batu 8 clinic (private clinic established for estate workers), but not the normal (public) clinic because they usually don’t have supplies for wound cleaning.”[FGD-BK06]

“Patients prefer the wound cleaning from Batu 8 (clinic) than the Bekok clinic (public) here because the wound dressing at Batu 8 is better, and sometimes nurses from the Bekok clinic refused to help and told patients to do the dressing by themselves at home instead. Nurses from the Bekok clinic also do not provide wound cleaning at home for those who cannot go to the clinic due to disability or bedridden.” [IDI-05]

Inpatient care

Only a small number of respondents (five) sought secondary care in the study. This amounted to RM11.3 (SD7.3) (USD2.7) per month in average across the study population, but the cost can range up to RM2,087.5 (USD490.5). In Malaysia, though public secondary care for citizens is heavily subsidised, it is not entirely free. There are still numerous costs involved, which can still impose a burden on lower-income households depending on the types of complications and treatment sought. For example, in the case of intraocular lens replacement (for cataract), patients will still need to buy the artificial lens OOP. The hospital will only bear the cost of the surgery and the ward.

“We got them (intraocular lens) from the government hospital. Yes, we did pay for the lens, but operations were free.” [IDI-05]

Some sought secondary care treatment outside of Segamat district, traveling as far as the city of Kluang (110 kilometers away). Better quality of care was cited as the primary reason for such a willingness to travel and pay OOP. The range of care provided was also more comprehensive.

“Of course it’s ok though it’s expensive (private care). This one (showing amputated toes) where I got it cut, and it costs RM8,000 (USD1880) in Melaka (an adjacent state approximately 101.3 kilometers away),” [FGD-BK06]

“They (Segamat hospital’s doctors) didn’t check thoroughly. Then I told my son, ‘your dad has this problem now, and he has to operate, how do we do about it?’ He said, ‘no need mom, we go to Kluang (private hospital).’ We brought him over to Kluang and he was operated on the next day.” [IDI-08]

Government hospitals also face resource limitations in terms of human resources and medical equipment, which drives patients to seek private care.

“No (unavailability of a public surgeon). This is why most people will go to KPJ (private hospital) for this surgery (eye lens replacement for cataract due to diabetes) though it is a private hospital. We buy the lens by ourselves from the list of places given by the (public) hospital.” [IDI-05]

Traditional and complementary medicine (TCM)

Spending on TCM care was found to be the largest cost item, with a monthly average of RM20.8 (SD2.3) (USD4.9) spent on purchasing health supplements and traditional medicine to treat and/or maintain good blood glucose control. A total of 138 respondents (42.2%) are willing to pay OOP to consume a variety of TCM care products. Consumption was found to be influenced by two key factors: product advertisement and word-of-mouth in the community. Health supplements are typically sold in retail pharmacy outlets and also through direct sales marketing. At the same time, traditional medicines are available through direct sales, Chinese medical halls, and also sharing among community members. Health

supplements are sold over-the-counter and are not as strictly regulated like pharmaceutical drugs. Often, supplements and traditional medicine products promote a wide range of health benefits and therapeutic claims, and some examples collected from respondents are illustrated in Image 4.1 to Image 4.5.

“Recently, I buy this Rama-Rama tea. I saw it in the newspaper, and then I buy it. My blood pressure went down, from over 200 to 100 something.” [FGD-SG02]

“All sorts, like calcium... I buy it on my own. I go to the shop and ask them (sales personnel). And these (a new batch of medical items) are the items he needs for wound cleaning. I bought all of them.” [IDI-08]

“Yes, we buy vitamins. You see now that his (husband with diabetes) wounds have dried upright, so we have stopped buying the meds for his wounds and start buying vitamins. We buy them from the pharmacy. It's not cheap as well. Every time my purchase is about RM100 (USD23.5).” [IDI-08]

Image 4.1: Medical device promoted through direct sales marketing to improve blood circulation for people with diabetes



Image 4.2: Supplement consumed for maintaining nerve health



Image 4.3: Various types of supplements consumed for managing diabetes

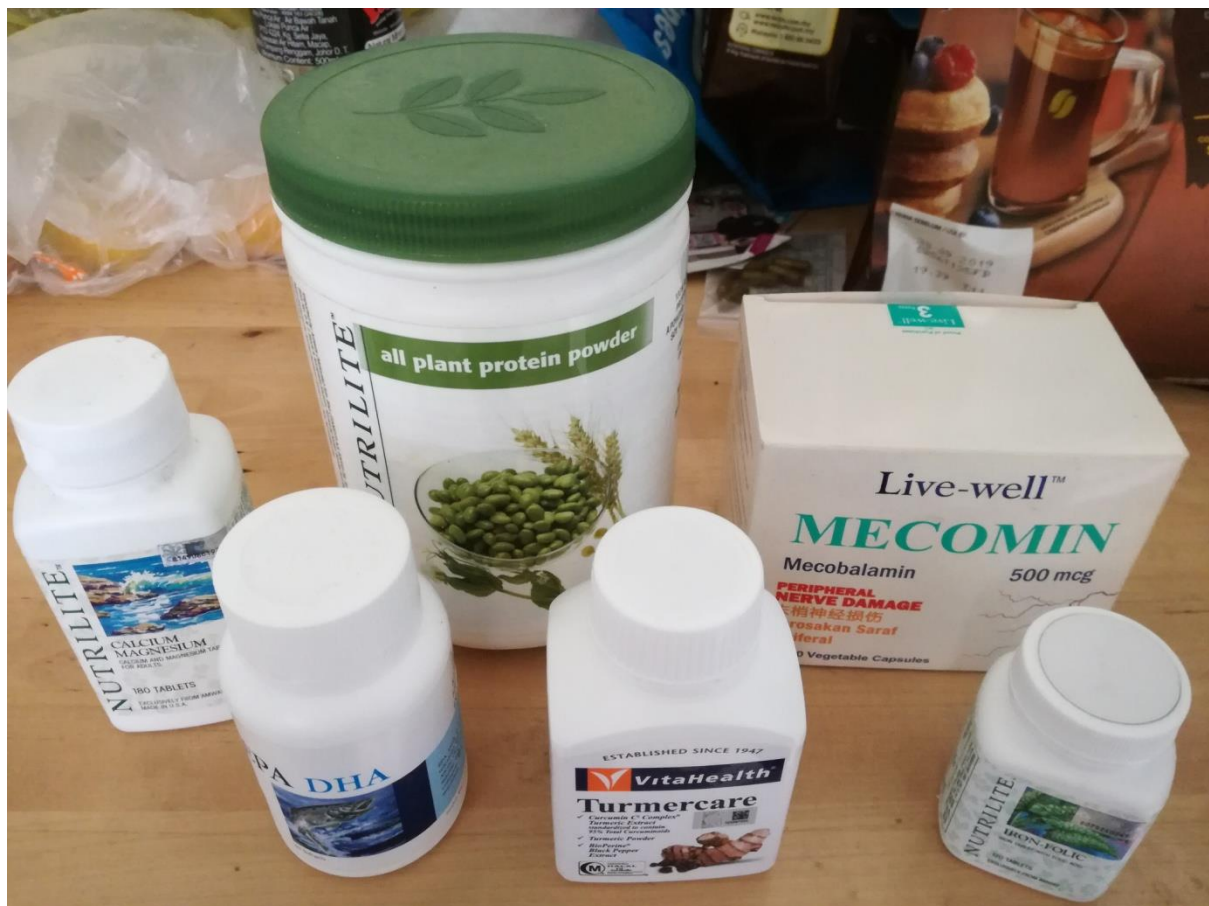



Image 4.4: Numerous health benefit claims of Stevia, an artificial sweetener promoted for people with diabetes



AGROFARM
STEVIA Premium Sini

PENGENALAN
 STEVIA (Disebut sebagai STEE-vee-uh), adalah pokok renek Amerika Selatan yang berasal daripada Paraguay, dimana daunnya telah digunakan sebagai pemanis oleh orang India Gu daripada beribu tahun dahulu.

KANDUNGAN STEVIA
 Bahan utama Stevia adalah Stevioside dan Rebaudioside, dan kedua-dua bahan ini mempunyai banyak kelebihan, ia bebas kalori, dan mempunyai rasa manis yang tinggi berbanding dengan gula. Telah dibuktikan 200 hingga 300 kali lebih manis daripada gula.

KELEBIHAN STEVIA
 Stevia adalah bebas dari kalori, tidak ada toksik, karbohidrat sifar dan memberi manfaat kepada masalah kencing manis, obesiti, tekanan darah tinggi, kerosakan gigi, dan kandungan gula dalam darah yang tinggi atau rendah (hypo- and hyperglycemia). Ia semulajadi, alternatif yang selamat menggantikan gula dan pemanis sintetik seperti aspartame dan saccharine.

BEBASKAN DIRI ANDA DARIPADA KALORI! GUNAKAN STEVIA HARI INI!

ANTARA CIRI-CIRI STEVIA :-

- ✓ Menurunkan kadar gula dalam darah.
- ✓ Melawaskan kencing.
- ✓ Mencegah kegagalan buah pinggang.
- ✓ Merawat Batu Karang.
- ✓ Mencegah Gangrene.
- ✓ Menghalang kerosakan saraf.
- ✓ Menurunkan tekanan darah.
- ✓ Membunuh dan anti-bakteria, kulat dan virus.
- ✓ Baik untuk Gastrik, Ulcer, dan Buasir.
- ✓ Membantu mata yang rabun akibat saraf.
- ✓ Mengurangkan keradangan.
- ✓ Membantu menurunkan berat badan.
- ✓ Kulit yang cantik dan bersih, merawat jerawat dan ruam.
- ✓ Mengawal Gout dan Sakit Sendi, Lutut dan Pinggang.
- ✓ Boleh digunakan di bahagian luar seperti luka, melecet, dan kulat air celah jari.

• 1 botol 12ml / 250 titik • Disyorkan dua titik untuk segelas air
 • Tahan sebulan jika digunakan setiap hari

Kesihatan Diutamakan, Huf

Word-of-mouth was also found to have a significant influence on consumption. Suggestions or recommendations from someone with whom patients are familiar seem to have a decisive influence on the choice of treatment.

“I buy this medicine, Sauda, it’s like fish oil. And then I buy olive oil—only these two. One packet cost about RM10-12 (USD2.4-USD2.8), I eat one of these each... yes, someone told me it’s good for diabetes, and so I eat.”[FGD-SG01]

“People are saying it. And that's why I drink it (bitter gourd juice), even though not very frequently. I take that to reduce my blood sugar. But if my blood sugar is four and below, I can't take it. I get weak. And I know it’s because of my diabetes.”[IDI-01]

“Yes, my father did. His friend recommended (traditional medicine) to him. My father paid this out from his pocket. He tries whenever someone recommends” - [IDI-05]

Image 4.5: Homemade dried bitter gourd traditionally consumed to reduce blood sugar level



Self-monitoring of blood glucose

Aside from treatment, the home management of diabetes also imposes additional monthly out-of-pocket costs with regards to self-monitoring of blood glucose (SMBG). Patients, particularly those with more advanced diabetes requiring insulin therapy, need to conduct regular SMBG tests using a glucometer to monitor their condition for any major spikes or drops in blood sugar level. This requires the purchase of not only a glucometer but also test strips, lancets, and alcohol swabs, which are not covered by public healthcare. An average of RM14.2 (SD1.5) (USD3.3) per month was spent on SMBG items.

“One more thing, if we use the machine to check our blood sugar right, the paper (glucose test strip) is expensive. One pack is more than RM40 (USD9.4). That also I will ask for free (from health minister).”[FGD-SG01]

“I also check my sugar levels regularly once a day, but sometimes only 3-4 times a week. The card (glucose test strip) is expensive. I can't take it.” [IDI-06]

4.2.1.2 Direct non-medical cost

Direct non-medical cost included costs for meal and transportation incurred when respondents were accessing healthcare services, as well as spending on hiring caregivers. The average cost spent on food while seeking outpatient treatment was RM3.5 (SD0.7) (USD0.8), traveling for outpatient care RM4.9 (SD0.4) (USD1.2). Malaysia has a high level of physical accessibility and coverage for healthcare services, with 92.5% of the population residing within 5 km of a government health facility. In the Segamat district, there are 35 public clinics located across all sub-districts to meet the national benchmark of one health clinic and four rural clinics per 20,000 people (Allotey et al., 2014). The location of the clinics are typically in town centers where the population concentration is the highest to provide ease of access.

“Yes, because we have clinics at Bekok. If there is no clinic at Bekok, there will also be transportation cost to the patients to travel to Segamat town.” [IDI-05]

On average, the spending on travel to secondary care was low at RM0.9 (SD 0.7) (USD0.2). From the qualitative data, we found that community carpooling was a common avenue for people to go to the hospital.

“Sometimes, people at Bekok will carpool with me if we happened to visit the hospital on the same day.” – [IDI-05]

Nonetheless, some respondents have spent up to RM212.5 (USD49.9) to access inpatient care. These households opted to travel outside of Segamat for secondary care due to dissatisfaction or lack of services by Segamat hospital. They traveled either to other districts such as Muar or Johor Bahru or outside the state of Johor to seek secondary care as far as Melaka and Kuala Lumpur (approximately 200 kilometers away).

“At first, it was a small operation in Segamat hospital; on the first day, the infection wasn’t that bad, but on the second day, it got worse and turned black. The doctor says need to amputate, and I asked when he said within two days. I went to Melaka straight on the same day at 7pm for the surgery, and it’s cut until here (showing toes), if it’s here (Segamat) then I might have to amputate till here (pointing ankle). I spent three nights over there.” [FGD-BK06]

“When I first got this foot injury, I went to Segamat hospital. After that, they send me to Muar (district hospital).” - [IDI-06]

Respondents from Bekok also incurred higher travel costs to access secondary care, as the nearest hospital is the Segamat district hospital, which is situated 40 km away.

“I pay for it too (taxi fare). It costs around RM6-7 (USD1.6) per trip from Bekok to Segamat.” [IDI-12]

“My friend’s car. I pay RM20 ((USD4.7) to my friend to go there and come back (from Segamat Hospital). It is considered cheap. If it’s a taxi, it’s RM35 (USD8.2). I can’t afford the Muar trip. I can’t really go far either as my son is still studying here. When he has finished studying, then yes.” – [IDI-07]

A small number of households (3) hired a maid or nurse to provide care for the person with diabetes. These helpers are either permanently (live-in) staying at the house, or come at particular hours of the day or week to do household chores and attend to the person with diabetes’ needs (e.g., feeding, bathing, monitoring blood sugar levels). Overall, the hiring of

caregivers cost an average of RM9.8 (SD5.9) (USD2.3) per month, which can range up to RM1,600 (USD376) monthly.

“They (her children) pay for the maid who is with me. It is about RM 1600 per month.” [IDI12]

4.2.1.3 Indirect cost

Patients

Respondents seeking outpatient care incurred an average loss of income of RM6.7 (SD 0.9) (USD1.6). Long waiting times was one of the key issues of public clinics, which may require those who are employed to take considerable time off from work to seek treatment at the clinic.

“On Thursdays, it’s long (waiting time). Treatments will only start after their meeting. It’s until at least 10am, I have fasted the day before, how can I bear the hunger? If they know they’ll be having meetings every Thursday, then don’t give patients appointments on that date. If anyone of you been there on Thursdays, you’ll know. I have experienced it two times.”[FGD-BK06]

Two respondents reported a loss of income for being hospitalised due to diabetes. In total, the average cost was found to be RM5.7 (SD 4.0) (USD1.3) per month for the study population, which ranged up to RM991.7 (USD233). Depending on the severity of their condition, some patients spent up to 20 days in the hospital.

“That time when I was unconscious (due to hypoglycaemia), they sent me to Segamat Hospital. For ten days I was there. I really want to go home; I cannot take it. The doctor comes and checks me every morning, and I keep asking him when can I go back” – [IDI-11]

Caregivers

The cost burden was not only felt by the respondents themselves but also imposed on the daily lives of their caregivers. Caregivers sacrificed their job or regularly took leave from work to care for the household member with diabetes, particularly those who are immobile (e.g., wheelchair-bound) due to diabetic foot complications. The overall average indirect cost

of informal caregivers (i.e., family members) was found to be RM2.6 (SD 0.8) (USD0.6), with an upper range of RM206.8 (USD48.6).

“Diabetes made my legs weak. Now my son helped me manage (plantation estate).”

[IDI-11]

“From Bekok I used to go there (Johor Baru hospital) every day for three whole months.” [IDI-01]

“I sell chendol (a local dessert) actually last time, now I just stay at home and take care of him (husband with diabetes).”[IDI-08]

4.2.2 Overall cost of illness

Overall, we found that households spent an average of RM93.1 (SD 14.2) (USD21.9) monthly OOP spending to manage diabetes. The largest cost component was direct medical cost, which amounted to an average of RM59.0 (SD8.5) (USD13.9) and accounted for two-thirds (63.4%) of the total monthly OOP cost (Figure 4.2). The high proportion of direct medical cost was mainly driven by spending on monthly consumable items, i.e., blood glucose monitoring and purchase of TCM care products (supplements and traditional medicine) at RM14.2 (SD1.5) (USD3.3) and RM20.8 (SD2.3) (USD4.9) respectively. Direct non-medical cost was the second-highest cost component, accounting for one-fifth (20.6%) of the total cost with an average monthly spending of RM19.1 (SD6.2) (USD4.5). Total average indirect cost was found to be the lowest, accounting for 16.1% with an average amount of RM15.0 (SD4.3) (USD3.5) (Table 4.3).

Table 4.3 – Estimated overall cost burden of diabetes

Types of cost	n	Mean (RM)*	Standard Deviation	Range [§]	Standard Error	
Direct medical cost	231	59.0	8.5	2287.5	0.09	63.4
Outpatient care	159	12.7	1.7	233.3	0.02	
Inpatient care	5	11.3	7.1	2087.5	0.07	
TCM care (supplements & traditional medicine)	138	20.8	2.3	400.0	0.02	
Self monitoring of blood glucose	102	14.2	1.5	200.0	0.02	
Direct non-medical cost	175	19.1	6.2	1620.0	0.06	20.6

Outpatient transportation	171	4.9	0.4	50.0	0	
Inpatient transportation	5	0.9	0.7	212.5	0.01	
Outpatient food/meals†	105	3.5	0.7	200.0	0.01	
Formal caregiver	3	9.8	5.9	1600.0	0.06	
Indirect cost‡	113	15.0	4.3	1027.1	0.04	16.1
<i>Loss of income of person with diabetes</i>						
Income loss (outpatient)	73	6.7	0.9	125.0	0.01	
Income loss (inpatient)	2	5.7	4.0	991.7	0.04	
<i>Caregiver cost</i>						
Income loss of informal caregiver	45	2.6	0.8	206.8	0.01	
Overall patient cost per month		93.1	14.2	3349.6	0.14	100

*Mean was estimated based on the total respondent of 327. Statistical bootstrap was used to estimate the standard deviation for positively skewed cost data

†Inpatient food was provided for by the hospital

‡Respondents who reported having employment

§Range value shown is unadjusted to illustrate maximum value

Figure 4.2: Distribution of key cost components

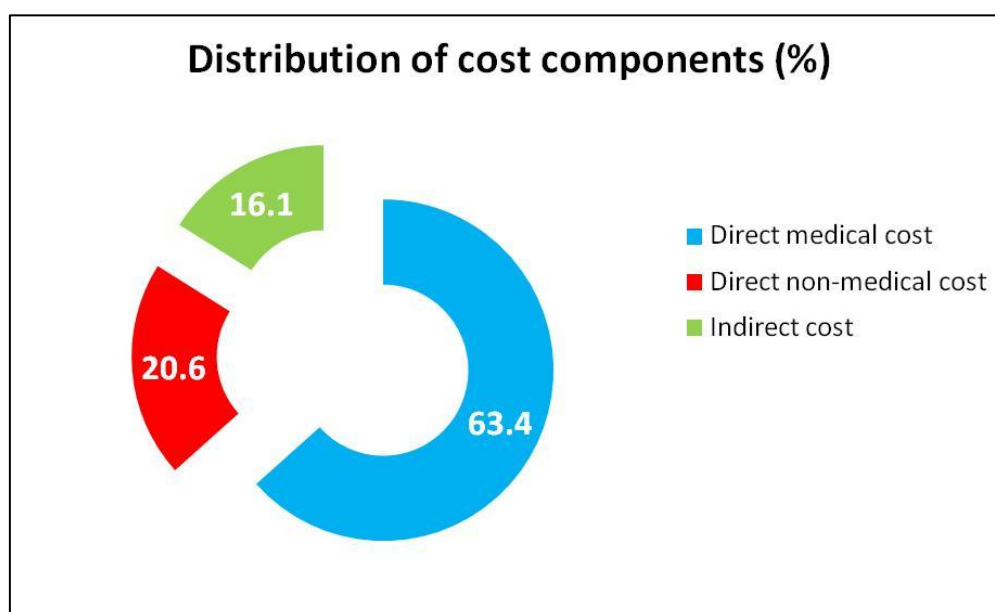


Figure 4.3: Mean monthly out of pocket payment by income quintiles

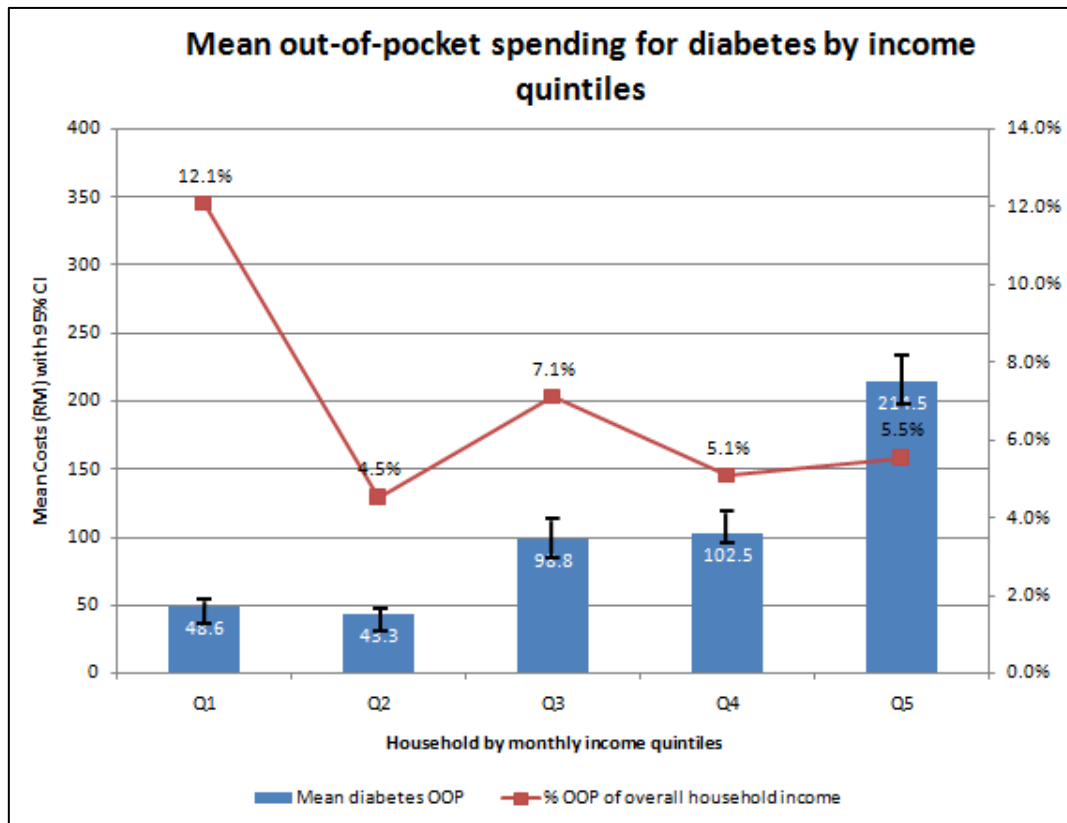


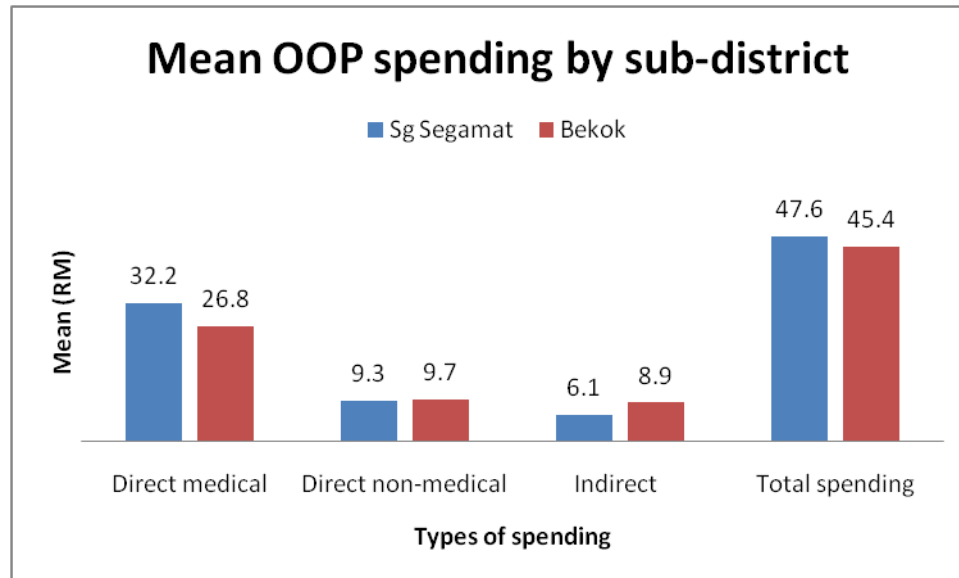
Table 4.4: Mean household income and expenditure across income quintiles

	Mean spending	Standard deviation	CI (95%)	Mean income	% OOP of income
Quintile 1	48.6	12.6	45.6 - 51.6	402.4	12.1
Quintile 2	43.3	6.2	41.8 - 44.8	959	4.5
Quintile 3	98.8	26.7	92.5 - 105.1	1393	7.1
Quintile 4	102.5	27.1	96.3 - 108.7	2016.4	5.1
Quintile 5	214.5	67.9	196.0 - 232.9	3880.4	5.5

In terms of the distribution of economic burden across sub-population groups, we found that the lowest income group spent less overall, with an average of RM48.6 (SD12.6) (USD11.4) compared to the richest income group average spending of RM214.5 (SD67.9) (USD50.4). Conversely, the lowest income group incurred the highest proportion of out-of-pocket spending from total household income (12.1%), and this proportion has a downward trend as household income increases. OOP expenditure also increased steadily by income quintile. The richest quintile (Q5) on average, spent four times more than the poorest quintile (Q1).

However, as a percentage of total household income, the poorest group spent more than twice as much as on managing diabetes than the richest group (Table 4.4).

Figure 4.4: Household mean out-of-pocket spending on diabetes by sub-district



In our study, respondents in Sg. Segamat (urban) were wealthier compared to Bekok (rural) (Chi-square test, $p=0.01119$). Overall, respondents of both sub-districts spent nearly similar amounts to manage their diabetes (RM47.6, SD7.6 (USD11.2) vs. RM45.4, SD12.5 (USD10.7)). Similar to the overall cost of burden, direct medical costs remained as the highest cost component (RM32.2, SD3.8 (USD7.60) and RM26.8, SD7.9 (USD6.3)) for both Sg. Segamat and Bekok respectively, with respondents in both areas spending nearly three times more than direct non-medical costs (RM9.3, SD2.8 (USD2.2) and (RM9.7, SD5.5 (USD2.3)). Indirect cost was the lowest cost component, with respondents in Bekok incurring higher average costs (RM8.9, SD3.2 (USD2.1)) than those in Sg. Segamat (RM6.1, SD2.9 (USD1.4)) (Figure 4.4) .

Closer examination of the cost items under each cost component revealed that under direct medical cost, consumption of TCM care products was one of the highest spendings in both Sg. Segamat and Bekok, with an average monthly spending of RM12.3 (SD1.6) (USD2.9) and RM8.6 (SD1.9) (USD2.1) respectively. Respondents in Bekok spent more on average on inpatient care than those in Sg. Segamat (RM9.4, SD6.9 (USD2.2) and RM2.1, SD1.8 (USD0.5)), with an upper range of up to RM566.5 (USD133) (Sg. Segamat) and RM2087.5(USD490) (Bekok). Inversely, Sg. Segamat respondents consumed nearly four

times more on self-monitoring of blood glucose (RM11.2, SD1.5 (USD2.6)) than those in Bekok (RM3.1, SD0.6 (USD0.7)).

Regarding direct non-medical cost items, the key expenditure was on the hiring of caregivers to help to manage the daily activities of the person with diabetes, which can range up to RM800 (USD188) in Sg Segamat and RM1600 (USD423) in Bekok. For indirect costs, income loss from hospital admissions was found to have a substantial cost impact, whereby these costs can range up to RM875 (USD206) and RM991.4 (USD233) respectively for Sg. Segamat and Bekok

Table 4.5: Household mean OOP spending on diabetes by sub-districts

Types of cost	Sungai Segamat				Bekok			
	n	Mean (RM)*	Standard Deviation	Range§	n	Mean (RM)*	Standard Deviation	Range§
Direct medical cost	120	32.2	3.8	696.8	113	26.8	7.9	2287.5
Outpatient care	73	6.7	1.3	233.3	86	6.0	1.2	207.0
Inpatient care	2	2.1	1.8	566.5	3	9.4	6.9	2087.5
TCM care (supplements & traditional medicine)	100	12.3	1.6	266.7	38	8.6	1.9	400.0
Self monitoring of blood glucose	64	11.2	1.5	200.0	38	3.1	0.6	100.0
Direct non-medical cost	120	9.3	2.8	866.6	56	9.7	5.5	1620.0
Outpatient transportation	117	3.2	0.3	33.3	54	1.8	0.3	50.0
Inpatient transportation	2	0.7	0.6	212.5	3	0.2	0.2	50.0
Outpatient food/meals†	78	3.0	0.7	200.0	27	0.5	0.1	20.0
Formal caregiver	1	2.5	2.5	800.0	2	7.3	5.5	1600.0
Indirect cost‡	48	6.1	2.9	906.3	70	8.9	3.2	1027.1
<i>Loss of income of person with diabetes</i>								
Income loss (outpatient)	27	2.9	0.7	125.0	46	3.7	0.7	104.2
Income loss (inpatient)	1	2.7	2.7	875.0	1	3.1	3.0	991.7
<i>Caregiver cost</i>								
Income loss of informal caregiver	22	0.5	0.1	12.5	23	2.1	0.8	206.8
Overall patient cost per month		47.6	7.6	1832.3		45.4	12.5	3349.6

*mean is estimated based on the total respondent of 32. Statistical bootstrap was conducted to estimate the standard deviation for positively skewed cost data

†inpatient food is provided for by the hospital

‡respondents who reported to have employment

§Range value shown is unadjusted to illustrate maximum value

4.3 Poverty impacts of diabetes

This subsection addressed Objective 2 of the study and assessed the poverty impacts from the economic burden of diabetes.

4.3.1 Catastrophic healthcare expenditure

In the surveyed population (Phase 1), the overall prevalence of catastrophic healthcare expenditure was found to be 19.9% (65 households). In terms of the distribution of CHE, households in the lower-income group (quintile 1) tend to incur less catastrophic spending as compared to richer households (quintile 3 and 4) (Table 4.6).

Table 4.6: Prevalence of CHE by household income quintile

Household quintile	Distribution of CHE (% , n)
Quintile 1	16.9 (11)
Quintile 2	15.4 (10)
Quintile 3	26.2 (17)
Quintile 4	33.8 (22)
Quintile 5	7.7 (5)

Under socio-demographic variables (Table 4.7), the place of residence ($p < 0.001$) was found to be significantly associated with CHE; with more households are experiencing CHE in the town area of Sg. Segamat (75.4%) compared to rural Bekok (25.6%). Ethnicity was found to be significant with CHE ($p < 0.001$), and the Malay community has the highest prevalence of CHE (72.3%) compared to other ethnic groups. Households experiencing CHE tend to spend less overall for the household, given the lower capacity to pay as compared to households without CHE.

We found that respondents who received secondary care for diabetes ($p = 0.024$) and those who have diabetes-related complications ($p = 0.09$) were significantly associated with household having CHE. Out of the many types of diabetes treatment sought, only the consumption of supplements ($p = 0.043$) was revealed to have a significant association with CHE. In contrast, no relation was found for standard of care treatments available in the healthcare service, namely lifestyle modification, oral anti-diabetics medication, and insulin therapy (Table 4.8).

Table 4.7: Baseline characteristics of CHE and non-CHE households

Baseline characteristics	Non-CHE	CHE	p-value
Social demographic			
Households with diabetes	262	65	
Age (mean (SD))	63.08 (11.07)	64.45 (10.99)	0.373
Number of household members (median [IQR])*	3.00 [2.00, 5.00]	3.00 [2.00, 4.00]	0.79
Residence, n(%)			<0.001
Sungai Segamat (town)	112 (42.7)	49 (75.4)	
Bekok (rural village)	150 (57.3)	16 (24.6)	
Gender n(%)			1
Male	90 (34.4)	22 (33.8)	
Female	172 (65.6)	43 (66.2)	
Ethnicity, n(%)			<0.001
Malay	103 (39.3)	47 (72.3)	
Indian	25 (9.5)	7 (10.8)	
Chinese	129 (49.2)	10 (15.4)	
Orang Asli	4 (1.5)	1 (1.5)	
Others	1 (0.4)	0 (0.0)	
Education level, n(%)			0.202
Not attended	42 (16.0)	6 (9.2)	
Primary	135 (51.5)	36 (55.4)	
Secondary	79 (30.2)	20 (30.8)	
Tertiary	5 (1.9)	1 (1.5)	
Professional certification	1 (0.4)	2 (3.1)	
Having employment, n(%)			0.503
Yes	61 (23.3)	12 (18.5)	
No	201 (76.7)	53 (81.5)	
Overall household income (median [IQR])*	1300.00 [900.00, 2000.00]	1500.00 [1000.00, 1800.00]	0.654
Overall household spending (median	1000.00	600.00	

[IQR])*	[700.00, 1500.00]	[500.00, 800.00]	
Diabetes condition			
Years with diabetes (median [IQR])*	72.00 [36.00, 123.00]	60.00 [39.00, 130.00]	0.985
Having diabetes-related complications, n(%)			
Yes	56 (21.4)	21 (32.3)	0.09
No	206 (78.6)	44 (67.7)	
Receiving secondary care, n(%)			0.024
Yes	13 (5.0)	9 (13.8)	
No	247 (95.0)	56 (86.2)	
Having co-morbidities, n(%)			0.121
Yes	211 (80.5)	46 (70.8)	
No	51 (19.5)	19 (29.2)	

* Kruskal-Wallis test conducted for non-normal distribution. For the remaining findings T-test was performed

Table 4.8 Healthcare utilisation of CHE and non-CHE households

Healthcare utilisation	Non-CHE	CHE	p-value
Household with diabetes, n	262	65	
Types of diabetes treatment, n(%)			
Lifestyle modification (%)	134 (51.5)	26 (40.0)	0.127
Oral anti-diabetics (%)	238 (91.5)	56 (86.2)	0.278
Insulin therapy (%)	55 (21.2)	8 (12.3)	0.15
Traditional medicine (%)	37 (14.2)	9 (13.8)	1
Supplements (%)	35 (13.5)	16 (24.6)	0.043
Other treatments (%)	6 (2.3)	1 (1.5)	1
Place of treatment, n(%)			
Public care	233 (88.9)	57 (87.7)	0.949
Private care	33 (12.6)	11 (16.9)	0.476
Pharmacy	16 (6.1)	5 (7.7)	0.854
Traditional and complementary medicine establishments	6 (2.3)	0 (0.0)	0.475

Direct selling	6 (2.3)	3 (4.6)	0.547
Friends	1 (0.4)	1 (1.5)	0.856
Public care as first treatment place n(%)	256 (97.7)	62 (95.4)	0.547

* T-test was performed

4.3.2 Predictors of CHE

The indicators of financial risk protection are all derived from a household's expenditure, which reflects existing inequalities in income and wealth. These indicators are increasingly being disaggregated in recent studies to examine the hardship imposed on different sub-population based on income, wealth, or other socioeconomic characteristics (127). Known socioeconomic determinants from related studies include gender, ethnicity, education level of the household head, residence (rural/urban), household size or composition, and the presence of chronic illnesses. As described in section 3.4.7.2, these determinants have been associated with increased incidence or severity of financial hardship in different settings. In our study, we conducted multivariate regression analysis in a forward step-wise method to identify the social predictors of catastrophic healthcare expenditure.

Table 4.9: Predictors of CHE

Predictors of CHE	Odds ratio	Confidence interval		P value	
		2.5%	97.5%		
Age	1.059	1.015	1.105	0.008	**
Gender					
Female (reference)					
Male	1.039	0.483	2.234	0.922	
Number of household members	0.993	0.866	1.139	0.921	
Area of residence					
Sungai Segamat (reference)					
Bekok	0.234	0.102	0.538	0.001	***
Ethnicity					
Chinese (reference)					
Malay	5.651	2.388	13.369	0.0001	***
Indian	6.811	2.065	22.460	0.002	**
Orang Asli	14.067	0.823	240.415	0.068	.

Education level					
Tertiary (reference)					
No education	0.508	0.044	5.831	0.587	
Primary level (age 6 - 12)	2.401	0.248	23.235	0.449	
Secondary level (age 13 - 17)	2.327	0.227	23.849	0.477	
Employment					
Yes (reference)					
No	0.764	0.292	1.999	0.583	
Overall household income	1.000	1.000	1.000	0.619	
Years living with diabetes	1.003	0.999	1.006	0.160	
Diabetes-related complications					
No (reference)					
Yes	1.020	0.437	2.380	0.964	
Hospitalisation					
No (reference)					
Yes	3.056	0.857	10.897	0.085	.
Co-morbidity					
No (reference)					
Yes	0.799	0.368	1.736	0.571	

Level of significance: *** = $p < 0.001$, ** = $p < 0.01$, * = $p < 0.05$, . = $p < 0.1$

Table 4.9 outlined the significant predictors of CHE among respondents, estimated using multivariate logistic regression. Covariates found to have a significant association with CHE included age, area of residence, and ethnicity. Older age respondents were found to have slightly higher odds (1.059 times) to experience CHE (OR=1.057, 95% CI: 1.015 – 1.105, p-value=0.008). The logistic regression analysis also strongly suggests ethnicity is the strongest independent predictor of CHE. Being of Indian ethnicity also has a 6.8 times likelihood to experience CHE (OR=6.811, 95% CI; 2.065 – 22.460, p value=0.002), while the Malay community exhibited 5.6 times the odds of facing CHE (OR=5.651, 95% CI; 2.388– 13.369, p-value=0.0001) compared to the Chinese community and after controlling for other risk factors. While non-significant, the Orang Asli community is the most vulnerable to CHE, having 14 times more likelihood of incurring catastrophic spending compare to other ethnic groups (OR=14.067, 95% CI; 0.823 – 240.415, p-value=0.068). We would suggest this was

due to the effect of the sample size rather than the lack of risk, particularly given the results for the Malay and Indian communities, and the suggested direction of risk for the Orang Asli community.

Living in rural areas was found to be protective against CHE, whereby respondents living in Bekok were found to have a decrease in the odds of experiencing CHE by 0.23 folds (OR=0.234, 95% CI; 0.102-0.538, p-value=0.001). Though hospitalisation episodes were not found to be statistically significant to CHE (OR=3.056, 95% CI; 0.857-10.897, p-value=0.085), similar to the CHE risk of the Orang Asli community, we also believed that the non-significance may be due to the effect of sample size, given the high OOP associated with hospitalisation. Other variables including gender, educational status, duration of diabetes, co-morbidity, overall household income, employment status, and the number of people living in the household were also found to be not significantly associated with CHE.

4.3.3 Impoverishment

Impoverishment was measured by two indicators: 1) a headcount measure showing the incidence and proportion of households pushed below the poverty line because of OOP payments, and 2) the poverty gap, which measures the intensity of poverty in terms of income shortfall by which a poor household falls below the poverty line.

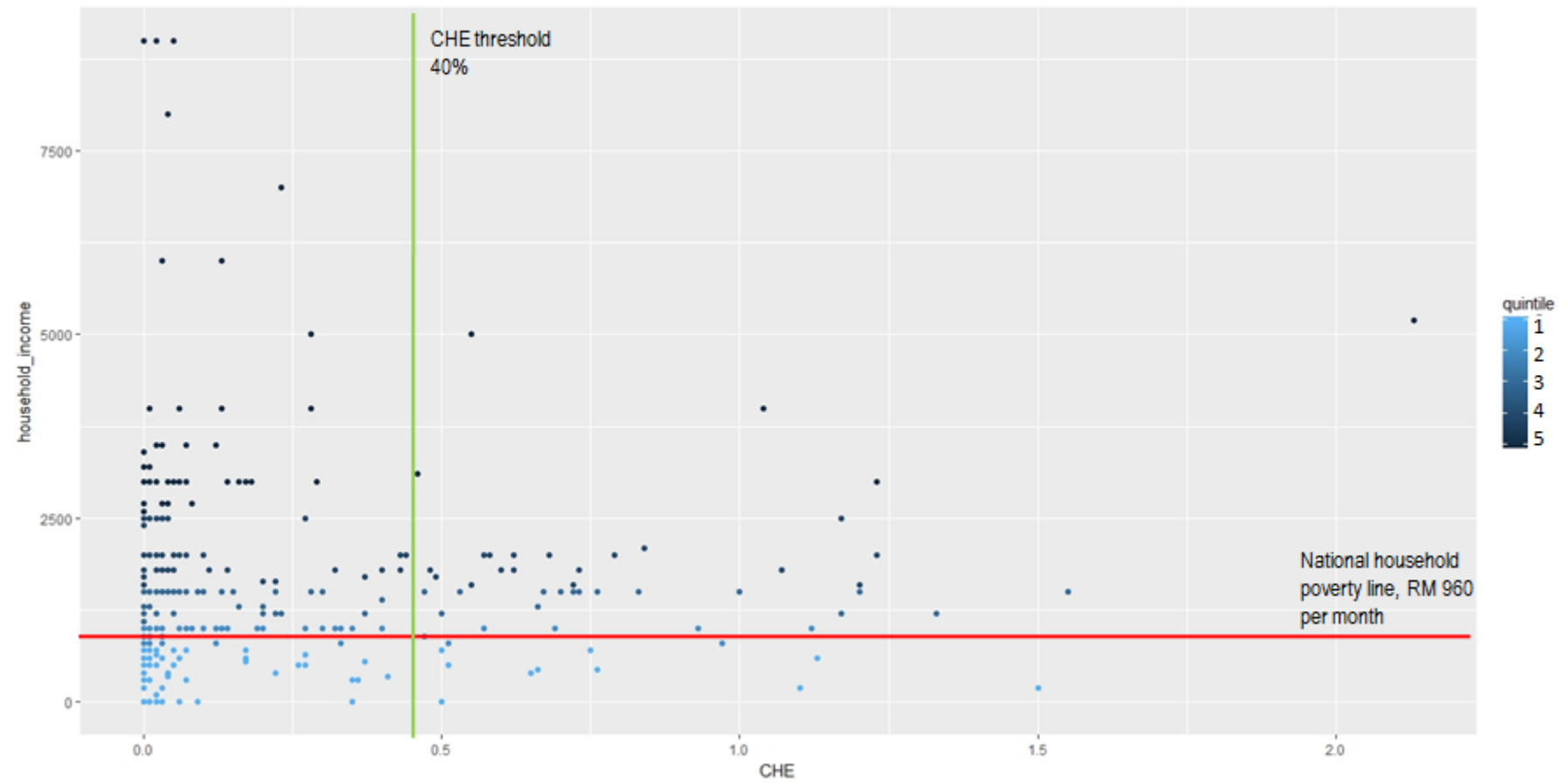
Table 4.10: Impoverishment impact of OOP expenditure on diabetes

	Poverty Headcounts (no, %)	Poverty Gaps (RM, mean (SD))
<i>Direct medical cost</i>		
Pre-payment	75 (22.9)	641 (268.5)
Post-payment	90 (27.5)	599 (246.8)
Poverty impact	15 (4.6)	42
<i>Direct non-medical cost</i>		
Pre-payment	75 (22.9)	563 (214.8)
Post-payment	75 (22.9)	557 (213.6)
Poverty impact	0 (0)	6
<i>Indirect cost</i>		
Pre-payment	75 (22.9)	610 (298.7)
Post-payment	80 (24.5)	560 (246.8)
Poverty impact	5 (1.6)	50

<i>Overall diabetes cost</i>		
Pre-payment	75 (22.9)	685 (309.5)
Post-payment	99 (30.3)	592 (290.3)
Poverty impact	24 (7.4)	93

Table 4.10 outlined the impoverishment impact of CHE, illustrating the findings of poverty headcount and gap. A total of 75 (22.9%) households in the study were below the poverty line prior to healthcare payments. Direct costs have the most impact, displacing 15 (4.6%) households below the poverty line, while direct non-medical cost has no impoverishing effects. When both direct and indirect diabetes costs were deducted from monthly incomes, 24 (7.4%) households were pushed below the poverty line. In terms of poverty gaps, the overall household income of the 24 households impoverished by diabetes fell by RM93 (USD21.9) after OOP spending on direct and indirect diabetes costs.

Figure 4.5: Impoverishment and catastrophic health expenditure headcount by household income



As described in the previous section, the two concepts of financial hardship (catastrophic health expenditure and impoverishment) measure different aspects of the lack of financial risk protection in health. Figure 4.5 above shows the headcount indicators by household income quintile groups for the two concepts. In higher-income groups, the incidence of catastrophic health expenditure is much higher than impoverishment, while conversely for households who live in near-poverty, the opposite is true. This finding suggests that the two indicators provide different information about the level of financial risk protection.

4.4 Implications of the economic burden of diabetes

This subsection addressed the second aspect of Objective 2 of the study, examining the impacts and consequences of living with diabetes to various aspects of the lives of the person with diabetes and the household. Through qualitative interviews, we engaged respondents who experienced CHE to explore in-depth the consequences and burden they encountered in their daily management of diabetes. From the thematic analysis, we found two emerging themes that relate economic impact to diabetes management, and consequences to the welfare of the household. The thematic framework is presented in Figure 4.6.

4.4.1 Impact on disease condition and diabetes management

The economic burden of living with diabetes has impacted the way respondents manage their conditions daily. Respondents informed that they were scaling back on their home treatment in terms of frequency and usage of medical supplies, ignoring their doctor's recommendations. Though the Malaysian healthcare system provides highly affordable public healthcare services to its citizens (nominal charge of RM1 (USD0.235) for outpatient, RM5 (USD1.2) for secondary care), illness-associated medical supplies beyond provided medicines, namely those for home care such as insulin pen needles, bandages, antiseptics, and glucose test strips need to be purchased OOP.

“Now, my needles (insulin pen) have also finished. I don't have the money to buy any.” [IDI-01]

“Now I buy (insulin pen needles) at the clinic here for 70cents (USD0.2) a piece, and they told me I could use up to four times. But I don't do that. I don't throw it away until I felt pain when I inject.” [IDI-06]

“There was a case of someone I know where he stayed in the private sector (hospital) for five days, and the bill came to RM8000 ((USD1,888), and the medicines cost RM1000 (USD235) per month. He can't take it anymore in the second month, and he just goes to the government clinic. If they (clinic) give medication, then he takes them, and if there isn't, then he goes to buy them at the pharmacy. He just doesn't have the money every month.” [IDI-11]

Aside from treatment, self-monitoring of blood glucose practices was also affected due to cost barriers.

“If my sugar level drops to 2, I can't even sit up. Nowadays, I didn't check because we couldn't manage to buy any new stocks (glucose test strips).” [IDI-01]

“I also check my sugar levels regularly once a day, but sometimes only 3-4 times a week. The card (glucose strip) is expensive. I can't take it.” [IDI-06]

Respondents also tried out TCM care as a cheaper option to manage their disease. Even if the efficacy may not be scientifically established, respondents were attracted by the health claims and benefits purported.

“I plant them (herbs). If you buy outside, it's about RM3-5 (USD0.7-1.2). There are seeds you can put in boiling water, and when you drink it your glucose level will go down, they say. When my legs were numb, after taking that, it will go away. You take those. You will be okay.” [IDI-07]

“People are saying it. And that's why I drink it (bitter gourd juice), even though not very frequently. I take that to reduce my blood sugar. But if my blood sugar is four and below, I can't take it. I get weak. And I know it's because of my diabetes.” [IDI-01]

“Yes, it (Chinese medicinal herbs) does help to control my sugar levels. My body also can feel more active, and I sweat more.” [IDI-03]

The lack of services by public clinics also affected patient's access to treatment. For patients with slow-healing open wounds such as diabetic foot ulcers who are bedridden or have

difficulty in walking, they have to resort to cleaning their wounds on their own or go without care as they lack the means to go to the clinic.

“Nurses from Bekok (public) clinic also do not provide wound cleaning at home, when some patients cannot walk to the clinic due to disability or bedridden (from diabetic ulcer).” [IDI-05]

“Previously, when I just came back from the operation, I went to the private clinic in Labis (30 kilometers away from Segamat town). One trip costs me RM30 (USD7.1), and one day I have to go twice. That's already RM60 for transport. After one month, I can't take it anymore. After that, I just go to Batu 8 clinic. One time cleaning, there is only RM3 (USD0.3).” [IDI-03]

“The biggest cost I think it's the traveling in between (healthcare premises).” [IDI-02]

4.4.2 Impact on the welfare of the household

Respondents in the current study reported that the costs of care and management of diabetes have also impacted the overall welfare of their families. This is more apparent for those who are on insulin therapy or having related complications admitted for secondary care.

Households who cannot afford to pay for their treatment have also found themselves in debt, where family members inevitably owed money not only to lenders but also to the hospital.

“We don't have the money. To me, if I have the money, I will definitely pay it back. My situation is I don't have enough for basic living. We also didn't have any additional support or whatever.” [IDI-01]

“More than RM8000 (USD1,888). My son paid for it until now he is still paying back the debt. If I didn't do it (operation) at that time, my leg would be gone. We still owe RM4000 (USD940).” [IDI-06]

“For those who do not have savings, who are unemployed, or do not have financial support from their children, but needed insulin medication, the burden is big for them.” [IDI-05]

When the costs of managing diabetes are placed against other equally compelling financial demands, the decision on what needs to be spent on and what is to be put aside brings the

harsh realities of chronic disease management to the surface, as described by some of the respondents;

“I’ll just be direct; the expenses are really high for us. For us, our livelihood is really pressured, but we believe that we must buy them still, find ways to get the money.”[IDI-01]

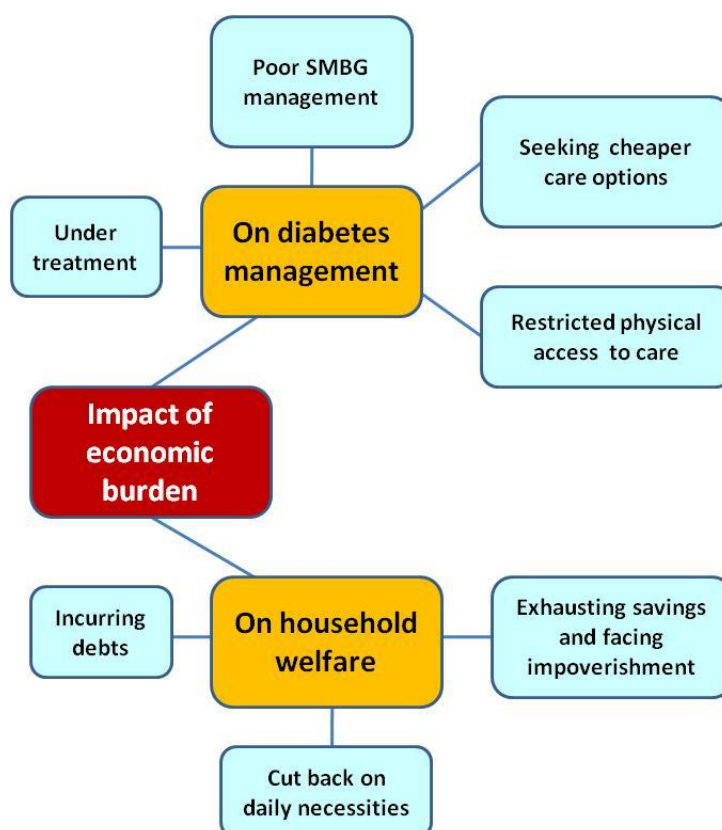
“Enough or not, we have to keep living. For now, I can still manage. I observed that if I only eat in the afternoon and not having dinner, the sugar level will drop a bit, to about 7.” [IDI-09]

Some respondents managed their conditions without going into debt but ended up depleting their life-savings.

“When I was selling cendol I used my own money, but now all of that is gone. All my savings were used to take care of him (husband with diabetes). Now he is much better. I told him to do some exercise” [IDI-08]

“Yes, luckily, I have my own money or else I do not know what to do. You see, they (children) only give me RM100 (USD23.5) per year, which is less than RM1 (USD0.2) per day. He (son) is still useless and is gambling still. He is over 50 years old now.” [IDI-12]

Figure 4.6: Thematic framework of the economic impact of diabetes management



4.5 Household coping strategies and resource allocation

The ways in which households financially cope with diabetes are presented in this section. From the qualitative interview conducted in Phase 2, two key themes were identified; 1) household financial coping strategies and 2) how decisions on household resource allocations for diabetes management were made. The thematic framework is illustrated in Figure 4.7.

4.5.1 Household financial coping strategies

From the thematic analysis conducted, five common financial coping strategies that households used to fund their diabetes treatment and management were identified;

- 1) Reliance on public healthcare
- 2) Income and personal savings
- 3) Borrowing money
- 4) Giving up personal assets
- 5) Social support

4.5.1.1 Reliance on public healthcare

We found that the majority of respondents (88.9% of non-CHE households and 87.7% of CHE households) rely on public healthcare as an affordable channel to seek and receive treatment. In addition, over 95% of them reported that they opted for public healthcare as the first treatment place.

“I get my medicines free from the clinic, why do I need to buy from pharmacies?” - [FGD-BK11]

“No, it is all the time with the government sector. My parents’ medical treatments are all coming from the government, so it is not that expensive compared to the private sector.” [IDI-05]

The reliance on public healthcare is heavier for poorer households, which implied the importance of the public health service as a crucial means of financial risk protection, particularly for lower socio-economic groups.

“No. No money, how to go to private clinics? We poor people cannot afford it; we can only go to the government clinic. Only rich people will go far for treatment. The Malays here many are poor.” [FGD-BK02]

4.5.1.2 Income and personal savings

Respondents facing CHE tend to cope with the long-term cost of diabetes management by themselves through their income and personal savings. For those who have retired or no longer working, personal saving was a critical source of funding.

“We don't have much bank savings. We mainly survive on my pension and dividends from some of my shares (share trading).” [IDI-03]

“We have savings. Usually, I will use my savings to overcome it because I still have savings.” [IDI-05]

“They (people with diabetes) use their income and saving to cover their diabetes cost.” [IDI-05]

4.5.1.3 Borrowing money

Respondents who do not have adequate savings sought to borrow money to pay for their care, particularly for high-cost inpatient treatments.

“Like the other day, when I went to the hospital, I borrowed money from him (employer) RM5000 (USD1,175). Every month he will deduct the money from my salary, but not all.” [IDI-01]

“Out-of-pocket myself. My son helped as well, and I also borrowed from friends.” [IDI-06]

There were instances when immediate emergency treatment was required, but the household did not have sufficient money, and hence have to owe money directly to the hospital.

“We don't have the money. To me, if I have the money, I will definitely pay it back (to the hospital). My situation is I don't have enough for basic living.” [IDI-01]

4.5.1.4 Giving up personal assets

Having a heavy economic burden can push households to consider selling or giving up their assets to pay for treatment costs. One respondent who owed money to the hospital can't afford to pay and was willing to surrender his household assets or even be arrested.

“If they force me to pay, then just take me to the police station. Just arrest me if I can't pay. You know what, it's not that we don't want to pay, but even for basic living, we're facing difficulties. If I have a bit of money, I will go and pay. If the hospital forces us to pay, then they can come to take what it's feasible from my house. I don't have a choice.” [IDI-01]

4.5.1.5 Social support

Family members and social networks were found to be important elements in the management of diabetes, that not only influence patients' decisions to seek care but also in the physical management of diabetes. Long after the patient had been diagnosed with diabetes, family members and/or social networks continued to play a significant role in influencing the nature of care and management sought and also in providing social and

financial support. The surrounding social support structure was found to play a critical role in sustaining the management of diabetes. The majority of the respondents preferred not to seek external help despite facing hardship and rather manage the issue internally within their family members.

“We don't ask from others. We supported ourselves.” [IDI-07]

“No. we take care of it by ourselves.” [IDI-08]

“I didn't ask for anything. I don't want to. To ask for help from the government is very tedious. If you take RM10 (USD2.4) from them, then next time they would come and ask you for donations. They always ask for donations here and there. I'm telling you, this politic is really useless. Like my hospital fees for this while they never offered any help. They know about my condition, but they didn't do anything.” [IDI-11]

“Oh no, no. I can still manage things myself. My children give me money every month.” [IDI-10]

Respondents relied substantially on informal social support, particularly from close family members (i.e., spouse and children) for financial support to pay for their healthcare needs.

“My husband is the sole earner. He is working in Singapore, and he comes once a month. He sends the money home monthly.” [IDI-07]

“My children supported them all (diabetes treatment cost). I do get some income myself, but now my children take care of me. Some of them come back once a month or two months once and will give me money. But for hospital costs, it's just my son here who covered it.” [IDI-11]

“Every day for 95 days, I go there (Johor Bahru hospital) by train after work and then come back.” [IDI-01]

Aside from giving support financially, household members also provided physical support to help manage the condition of the person with diabetes.

“My children helped me to check and told me ‘mom, 3-4’ (glucometer readings), and at that time, I’ll be drinking sweet drinks. My children also help with insulin injection.” [IDI-01]

“She (wife) is the one who takes care of me. If she is not around, it will be difficult. She scolds me too, but it’s ok.” [IDI-08]

“My children got it (glucometer) for me, but I don’t measure. Sometimes they cook for me, and sometimes I cook for myself. I use the money they gave to buy food and cook for myself. For buying groceries I ask the house opposite to help me buy. Whatever food I want to buy I will ask them” [IDI-13]

“Now, I’m asking my grandchildren to help me (to) inject.”[IDI-02]

Some respondents also reached out to seek help from members in their community and their employers.

“If my TV is not functioning, sometimes I ask them (neighbour) to come over to help to fix it, and they’re helpful. There’s a lot of singleton households here. For buying groceries, I ask the house opposite to help me to buy. Whatever food I want to buy, I will ask them.” [IDI-13]

Aside from receiving support from their social network, respondents also have options to seek formal social support, where various channels are available, ranging from welfare institutions, central government aids to offices of political parties. Those who have sought formal support complained of increasing difficulty in access and application, even for those under national poverty alleviation programs such as the Federal Land Development Authority (FELDA) agricultural scheme, that aims to provide resettlement of rural poor into newly developed areas and to organize smallholder farms growing cash crops such as palm oil.

“However, the amount may be lesser if the (dialysis) center is subsidized by MCA (Chinese-based political body) or any other charity bodies. It is actually upon application approval, and we need to fill up the form stating our financial information.”[IDI-05]

“You need to inform them, so they know. They have volunteers around, and for example, if they found out who has cancer, they will take note, and sometimes the YB

(state assemblymen) will visit. He typically helps those who are alone, and seldom for those who have children. You need to give children the opportunity to be filial.” [IDI-13]

“Now BRIM (national financial aid program for the poor) is getting hard to get, not like previously. Now you have to fill forms, they will check your details, and then 2-3 months still, you will get nothing.” [IDI-04]

“If you have a formal name registered here in FELDA when you want to seek welfare help, you won't get it. We'll die...having a plantation plot doesn't mean one is well off.” [IDI-04]

“I know they (MCA, Chinese-based political party) help, but I don't want to ask.” [IDI-11]

There were respondents who were receiving welfare support, but some encountered considerable delays in assistance.

“I receive SOCSO (social security) compensation for my eye, RM300 monthly, but the payments always come late.” [IDI-03]

“I take from the welfare department RM150 per month. I've taken BRIM before, this time around many people didn't get it but I got it.” [IDI-06]

“MIC (Indian-based political party) is useless. They never help at all. The MCA people, though, came and visited me here.” [IDI-08]

For those with only permanent resident status, access to social welfare institutions is even more limited.

“We have tried, and it's no use. For both Segamat hospital and in Johor Bahru, we have tried going back and forth, and eventually, there was nothing...then I said, let's forget about it and no need to burden ourselves with the back and forth to the hospital in Johor Bahru. Transportation cost is also very high, going to the Johor Bahru

welfare offices. I'm very tired of asking for help here and there. We never get any formal welfare support, like from the village chief or anything.” [IDI-01]

4.5.2 Decision on household resource allocation

Decision making on household resources was made only amongst the close family members (spouse, children). Resources in this context relate not only to tangible items such as money and materials, but also intangible resources such as time. While we interviewed households from various ethnicities, we did not encounter any distinctive cultural or ethnic practices on household resource allocation across different community groups. Decisions on household resources were primarily based on financial and medical urgency at hand.

Resources were pooled and contributions took into consideration the financial capabilities and living circumstances of each contributing household member.

“Yes. We understand their situation like my brother; he needs to support his children’s education. We are fine with supporting expenses ourselves. For example, I am staying with my sister, and we split household utility bills.” [IDI-05]

“Yes, they (their children) do as well (provide money for treatment), a little bit. Even if we want to ask for more, we can’t as they also have many children of their own. They sometimes would pay my household bills, and give us money.” [IDI-09]

“No, we usually do not, because they know I have savings. As you can see, my parents’ medical treatment is all coming from the government, so it is not that expensive compared to private sectors. The AVF (arteriovenous fistula) expenses in KPJ Kluang (private clinic) in 2014 (RM2600) (USD611) were paid by me too.” [IDI-05]

Household members prefer to discuss and address issues among themselves and make decisions collectively.

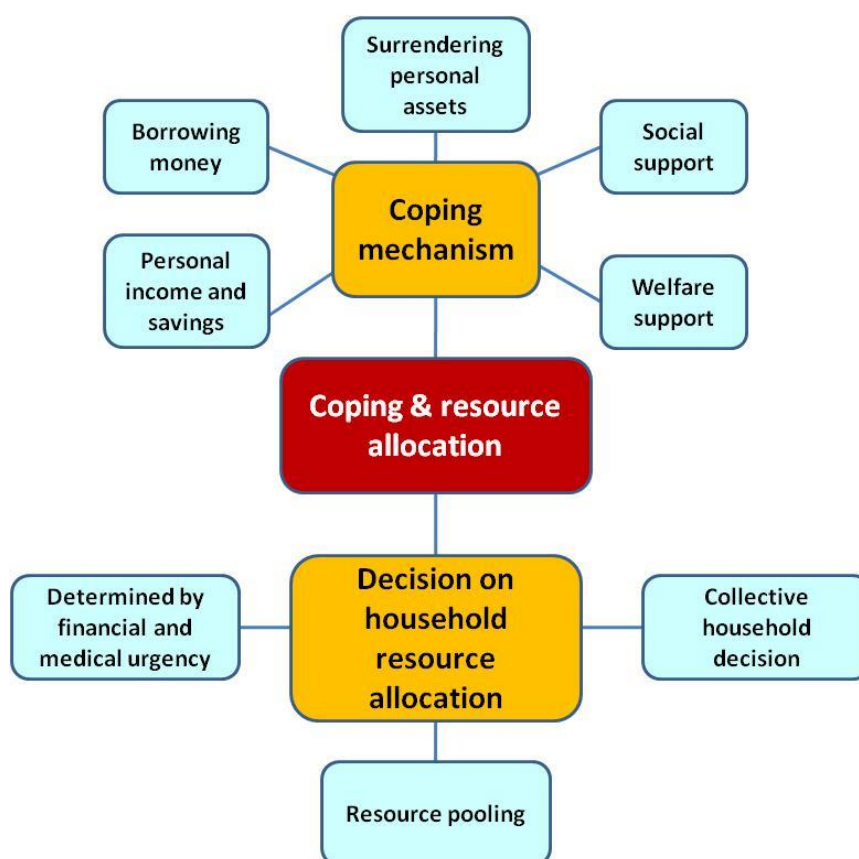
“It's just me and my children discuss and see how to go about it. If they can help, they help. For me, good or bad times, I have my family. Because even if we ask for help, people may not help us. Typically it’s more frustrating as people tend to say bad things. So in times of need, we will discuss within ourselves. I’ll call the eldest and

ask, 'do you have money?', and if he has we'll take a little bit. Then I'll call the second son and ask if he has money. That's it." [IDI-01]

"Our children don't always give; sometimes if we need to use a bit more, they will help. But you see, our children have their own families and have to pay for their own expenses." [IDI-03]

"Last time when I was working, my brother is the one (sending parents to the hospital). Since I am back in home town now, I am the one who sends them. We are not calculative among us who sends parents to the hospital. Whoever is free and at Bekok, they will send my parents to the hospital." [IDI-05]

Figure 4.7: Thematic framework of household coping and resource allocation



CHAPTER 5.0: DISCUSSIONS & RESEARCH IMPLICATIONS

5.1 Discussion of principal findings

In the sections below, we discussed the principal findings of the current study in comparison with the current literature. The discussions are organised into three interrelated themes corresponding to the study objectives; household cost burden from managing type 2 diabetes, poverty impacts of living with diabetes, and household financial coping strategies and resource allocation. Deliberations on the implications of the study then followed, touching on different aspects of household financial risk protection, the economic burden and poverty impacts, and the long-term sustainable management of chronic diseases.

Diabetes was used as a tracer condition for examining the broader question of expenditure associated with NCDs. In the discussions, we interplay the use of “diabetes” and “NCDs,” and in the limitations, the extent to which diabetes may fail as an overall indicator and the degree to which one may generalise were also discussed.

5.1.1 Household diabetes cost burden

5.1.1.1 Overall household cost of illness

Table 5.1 shows a country comparison of the average cost of diabetes per patient per year. Our findings of the average annual household cost of illness for diabetes of RM1117.2 (USD262.5) is comparable to the studies in LMICs such as India, Pakistan, and Nigeria which ranged from USD29.9 to USD284.6 (268–271). However, our figures are considerably lower compared to developed countries such as Singapore and the USA, which amounted to USD1576 and USD7888 respectively from direct medical costs alone (272,273). This difference is not surprising given higher visit costs, access to more advanced medical facilities, technology and drugs, and overall higher cost of living. In the Malaysian setting, available cost of studies on diabetes was conducted from a provider perspective, with an average annual treatment costs ranging from RM802 (USD188.5) (at the outpatient clinic setting) to over RM10000 (USD2350) for secondary care costs (86–88).

Table 5.1 – Country comparison of average cost of diabetes per patient per year

Country	Average cost of diabetes per patient per year (USD)	Reference	GDP per capita (USD, year 2019)*
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Malaysia	262.5	Thesis findings	11,415
India	29.9	Akari et al., 2013	2,104
Pakistan	197	Khowaja et al., 2007	1,285
Nigeria	284.6	Suleiman and Festus, 2015	2,230
Singapore	1,576	Ng et al., 2015	65,233
United States	7,888	ADA, 2013	65,118

**Source: World Bank national accounts data, 2020*

5.1.1.2 Cost components

We also found that direct medical cost is the largest cost component (63.4%), and this finding is similar to many review studies that both looked at diabetes specifically at the national level (18,203), and globally (31). In the review by Bommer et al. (2017) (31), the researchers revealed that two-thirds of the total global economic burden of diabetes (from a total of USD 1.31 trillion) were direct medical costs (USD 857 billion) and one third were indirect costs in the form of lost productivity. However, while studies have identified the cost of medication and hospitalisation to be the primary drivers of direct medical costs, our findings differed. We found that the main cost drivers were consumption of traditional and complementary medicine (mean RM20.8 (SD 2.3) (USD4.9)), followed by consumable items for home care management such as blood glucose monitoring and usage of medical supplies (mean RM14.2 (SD 1.5) (USD3.3)). Malaysia has a universal health coverage system that provides heavily subsidised public healthcare for its citizens that includes consultation, treatment, and drugs, but not for related medical supplies in which patients need to purchase OOP (21). This finding has similarities to Germany, where the largest proportion of direct costs among young patients with diabetes was found to be the cost for self-monitoring of blood glucose levels, due to the lack of public provision for medical supplies (274).

Our findings showed that OOP spending for TCM care is the highest average monthly costs incurred. As with many parts of the world such as Africa, Asia, and Pacific nations, TCM care such as traditional medicine is commonly consumed in Malaysia as a form of primary care. It is culturally embedded in daily health-seeking behaviours, and is considered an important component of health care (275). TCM care and medicine are not covered under the public healthcare service, and usage is an OOP expenditure. In the study by Ching et al., (2013) (226), the authors found a high prevalence (65%) of TCM care and medicine consumption in Malaysia amongst diabetes patients. The Muslim community was found to be

the largest consumer, which the authors relate to the Muslim belief system and cultural heritage that has a long history of TCM medicine use deeply integrated into their lives (276).

The consumption of TCM care amongst diabetes patient is prevalent in both developing and developed countries, such as in Taiwan (61%) (277), Mexico (62%) (278), India (67.7%) (279), and also in the U.S. (72.8%) (280). In the study by Okoronkwo et al. (2015) (206) in Nigeria, the researchers found that under the influence of marketing, diabetes patients paid most substantially for traditional medicine and herbalists.

Households also bear indirect costs due to NCDs, and these relate to time and productivity loss by patients and caregivers, in addition to direct income loss of being bedridden or needing to provide homecare. In the working-age population, the cost of lost productivity can far exceed the diabetes-related medical costs. In a study in Singapore on the economic burden of diabetes on the working population, Png et al., (2016) (281) found that 58% of the total estimated economic burden was indirect productivity-related losses, highlighting the impact of lost productivity to employers and society overall. In welfare states such as the Netherlands, that have extensive social welfare coverage, indirect costs have a direct impact on national budgets. Peters et al., (2017) (282) found that out of an estimated total cost of four billion euros that were attributable to indirect costs of diabetes, three billion euros was from government welfare payments. The authors posited that such high indirect costs are primarily related to the long-term complications of diabetes and the disability that these inflicted. Nonetheless, contrary to these studies and other COI studies which found indirect cost as the largest cost component (16,232,281,283), we found that it is the smallest in our study. We surmised that this might likely be due to a sizeable number of respondents in the study who were retirees. This may necessarily result in lower indirect costs because there is no loss of income. However, even though the indirect cost burden may not be substantial, the implications it places on caregivers were clearly illustrated in our qualitative findings, where social support from family caregivers is a critical support pillar for sustainable long-term care.

Overall, in terms of cost components, our data suggests that direct medical cost imposes a higher economic burden than indirect cost. This finding aligns very similarly to the recent systematic review findings of Bommer et al. (2017) (31), which examined the global economic burden of diabetes across 184 countries. The authors concluded that the economic burden as a percentage of GDP on average was larger in middle-income countries than in

high-income countries, but also noted that data limitations at the country level make it difficult to accurately gauge the economic burden of diabetes in LMICs.

5.1.1.3 OOP expenditure by income quintile groups

In our study, we observed that the share of OOP expenditures in total household expenditure rose from the poorest to the wealthiest group. The more urban group (Sg. Segamat) also allocated a greater share of their out of pocket health expenses on diabetes, compared to their rural counterparts. Although these findings may appear to go against the idea that NCDs are creating a financial burden on the poor, we believed that this could be due to the universal health coverage provided in Malaysia that provided affordable healthcare access to the lower-income group. Another plausible explanation is that the poor seek less care for these conditions, with potentially adverse implications for employment and incomes (284). Because households belonging to the lowest expenditure quintile live much closer to the survival/poverty threshold, even the allocation of a small proportion of income is likely to increase their likelihood of being impoverished.

On the other hand, the higher spending by higher quintile groups may be attributable to the consumption of private care. Our qualitative data revealed that there are preferences and willingness to pay for private care despite the availability of public health services. The underlying reasons are similar to the findings of a health system review conducted by the Malaysian Ministry of Health (2016) (11) - dissatisfaction on the service quality and responsiveness of public services, uneven distribution and lack of comprehensive primary health care for managing and treat NCDs (particularly in peripheral facilities), and perceptions of poor public care which drives demand for private services. Shortfalls in qualified staff and supply, as well as population skepticism about the quality of the public sector is also evident across LMICs such as India (285), Thailand (132), and Mongolia (286).

Overall, when we look at the trend of OOP spending as a proportion of household income across the income quintiles in our study, we can also observed that the more affluent group had greater out-of-pocket costs compared to the least affluent, but were less financially burdened by the illness. This trend is similar to the findings noted other COI studies (132,271,287,288). Malaysia implements the concept of a public-private mix to finance the healthcare system. Those who can afford it are encouraged to access the private sector, while public healthcare is catered primarily to the lower and middle-income rungs of society (21).

Households with diabetes are driven to spend more OOP for care due to inadequacies of public healthcare services, which raises their risk of catastrophic health spending. On a national level, private household OOP spending amounted to RM19.6 billion (USD4.6 billion) in 2016, accounting for 78% of total private spending, 38% of the total expenditure on health, and 1.59% of GDP (289).

5.1.2 Poverty impacts of the household economic burden

5.1.2.1 Catastrophic spending and impoverishment

In our study, we found that the OOP from managing and living with diabetes has caused 19.9% of households to encounter catastrophic healthcare expenditure and 7.4% driven to impoverishment. This figure is similar to a recent study by Gwatidzo (2017) (153) on the economic burden of diabetes among adults over 50 years old in China and India, where 16.6% of people living with diabetes in China experienced CHE from OOP for diabetes medications alone. A large study by Niens et al. (2010) (290) in 16 LMICs quantified the impoverishing effects of purchasing medicines for diabetes. Buying the lowest price generic or originator brand *glibenclamide* (off-patent sulfonylurea) would plunge 5 % of patients below the 1.25 USD/day poverty line. When stratifying across the 16 countries, these percentages ranged between 0 and 58 %. A systematic review by Jasper et al. (2014) (204) on the global impact of NCDs on household impoverishment found that for diabetes, CHE prevalence can range from 13% up to as high as 40% for patients in the United States. They also showed that in LMICs, 6–11% of the total population would be impoverished if they had to purchase even low-priced generic medications for diabetes. Smith-spangler et al. (2012) (154) assessed the financial impact of diabetes on individuals in 35 countries using the World Health Survey data and estimated that people with diabetes have a 17.8% higher risk than those without diabetes in incurring catastrophic spending.

Broadening to studies on the poverty impacts of NCDs in LMICs, households with chronic illness are found to be more susceptible to catastrophic spending and impoverishment. A recent study in Bangladesh by Datta et al. (2018) (291) found that NCD-afflicted households had a 6.7 percentage point higher probability of incurring catastrophic medical expenditure compared to the households with no reported conditions. They further reported that the proportion of households incurring catastrophic medical expenditure is 9.5% for NCD-only households and 13.1% for NCD and non-NCD households, both of which are higher than those for households with no diseases or with non-NCD only (2.2% and 7.4%, respectively).

In Vietnam, the proportion of households with NCD patients that incurred catastrophic health expenditure (20.8% in rural and 23.8% in urban households) was found significantly higher than households without NCD patients. Similarly, impoverishment rates were also noted to be in similar proportions - 9.1% in rural and 11.4% in urban households with NCDs vs. 2.9% in rural and 3.5% in urban non-NCD households (292).

Our findings on poverty impact indicate a notable gap in financial risk protection, which we consider unexpected given that Malaysia is a country with universal health coverage provided through subsidized public provision funded by a progressive tax-based financing system. However, while the scenario may be uncommon, it is not unique. A similar scenario is also evident in neighbouring Thailand, where despite implementing universal coverage policy, there are still poor households who persistently experienced catastrophe due to OOP spending for health care. Households with a member who experienced chronic diseases were also found to have a greater likelihood of incurring catastrophic OOP spending on health (132). Mongolia is another example of a country that has extensive population health coverage through a combination of social insurance and subsidized public provision, but yet the population incurs a significant share of OOP spending for NCDs and faces the risk of CHE (286).

In addition, we also found that between income quintile groups, the lowest quintile (Q1, poorest) is experiencing less CHE than those in the higher quintiles (Q2 to Q4). This pattern is consistent with the findings of OOP spending of quintile groups in section 5.1.1.3 and in accord with those of Reddy et al. (2013) (207), where it was found that catastrophic health spending in Malaysia was significantly more common among non-poor households. The authors suggested that the finding may be a sign that many poor households were in fact, protected against catastrophic spending by Malaysia's equitable financing policies that heavily subsidises public healthcare and exempts the poor from payments. The CHE burden hence shifts to non-poor households, who were either ineligible for social safety net programs (e.g., MySalam and PEKA schemes targeted for low income B40 population) or those preferring private sector care due to public sector inadequacies. Insights from our qualitative findings also attest to this.

"But if you have a formal name registered here in FELDA, when you want to seek welfare help you won't get it. We'll die...having a plantation plot doesn't mean one is well off enough."[IDI-04]

It is important to note however, that the highest quintile group (Q5) was found to have the lowest occurrence of CHE even though their mean OOP spending is the highest. This suggests that while more affluent people had greater OOP costs, but were less financially burdened by illness, compared with those from lower socioeconomic backgrounds.

In the broader LMIC context, Somkotra and Lagrada (2009) (132) and Dugee et al. (2018) (286) also shared similar outcomes in Thailand and Mongolia whereby households in the higher income quintiles are more likely than the poorest to incur high health expenditures and face financial catastrophe. We have observed that this scenario is only evident in countries with UHC - studies of economic burden of diseases in non-UHC LMICs reported that lower-income groups are the ones bearing the brunt of catastrophic health spending such as in Nepal (293), Bangladesh (291), Vietnam (292), and Albania (294). One plausible explanation is the existence of a distinctive healthcare-seeking behaviour - the affluent exercise consumer choice and demand services from the private sector that are perceived to be of high quality. This is shown from our qualitative research findings, where households prefer to pay OOP for private care to obtain faster and better quality treatment. Particularly for secondary care, due to the urgency for treatment, households would go to lengths of borrowing money to access secondary care. Somkotra and Lagrada (2009) (132) reported a similar situation in Thailand, which is also common among other urbanizing LMICs as well. Given the higher cost and the need to pay OOP, these may cause the better-off group to incur higher payments for health services, in either absolute or relative terms, which may end up constituting catastrophic amounts.

On the other hand, there were also studies suggesting that a lower rate of CHE in poor households indicates poor households not having the financial means to seek care, hence health services were avoided to lessen household expenditure (149). We did not explore this aspect in our study as we aimed at mapping out diabetes-related cost items for those who accessed care, and those who did not seek care were not explored.

Overall, our findings reiterated the fact that living with NCDs such as diabetes imposes significant poverty impacts on households. This echoes the findings by Saksena and Xu (2011) (19) on the impact of OOP for the treatment of NCDs in developing countries. The authors found that despite using different cut-points for defining financial catastrophe, the risks of suffering financial catastrophe as a result of OOP health payments were consistently higher for households with NCDs than other conditions. In addition, owing to the chronic

nature of NCDs requiring long-term care, the households' longer-term financial status was also adversely affected through the accumulation of debt and other risk-mitigating strategies.

5.1.2.2 Social predictors of catastrophic healthcare expenditure

In our multivariate analysis, predictors of CHE included age, area of residence, and ethnicity. Older age respondents were found to have slightly higher odds (1.059 times) to experience CHE, and this finding is consistent with other studies (129,132,292). Similar to other rapidly developing countries, with increasing affluence, Malaysia is moving towards an aging population (11). Even though the Malaysian healthcare system assures the provision of health services for the elderly, non-medical expenses such as travel and homecare that incurred to manage their illness require OOP payment by the patient. Public provision of healthcare services for long-term geriatric care is still lacking (295,296), and this poses concerns when the elderly become a significant dependent in the household needing constant care.

Our findings also strongly suggest ethnicity to be a significant independent predictor of CHE, after controlling for other factors. Being of Indian ethnicity has a 6.8 times greater odds of experience CHE than being Chinese while being Malay has 5.6 times greater odds of CHE. One probable explanation for the CHE risk in the Indian and Malay population could be related to the fact that ethnic groups have the highest and second highest prevalence of diabetes nationally (22.1% and 14.6% respectively) (30). This may also be a contributing factor to the higher healthcare consumption for diabetes. The results for the Orang Asli were not significant. We would suggest that this was an effect of the sample size rather than the lack of risk, particularly given the results for the Malay and Indian communities, and the suggested direction of risk for the Orang Asli community. While non-significant, the estimate was 14 times greater odds of incurring catastrophic compared to the Chinese community.

The Orang Asli community is a vulnerable and marginalised population in Malaysia who lives primarily in remote rural areas and has low social economy status (297,298). In terms of healthcare access, the Orang Asli community is the sole recipient of a discrete government-run medical service. While they are entitled to receive free treatment at any government clinic, the Medical Division caters almost exclusively for the Orang Asli. The flipside to this positive discrimination is that the community, already a numerical minority— socially, economically, politically, and culturally— is further marginalized by a healthcare system that

is outside the mainstream provision of the Ministry of Health. In addition to these inequities, the standard of Orang Asli health remains far below the national average, and the community carries an increased burden of illness and disease (298). The disparities in both health status and healthcare provision continue to set the Orang Asli apart from the rest of the population. Under these challenging circumstances, we find it unsurprising that the Orang Asli community is the most at risk of catastrophic healthcare spending.

Respondents who were hospitalised due to diabetes were also found to have three times the odds of experiencing CHE, and this finding is similar to numerous other studies (17,132,167,203,299,300). Although the relationship is not statistically significant, similar to the CHE risk of the Orang Asli community, we believed that the non-significance may be due to the effect of sample size, given the high OOP associated with hospitalisation. A global study by WHO also found that inpatient OOP is a key driver of catastrophic health expenditure (65). Hospitalisation episodes can impose health shocks to households due to the high economic burden associated with direct medical costs (treatment, boarding), direct non-medical (long-distance travel), and also loss of income (17). This is mainly evident in our qualitative findings.

Living in rural areas was found to be protective against CHE, whereby respondents living in Bekok were found to have a decrease in the odds of experiencing CHE by 0.23 folds. This finding is dissimilar to other studies where poorer households in rural areas are more vulnerable to catastrophic health expenditure (129,133,141,251,292,301,302). Nonetheless, it is consistent with our other findings, where CHE is more prevalent in higher quintile groups. Our finding is also similar to the study by Somkotra and Lagrada. (2009) (132) in Thailand, which also has a UHC system like Malaysia, suggesting that implementation of UHC provided effective financial risk protection for the poor.

On the whole, we found that predictors of CHE are spread across facets of disease status, socio-demographic, and socioeconomic factors. This list of predictors correspond closely with known risk factors of developing diabetes and NCDs, including being of a specific ethnicity and increasing age (3), and of different SES level (303). If we look at the broader health system context, our findings also echoed correspondingly to the study by Somkotra and Lagrada (2009) (132), who also explored the determinants of catastrophic health spending in Thailand post-implementation of UHC.

5.1.2.3 Implications of financial catastrophe to disease management and household wellbeing

The implications of catastrophic health expenditure can be severe and far reaching, with studies showing that it forces poor households to reduce expenses of essential items such as food, shelter, or even their children's education (67). One of the notable findings we discovered in our qualitative interviews was the impact on disease management. We found that households in our studies were scaling back on home care and needed medical supplies, and also practiced self-medication and dosage adjustments without adhering to doctor's instructions. This also extends to self-monitoring of blood glucose practices, which also requires OOP spending for glucometers and test strips. Such cost-prevention strategies were also observed in West African countries and were found to be a significant factor in the study by Okoronkwo et al. (2015) (206). The direct implication of this is poor control of their health conditions, which can likely worsen their disease progression in the long run and imposes a high risk of having acute complications of diabetes that entail high cost burdens.

The impact on household finances is evident through the reallocation and seeking of resources within and outside the household to support the medical needs of the diseased household member. These include money (e.g., payment for healthcare, formal carers), selling of assets, and borrowing money from others. These are further discussed in detail in the following section (section 5.1.3). In terms of social impacts, we found that caregivers typically close family members such as the spouse or children experienced a range of psychosocial distress and disruptions to daily activities that could affect their quality of life, similar to studies by Golics et al. (2013) (304) and Schulz (2008) (305). Clinical observation and empirical research showed that caregiving for patients could be stressful and burdensome (306,307), as considered to be a form of chronic stress (308). Caregiving, particularly for long-term care, creates physical and psychological strain over extended periods and is accompanied by high levels of unpredictability and uncontrollability. This creates secondary stress in other life domains such as work and family relationships, and constantly requires high levels of vigilance to manage (305). With limited and constrained healthcare resources, healthcare service providers are shifting the management of long-term, complex health problems such as chronic diseases to home-based care (309). This is particularly more prevalent in LMICs, where healthcare systems are still predominantly biomedical, curative, and fragmented (310).

As Han and Haley (1999) (311) noted, attending to the impacts of chronic illness on family members is critical, as the physical and emotional health of family caregivers can influence the health, welfare, and successful rehabilitation of persons with chronic illness. Structural support for family caregivers, in the form of interventions by social workers and healthcare professionals, is highly beneficial both to caregivers and the patient, as well as the family wellbeing (309). Effective intervention support includes an assessment of the caregiver and family's wellbeing status and behaviour, developing a stress management plan (309), education on effective communication for family members and basic home nursing skills for caregivers (312), heavier involvement and ongoing care from healthcare professionals with the caregiver and patient (313), and long-term counselling and early involvement of caregivers (311).

On the whole, managing NCDs requires a continuum of care that goes beyond the healthcare facility, with the health outcomes and wellbeing of the patient falling squarely into the hands of home-based care. Shortfalls in home-based care not only will worsen the disease condition of the patient, but also impose higher healthcare demands, that may push families to poverty as well as straining the healthcare delivery system.

5.1.3 Coping with the financial burden of diabetes

5.1.3.1 Household financial coping strategies

High OOP may likely trigger the use of short-term payment coping mechanisms to cope with healthcare costs, and the choice of coping strategy differs in different contexts among households depending on a household's asset base (314). While such strategies may likely meet the short-term goal of paying for treatment and minimizing costs, financing healthcare with payment coping mechanisms is known to lead to sacrificing necessary household consumptions that may push the household into deeper poverty (315).

Coping mechanisms include strategies that directly adjust household consumption or resources, such as reducing and shifting overall household expenditure (316), selling productive assets, spending savings, and borrowing from either formal or informal sources. Other ways of coping may also include a change in healthcare utilisation practices that exhibit perceived cost-saving behaviours – such as missing healthcare appointment, skipping doses of drugs to lengthen the duration of drug use or seek cheaper alternative treatments at the expense of quality and efficacy (314).

In this study, our qualitative findings informed that respondents utilised different strategies to cope with the treatment expenditures. These included reliance on public healthcare services, spending on savings, borrowing from others, selling personal assets, and seeking both informal and formal social support. The preference for public care was also affirmed in the qualitative findings, whereby respondents noted the key reason for the popularity was due to ease of access and issues of affordability. This indicates the effectiveness of UHC as a safety net for healthcare access - a salient feature for equitable healthcare that is also visible in countries with UHC-based health systems such as Thailand (132,167,317). Mongolia also shared a similar case whereby its social protection mechanism that features extensive population health coverage and subsidised public healthcare has successfully limit the exposure of the poor to financial implications of NCDs (286).

The use of personal savings was one of the immediate coping options utilised, which are similar to findings in previous studies where individuals fell back on their savings to cope with healthcare payments (315,318). Incomes and savings have also been reported as a popular payment coping mechanism in LMICs such as Vietnam (251), Bangladesh (205), Colombia (319), and also in African countries like Zambia, Cote d'Ivoire, and Chad (314). A systematic review by Kankeu (2013) (62) also found that in India, 89% of patients fund the monitoring and treatment of their diabetes using their household income, while household savings were used by 22% of retired patients and by 19% of those in the lowest income group. When faced with hospitalization, Kapur (2007) (320) found that up to 56% of patients had to utilise their savings or borrow money.

The compounded risk of using savings may result in foregoing the money saved that may be intended for household necessities. This could potentially increase vulnerability to future shocks in the longer term because total expenditure is inflated, and necessary consumption is temporarily sacrificed to pay for healthcare (314,318).

Borrowing money to cope with catastrophic health payments is evident in rural areas in LMICs, where there is still a high level of reliance on informal borrowing from close groups such as friends and relatives to illegal moneylenders (321). The study by Datta et al. (2018) (291) in Bangladesh found that NCD households are 85% more likely to sell assets or borrow from informal sources to finance treatment costs. To be able to afford the cost for healthcare, households have taken unsecured loans, used up substantial savings or sell household assets, all of which affect the longer-term household economic stability. For example, studies found

that loans taken by households for health expenses come at very high interest rates that can take generations to repay (322). Utilising these types of coping mechanisms has been shown to mask the longer-term impoverishing effects of OOP payment (323), but the extent of this impoverishment may also depend on the interest rates and conditions (such as the need of collateral assets) imposed by the lender (157). The issue is more apparent in LMICs, many of which rely extensively on direct OOP payments to access healthcare services.

Nonetheless, dedicated lending schemes targeted for low-income individuals or groups such as micro-financing have shown evidence of smoothing out the impacts of financial shocks (324,325). It is a popular avenue of money lending in LMIC, particularly in South Asia (326,327). In our study, respondents were borrowing money from informal sources such as family members, friends, and even employers rather than from money lenders to support their diabetes healthcare costs. The preference is for intra-household cross-subsidisation, as respondents opted to “*take care of it ourselves*” (*qualitative quote – IDI-08*) and “*we don’t ask from others*” (*qualitative quote – IDI-07*) to resolve matters within the family. While this may seemingly reduce the risk of high interest loans and repayment, Binnendijk (2012) (285) posited that cross-subsidisation is effective provided that the proportion of people with NCD in the household remains relatively small.

Intra-household cross-subsidisation is an example of the wider scope of a social support network that was found to be an integral key element to how respondents in this study sustain their diabetes treatment and management in the long term. While there was a heavy reliance on the family institution as an informal support mechanism, particularly of close family members such as the spouse and children, members of the broader community such as neighbours and friends also assisted in terms of company and travel needs. The study by Okoronkwo et al. (2016) (206) found that community-based support was statistically significant as a household coping mechanism for treating diabetes, with the support in the form of cash or kind to boost up patient’s income for diabetic supplies. The authors concluded that the extended family system and other social groups if effectively organized and harnessed, could form dependable cushion in times of ill health. Nonetheless, caution was noted as well that these supports may not be consistent and sustainable, which still prompts the need for governments to provide financial protection mechanisms.

Our findings on the high reliance on social support networks and minimal external borrowing differ from the study conducted by Mirelman (2018) (205), which found that the bottom 40% of their study respondents (in terms of economic condition) led to a positive relationship with taking out a high interest institutional loan. The authors found that the poor are less likely to have informal networks such as friends or family who can smooth the financial impacts of health events, which forces them to seek high interest loans that will likely worsen their economic situation. Such limited options for the poor further emphasizes the need to establish affordable coping options for these households.

On the other hand, respondents in our study did not prefer to seek formal social welfare support, even though formal channels are available and provided by political party institutions (i.e., members of parliament for the designated area) and by national and state welfare programs. Among the reasons cited were difficulties in the application process and its limited availability that caters more to the hardcore poor with critical medical conditions. This places an even heavier importance and reliance on informal social channels for households to sustain their chronic disease management in the long term.

In summary, our findings on household coping strategies informed that a UHC-based health system serves as an important safety net for the population, particularly for the lower-income group who has no other means of accessing healthcare. Nonetheless, in tandem with the consistently growing prevalence of diabetes and other NCDs (30), the issue then falls to the ability of the public system to cope with rising healthcare demands without compromising service quality and access availability. As discussed earlier, we have observed in our study a tendency for patients to opt for private care for faster access and higher quality of care, even at the expense of incurring high OOP. Reliance on social support from then comes into play as a critical means of coping, particularly on the family institution, which becomes a critical pillar of support both physically and financially to manage the long-term living with chronic conditions.

5.1.3.2 Household resource allocation

When the costs of managing diabetes are placed against other equally compelling financial demands, the decision on what needs to be funded and what is to be put aside brings the harsh realities of chronic disease management to surface. In this study, we found that decision making on utilising household resources was largely made through discussions with family

members (includes those living outside the household) on who has the resources (time and money) to provide and what to prioritise. Decisions were made mainly based on economic circumstances and resource availability, with no discerning bias or preference on gender nor position in the household. We found this to be similar across all ethnic groups interviewed in this study. In some countries such as in South Asia, healthcare decision-making in the households can be patriarchal where the healthcare need of the head of household (typically men) is prioritised (177).

The availability of resources fundamentally determines the frequency and quality of care accessed. Available studies showed that the decision to use a particular coping strategy might be related to the characteristics of the household. Poor households may be more likely to use harmful coping strategies because safer ways of adjusting to the cost of the shock are not available to them (328). Previous works examining household coping strategies found that wealthy households have more access to resources and social capital and can use private transfers, whereas the poor may have no choice but to rely more on borrowings and be less likely to replace human capital (329,330).

High dependence on coping strategy will reduce the ability of families to deal with unprecedented health shocks in the future and increase debt in a poor household (24). The understanding of the coping strategies that households use after a health shock may provide valuable insights for policy. It is useful to unpack the link between illness and poverty through coping mechanisms that have implications for designing policies for financial protection for households in low- and middle-income countries.

This study provided insights into the financial coping strategies of a relatively rural population, where population dynamics, characteristics, and living environment can be vastly different than their urban counterparts. In Rijal et al.'s (2018) (149) systematic review, they found that the proportion of households adopting coping strategy varied inconsistently between rural and urban households. Due to poor economic conditions, rural populations are pressed to find alternative measures to pay for health (81). In contrast, in urban areas, the high percentage of distress financing reiterates that coping behavior is strongly correlated with the availability of social capital, valuable assets ownership, and the possibility of getting a financial loan, which is higher in an affluent urban household (250,314).

Ultimately, households tend to use a mix of different coping strategies to maximize their specific objectives, given the trade-offs of the strategy and their constraints and circumstances. Future work should attempt to understand how these coping decisions impact on long-term poverty associated with long-term chronic disease management.

5.2 Study Implications

This section discusses the implications of the study. It focuses on four primary areas where the current findings may be informative to influence policies and interventions that enhance financial risk protection for households living with NCDs. These areas include household cost burden, healthcare financing, healthcare service delivery system, and social support mechanisms.

5.2.1 The cost burden of NCDs

Our study findings revealed the magnitude of household economic burden from managing diabetes, and bring attention to the urgency to address potentially overlooked cost burdens chronic care imposes on households. Household welfare can be affected both in the short and long-term, given that OOP payments can lead to an immediate reduction in essential household items, and the borrowing of loans and sale of economically productive assets affect future household wellbeing. While evident in many studies where the poverty impact of OOP is the heaviest on low-income households (106,148,169,203), our study illustrated that catastrophic healthcare spending is shifting to non-poor households. Facing issues of service quality and crowdedness in public healthcare services (11), non-poor groups opt to seek private care, which places them at a higher risk of catastrophic spending. Compounding the cost burden is also the recurrent OOP spending on related medical supplies, as well as the widespread consumption of TCM.

Our findings corroborate with the works of Reddy et al. (2013) (207), where catastrophic health spending in Malaysia was significantly found to be more common among wealthier households. Low-income groups were being protected from financial risk by the public healthcare system, but the authors also noted that their findings might not accurately reflect the larger majority of non-poor households who seek private care and incurred catastrophic payments in the process. This will further increase the overall proportion of OOP spending as part of national total health expenditure from 37.6% in 2017 (289). OOP expenditure is an

inequitable and regressive source of financing for health care that do not achieve the benefits (both in terms of economies and financial risk protection) of pooled financing (26).

Our mapping of direct and indirect cost items that households consume can also indicate the critical cost components to focus on and their cost range. For managing NCDs such as diabetes, substantial costs may still incur for hospitalisation, home care (e.g. wound care, medical equipment such as orthopaedic shoes, wheelchairs), medications (including TCM care and insulin pen needles), and regular self-monitoring of blood glucose (glucose test strips). Knowing the household consumption cost of these items may inform policy makers of the cost of implementing intervention or prevention programs that can effectively shield vulnerable populations from financial hardship, as well as avenues to reduce financial risk beyond low-income groups. Health financing strategies can also focus on these key cost components of NCDs care to minimize the cost impacts of NCDs on households.

5.2.2 Universal healthcare financing for NCDs

Malaysia's existing tax-based health financing has been successful in providing universal care of a wide array of public health care services with extensive geographical coverage (10). However, our findings suggest that this may be insufficient to cater for the intensive resource demands of long-term care, and signals the need to explore innovative financing mechanisms to supplement existing financing sources. One potential financing mechanism is a progressive national health insurance scheme that maintains the same principle of risk pooling and prepayment as general taxation, with higher ability-to-pay groups contributing more proportionally to a ring-fenced health fund. In their modelling projections, Yu et al. (2011) (331) found that such a scheme has the potential to generate additional health funding for an enhanced healthcare package that can cater for chronic care, while preserving the equity in health care financing.

While UHC is still the health goal of many LMICs, those already with a universal or near-universal healthcare system should begin to look beyond financial risk protection to incorporate broader social protection elements to enhance healthcare financing capacity. Even though measures towards minimization of out-of-pocket health care expenditures are essential for financial risk protection, they may not be sufficient. Social protection interventions designed to prevent or mitigate non-medical costs and income loss during the lengthy treatment may also be critical. There is mounting evidence that social protection

interventions can help to improve, directly and indirectly, clinical outcomes for people with chronic illness, especially among the poorest (332,333). The linkages between actions towards UHC and broader social protection are increasingly being addressed, especially when improving equity is a key aim (108). The approach is relevant for highly debilitating health conditions and health interventions that require repeated or timely interaction with health services, such as for many non-communicable diseases.

Malaysia provides a showcase of a country that has embarked beyond the conventional concept of UHC through the inclusion of social protection elements, creating a 'UHC+' package to supplement the current healthcare system. Since early 2019, the Malaysian government initiated the *MySalam* social protection health scheme that automatically enrolls eligible lower-income groups (B40, bottom 40 percent of the population) age 18-55 into a nationwide private health insurance plan. Through a public-private partnership, coverage is provided by the private health insurer (Great Eastern Takaful) while the premiums are fully paid for by the government. The plan provides a one-off payoff of RM8000 (USD1880) for upon diagnosed with one or more of 45 common critical illness listed, and RM50 (USD11.8) daily hospitalisation allowance up to 14 days up (maximum of RM700 (USD164.5) per year) applicable to all public hospitals in Malaysia (334,335). Concurrently rolled out beside *MySalam* is the *PeKA* scheme, which caters to those in the B40 group above the age of 40. *PeKA* is a collaboration with private general practitioners to offer free medical check-up (fully subsidized by the government), a lifetime claim of RM20,000 (USD4700) for the purchase of medical devices/equipment from public hospitals (from a list of 10 selected items), cancer completion incentive of RM1,000 (USD235) (to encourage completion of cancer treatment) in public hospitals, and RM500 (USD118) (Peninsula Malaysia) to RM1000 (USD235) (East Malaysia) travel cost to government healthcare facilities for each disease (335,336). In a move to bridge the financial protection gap and transition the B40 to a sustainable private insurance market, the Central Bank of Malaysia has also introduced the *Perlindungan Tenang Scheme* in late 2017. The scheme encourages private insurance companies to offer affordable, accessible, and simple products that are targeted to meet the needs of underserved B40 Malaysians (335).

While the concept of public-private schemes may present a potentially promising untapped resource, their implementation and effectiveness in enhancing UHC remains to be seen and will be a key area of interest for future evaluation. Nonetheless, there have been numerous

concerns raised by civil society organisations that these private-based initiatives are promoting a neo-liberal agenda that may lead to the marketization of healthcare and erosion of health equity (337).

5.2.3 Enhancing primary care towards sustainable NCD management

Chronic diseases alongside ageing population have significant impacts on the pattern of health care needs, with implications for all aspects of a health service. It raises fundamental questions about the allocation of resources between the different levels of care, the roles of public and private health sectors, and the relative responsibilities of individuals and the formal health service in managing chronic disease (338). Primary health care (PHC) is generally regarded as the mainstay of NCD services and is foundational to achieving sustainable, equitable UHC mechanisms (339). While countries like Malaysia already have a well-established public primary care service, there still exist challenges of uneven distribution of resources and variable physical access to comprehensive primary health care services. This is especially so for chronic care management, where there is a shortage of trained staff to manage NCD patients, and lack of integration among health services (11). There is a global call to integrate PHC-based chronic care into existing healthcare services and programs, as chronic diseases should view as part of the overall health status of the individual, who is equally as susceptible to other health risks (340).

PHC is typically the first point of contact for care and is a natural entry point for delivering integrated care and services (338). Integrated care models such as the Chronic Care Model (CCM) utilises a multi-disciplinary team approach to provide collaborative care to patients with chronic conditions. At its core, CCM focuses on linking informed, activated patients with proactive and prepared health care teams, with an emphasis on the central importance of PHC, and the recognising that the best clinical outcomes can be obtained when all model components (patient, community, healthcare provider, and healthcare system) are interconnected and working in a coordinated manner (341). Studies have shown that implementing CCM in the primary care setting significantly improves the quality of life of patients with chronic diseases (342), and also improves the clinical and behavioural outcomes of patients with diabetes (343). It has been shown that chronic disease can be more cost-effectively managed at the primary care level, including for care of patients following hospital discharge (2).

At a global level, guidelines such as the WHO's Global Strategy for the Prevention and Control of NCDs were developed to support countries to draft national protocols for NCD management in primary health care (344). These guidelines however, will need to be linked to other measures aimed at modifying the performance of service providers also to meet the needs of those who currently rely on the non-government providers, and they pay out-of-pocket for managing NCDs. Given the consistent consumption of private care in LMICs (62), national NCD programs can also benefit from better integration between public and private sectors, which could build upon widespread dual practice by physicians. However, this requires an understanding of the quality and efficiency of care delivered in both the public and private systems to ensure that obtaining good outputs for the money spent. With health services likely to serve as a key factor in controlling the economic burden of NCDs (62), assuring their affordable access in the future will increasingly gain policy prominence.

Our study also illustrated that similar to countries in Africa, Asia, and Pacific nations, the use of TCM care such as traditional medicine is a form of primary care that is culturally embedded in daily health-seeking behaviours, and forms an important component of health care (275). Considering the medical pluralism of healthcare utilisation with patients accessing both traditional and modern medicine for their illness, the sustainable management of chronic care should also look at policies to integrate the two more cohesively. Global health institutions such as the WHO and many governments, including Malaysia have recognized the role of traditional medicine and developed national policies and strategies to protect public health and maximize the potential contribution of traditional practices and providers (345). Extending the availability to primary health care can hence be harnessed to advance UHC. The WHO Beijing Declaration in 2008 has prompted many governments to recognise and integrate traditional medicine into their national health systems and be part of the universal coverage provisions and services (346).

The integration of traditional medicine into key infrastructure components of national health systems (e.g. basic care packages) may also contribute to advancing health system attributes essential to achieve UHC; i.e., quality; efficiency; equity; accountability; and sustainability and resilience (275). Active community engagement and empowerment in the process of integration will be fundamental to enable health systems to be more sustainable and resilient. This is particularly in low-resourced settings where traditional medicine can be a significant resource that contributes to preserving culturally-situated wisdom, promoting health, and

helping to address public health challenges. A deeper understanding of the utilization pattern of traditional medicine may also inform policy solutions on health-seeking behaviour, and should be considered in the context of overall health services financing.

5.2.4 Strengthening social support systems

Individuals and their families play an important role in managing chronic illness. With experience and knowledge in home-based disease management over time, it is recognised as a critical resource to support many health systems that are unable to provide consistent medical support to effectively manage chronic illnesses (144). Home-based care has a critical impact on the health outcomes and wellbeing of the patient, and as evidently shown in our study, household members with diabetes rely substantially on family support to continuously manage their conditions.

Beyond the family institution, the broader community environment can also form an enabling factor to manage chronic illness sustainably. Health systems that establish formal linkages with their communities leverage have the potential to tap in community resources to create facilitative environments for people living with NCDs. These linkages range from sporadic collaboration to full integration between health care organizations and community services, and they leverage the community as a health care partner (347). Moreover, links to community resources can also be further strengthened to enhance care for elderly or disabled patients, who require both health and social services. Non-governmental organizations, social enterprises, and medical care funds can also be approached to provide services that health facilities do not offer and for patients who cannot afford (341).

The aspect of community engagement is also one of the core pillars of the Chronic Care Model to enhance patient-provider interaction through more inclusive participation in community health programs and partnerships in developing healthcare interventions (68). Within the context of UHC, effective community engagement would enable communities to participate in the decision making process on the provision and delivery of healthcare services in the community (347). Communities are also empowered to hold providers accountable for the quality and outcomes of their care and be proactive in managing their healthcare (348).

5.3 Study strengths and limitations

We believe our study has notable strengths that may guide similar researches in the future, as well as the presence of several limitations characteristics of study design and research implementation. We have discussed these in a broader context in chapter 3.7, and the further details of key strengths and limitations are presented below.

5.3.1 Study strengths

Our use of mixed methods as the methodological approach for the study covered a comprehensive scope to identify the economic burden of households living with diabetes. Combining both quantitative and qualitative research methods allowed us to investigate the three interrelated aspects of cost burden, its poverty impact, and how households financially cope in a single study, which gave us a more complete picture of the issue. In the Malaysian context, to our knowledge available studies on the economic burden of diabetes in Malaysia were conducted from the provider perspective (84–88). Our study is the first in Malaysia that is conducted in an HDSS site to estimate the economic burden at the household/patient level. With a longitudinal community cohort, there is high potential to bridge crucial data gaps for future COI studies that aim to estimate the total cost burden from a societal perspective.

Conducting the study in an HDSS site may have also improved data quality with a longitudinal cohort and proficient data collection process. With the availability of baseline data of the enumerated population, households with diabetes can be identified quicker and easier for surveys and interviews. In addition, the frequent engagement of the HDSS with the community has fostered better relationship and trust, which has also provided the advantage of easier reach out to respondents and obtaining rich qualitative data. A stable longitudinal cohort and an experienced team of local data collectors have also provided advantages to reduce non-response and non-sampling errors. This is particularly in terms of coverage error and responder bias, given that the whole population is mapped, and households are regularly engaged. In addition, the usage of EDC has also allowed us to enter and manage data more effectively, and having immediate access to the study database enabled us to check for data discrepancies. Also, we saved considerable resources in terms of time and cost-savings as compared to conventional paper surveys with the omission of manual data entry.

5.3.2 Study limitations

The main limitation of the study was the utilization of a cross-sectional study design. We are unable to determine for certain whether the catastrophic and impoverishing effects observed, and the coping strategies adopted by households occurred in a unit of time, or is it an aggregation of over a period. Some have also argued that the duration a household experiences catastrophic or impoverishing effects may be more critical than the incidence of the results in the population, particularly for NCDs, which require lifelong care (349). Nonetheless, the value of the evidence from cross-sectional studies is the insight gained into the lived experience of people with chronic illness through the quantification of the burden across different income groups (20).

We collected retrospective data using a 3-month and 12-month recall period, which may introduce some potential recall bias. As far as OOP is concerned, the issue of recall typically causes a downward bias as respondents may not recall the expenses made (150). Thus, the overall catastrophic spending and impoverishment impact found in the study may prove to be an underestimate. Another assumption we made was that household expenditures would have remained unchanged in the absence of health expenditures associated with diabetes. If the increase in health care expense is financed by borrowing or drawing down on savings, we may overestimate the impoverishing effects of ill health. Thus, our findings relating to poverty impact are subject to these appropriate caveats.

We also acknowledge that identifying causal labour market effects is challenging, in view of the number of important comorbidities of diabetes, such as obesity, smoking, or unobserved confounders. Thus, our estimated total costs of diabetes might overlap in part with the economic burden of obesity or other conditions causing diabetes. Our estimation of the cost of diabetes also did not take into account undiagnosed diabetes. The fact that people with diabetes already have complications at the time of diagnosis suggests that diabetes-related costs are also present among the undiagnosed (350). While these individuals may not be receiving treatment for diabetes, they may be incurring additional healthcare costs compared to those without diabetes. As a result, it is highly likely that the aggregate costs associated with diabetes may have been underestimated, and the actual economic burden may have been even more substantial. According to the International Diabetes Federation, approximately

50% of diabetes patients were undiagnosed (3), and in Malaysia, undiagnosed diabetes in adults accounted for 52% of the total diabetes prevalence (30).

Because of the varying travel distances, transportation, and related logistic limitations, we are unable to send back the transcripts of the information generated during the in-depth interviews and focus group discussions for respondents to comment and verify what was recorded, transcribed, and analysed. Instead, respondent validation was done immediately after every interview and focus group discussions. We went through the responses with the respondents at the end of the interview, and narrate it back to them to verify that what was said and to ensure the accuracy of the context. Through this process, some issues were identified, and omissions and errors were included in the interview notes. This strategy enhanced the reliability and validity of the information collected (214).

Finally, the findings of our study may not be generalizable at the national level, especially for an urban or metropolitan population, given the limitation of the data collection site conducted only within the Segamat district which has a suburban and rural setting. The apparent data gap present is the cost data of households living in highly urbanised city centres which have stark differences in terms of cost of living and cost of healthcare. Nonetheless, our study may provide a distinct picture of the economic burden of households living with a chronic NCD in a suburban and rural setting. It would be unlikely that the SEACO sub-district would be radically different from other rural and suburban areas in peninsular Malaysia (209). Even so, the difference may merely be highlighting the inflexibility of the healthcare system in catering for those in need and anticipated future needs. As noted by Jahan and colleagues (2014) (209), given that Malaysian public health services are delivered through a tiered system of tertiary, secondary (district-based) and primary services (sub-district based), national demographic profiles cannot be generalised to respond to district level (i.e. Segamat) population-specific healthcare demands.

CHAPTER 6.0: CONCLUSIONS & AREAS FOR FUTURE RESEARCH

6.1 Study conclusions

The need for large OOP health care payments threatens health care affordability and access, and impacts household economic stability and wellbeing. Our findings uncovered that despite having a UHC-based healthcare system in Malaysia, the economic burden from out-of-pocket payment for managing NCD is still substantial, and households incurred catastrophic spending and faced impoverishment from managing their conditions.

While evident in many studies where the poverty impact of OOP is the heaviest on low-income households, our study illustrated a differing scenario that may be more apparent in countries with UHC. With universal coverage providing access and financial risk protection to the poor, catastrophic healthcare spending has shifted to non-poor households. Middle-income groups are now at risk of impoverishment as they opt for private care to avoid crowdedness and service quality issues in public healthcare services. Compounding the cost burden is also the recurrent OOP spending on related medical supplies and the widespread consumption of TCM care associated with long-term chronic care management.

With the practice of medical pluralism in many countries (345), formally integrating traditional medicine into the national health systems particularly at the primary care level (e.g., insurance coverage and care packages) may also contribute to advancing health system attributes essential to enhance financial risk protection, given that their consumption are primarily OOP. In low-resourced settings, traditional medicine can be culturally rooted in communities which has the potential to be a significant resource to promote health and address public health issues. The active community engagement and empowerment in the process of integration will be essential to enable health systems to be more sustainable and resilient. Deeper insights into the health-seeking behaviour on traditional medicine consumption may also inform policy solutions on healthcare utilization, which should be considered in the context of overall health services financing.

Our findings may help to inform the design of equitable healthcare financing systems that can effectively address the threats of NCDs. With the emphasis on the future need for a public policy response to the expected rise in economic vulnerability due to NCDs, the effective measurement and monitoring of household economic burden are therefore necessary to inform healthcare policies and financing strategies. Policies that focus exclusively on measures to protect from the OOP costs of healthcare may overlook the broader economic effects of NCDs for costs of accessing care extend beyond user charges, such as transport and loss of income for patients and carers. As highlighted by Schmidt et al. (2015) (351), placing a narrow focus on population-wide coverage of clinical services and subsidies alone could divert crucial healthcare funds from public health and preventive services that could be more cost-effective to address the burden of NCDs at a population level.

NCD is threatening the core of UHC to provide equitable healthcare available for those who need it without risking financial hardship. While UHC is still very much a goal to pursue by many LMICs, middle-income countries with a readily established healthcare system with universal or near-universal coverage should begin efforts to look beyond financial risk protection to incorporate broader social protection elements. Measures towards minimizing OOP healthcare expenditures are essential for financial risk protection, but as demonstrated by our study, they may not be sufficient, particularly with regards to managing long-term care. Social protection interventions designed to prevent or mitigate non-medical costs and income loss during the lengthy treatment are also crucial (332). Economic support, in combination with other types of social assistance, has been associated with improved service uptake (352), treatment adherence (353), and treatment outcomes of chronic diseases such as tuberculosis (354).

Given the global magnitude of both health and socioeconomic impacts NCDs impose, addressing the household economic burden of NCDs is an important step in efforts to alleviate global poverty and achieve the UN's SDG. Supporting countries to achieve SDG health targets is the new World Health Organisation five-year strategic vision and framework for UHC – the 'triple billion' goal of having one billion more people benefit from UHC; one billion more people have better protection from health emergencies; and one billion more people enjoy better health and wellbeing (161). Efforts to realize the triple billion goals of WHO will rely on the design of sustainable financial protection programmes that prioritise

the poor and broader measures that enable individual health systems to comprehensively deliver clinical and population-based prevention programmes of reasonable quality and reach.

The UHC agenda has returned to the front seat in the global health agenda, with the recent convening of the UN High-Level Meeting on Universal Health Coverage in September 2019. Calls were made for heads of states and governments to reinvigorate efforts to mobilise action against NCDs, which is seen as progressing too slowly since the global commitments made in the 2011 Political Declaration on the Prevention and Control of NCDs (48). Our study may contribute as part of the research effort to generate evidence to further drive the momentum for action.

6.2 Areas for future research

Our study provided a snapshot of costs incurred in a particular year, but for the estimation of lifetime costs associated with long-term chronic care, incidence-based COI studies coupled with cost modeling techniques will be useful to provide a more accurate understanding of the lifetime costs of diabetes or any other NCDs at the patient/household level. Given the chronicity of diabetes or any other NCDs, this is an important consideration. As life expectancy increases across many rapidly developing middle-income countries such as Malaysia, individuals can expect to live longer with these diseases with increasing risks of developing associated complications and therefore, an escalation of related health care costs. It is unclear how accurate annual estimates are for cumulative costs for patients and society over the individual's life, and studies that calculate costs over the medium to long-term are much needed and lacking (355).

In addition, the estimation of long-term costs could also help to identify the potential cost savings accrued from intervening at different disease stages. Forecasting models can be utilised to evaluate further the potential impact of preventive policies on NCDs and their economic consequences (356). To further enhance the accuracy of the cost models, cost data can also be collected prospectively using cost diaries and panel survey studies, which may address the issue of recall bias. With a longitudinal cohort and a research site in place, HDSS can be an ideal platform to carry out further economic analysis to estimate long-term costs. In a similar vein, the equity implications of specific interventions can also be routinely evaluated and monitored through extended cost-effective analyses carried out in HDSS sites. This is critical to provide the necessary evidence to be factored into decisions made prior to

investing in programmes that expand financial protection. As posited by Jan et al. (2018) (20), evaluation activities should be an integral component of programme implementation to achieve UHC given the absence of a one-size-fits-all template for designing optimal financial protection programmes, as each health system needs to assess their own needs and tailor their solutions.

While the SEACO platform collects extensive population baseline data, they only reflect the social demography of the Segamat district - which is a mixture of rural and suburban areas. For assessing the fuller picture of the cost burden and its impacts, it will be necessary to conduct a larger study with a more diverse population that includes a more extensive urban setting. Urban areas have a broader range of healthcare services offered in both public and private care, with different patterns of health-seeking behaviours, healthcare utilisation, and resource consumption. Within the household setting, future studies can also seek to explore intra-household risk factor exposure, co-morbidities, and household member disease dependencies to further examine the dynamics of long-term resource use in NCD management.

In the review from the *Lancet Taskforce on NCDs and economics* (20), the group suggested the inclusion of a broader range of indicators of household economic outcomes in demographic health surveys to longitudinally capture the important dimensions of the economic burden on households. Considering that household burden from NCDs includes long-term expenditures as well as costs outside of healthcare, the proposed indicators include; 1) measures of economic hardship or financial stress to assess the ability of households to meet day-to-day financial commitments, 2) the use of coping strategies (such as the use of informal credit networks, depletion of household assets, and accessing social support), 3) the ability to access cash for an emergency and financially driven non-adherence with treatment, and 4) the non-utilisation of healthcare services because of financial barriers.

Bibliography

1. World Health Organisation. Global status report on noncommunicable diseases. Vol. 53, World Health Organization. 2011.
2. NCD Alliance. Ensuring health lives for all: Noncommunicable disease and Universal Health Coverage [Internet]. NCD Alliance. 2018. Available from: [https://ncdalliance.org/sites/default/files/resource_files/UHC and NCDs_EN.pdf](https://ncdalliance.org/sites/default/files/resource_files/UHC_and_NCDs_EN.pdf)
3. International Diabetes Federation. IDF Diabetes Atlas, Eighth edition 2017. International Diabetes Federation. 2017.
4. Goldhaber-Fiebert JD1, Li H, Ratanawijitrasin S, Vidyasagar S et al. Inpatient treatment of diabetic patients in Asia: evidence from India, China, Thailand and Malaysia. *Diabet Med*. 2009;27:101–8.
5. WHO. Global status report on noncommunicable diseases 2010. Geneva: World Health Organization; 2011.
6. United Nations. Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases. United Nations. 2011.
7. Niessen LW, Mohan D, Akuoku JK et al. Tackling socioeconomic inequalities and non-communicable diseases in low-income and middle-income countries under the Sustainable Development agenda. *Lancet*. 2018;391:2036–46.
8. Checkley W, Ghannem H, Irazola V et al. Management of Noncommunicable Disease in Low- and Middle-Income Countries. *Glob Hear*. 2014;9(4):431–43.
9. Boutayeb A, Boutayeb S. The burden of non communicable diseases in developing countries. *Int J Equity Health*. 2005;4(2).
10. Yasin S, Chan CKY, Reidpath DD et al. Contextualizing chronicity: A perspective from Malaysia. *Global Health* [Internet]. 2012;8(4). Available from: <http://www.globalizationandhealth.com/content/8/1/4>
11. Ministry of Health. Malaysia Health Systems Research Volume 1: Contextual Analysis of the Malaysian Health System, March 2016. Ministry of Health Malaysia. 2016.
12. Lin JS, Resch SC, Brimmer DJ et al. The economic impact of chronic fatigue syndrome in Georgia: direct and indirect costs. *Cost Eff Resour Alloc*. 2011;9(1).
13. Schofield D, Passey M, Percival R et al. Retiring early with cardiovascular disease - impact on individual's financial assets. *Int J Cardiol*. 2010;9(2):125–6.
14. Langa K. Out-of-pocket health-care expenditures among older Americans with cancer.

- Value Heal. 2004;7:186–94.
15. Bloom DE, Cafiero ET, Jane-Llopis E et al. The global economic burden of noncommunicable diseases. World Economic Forum. Geneva; 2011.
 16. Barceló A1, Aedo C, Rajpathak S et al. The cost of diabetes in Latin America and the Caribbean. Bull World Heal Organ. 2003;8(1):19–28.
 17. McIntyre D, Thiede M, Dahlgren G et al. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts? Soc Sci Med. 2006;62(4):858–65.
 18. Seuring T, Archangelidi O, Suhrcke M. The Economic Costs of Type 2 Diabetes: A Global Systematic Review. Pharmacoeconomics. 2015;33(8):811–31.
 19. Saksena P, Evans D, Xu K. Impact of out-of-pocket payments for treatment of non-communicable diseases in developing countries: A review of literature. Vol. Discussion, World Health Organization. 2011.
 20. Jan S, Laba TL, Essue BM et al. Action to address the household economic burden of non-communicable diseases. Lancet. 2018;391:2047–58.
 21. Chua H, Cheah J. Financing Universal Coverage in Malaysia: a case study. BMC Public Health. 2012;12(Supp 1).
 22. Chaker L, Falla A, van der Lee SJ et al. The global impact of non-communicable diseases on macro-economic productivity: a systematic review. Eur J Epidemiol [Internet]. 2015;30:357–95. Available from: <http://dx.doi.org/10.1007/s10654-015-0026-5>
 23. Wagstaff A, Van Doorslaer E. Paying for health care: Quantifying fairness, catastrophe and impoverishment with applications to Vietnam 1993–98. World Bank. 1993.
 24. Whitehead M, Dahlgren G, Evans T. Equity and health sector reforms: Can low-income countries escape the medical poverty trap? Lancet. 2001;358:833–6.
 25. Kabir MA, Rahman A, Salway S et al. Sickness among the urban poor: A barrier to livelihood security. J Int Dev. 2000;12:707–22.
 26. World Health Organisation. The World Health Report: Health Systems Financing - the path to universal coverage. World Health Organization. 2010.
 27. Schoen C, Osborn R, Squires D. How health insurance design affects access to care and costs, by income, in eleven countries. Heal Aff. 2010;29:2323–34.
 28. Genuth S, Alberti KG, Bennett P et al. Follow-up report on the diagnosis of diabetes. Diabetes Care. 2003;26(11):3160–7.
 29. Letchuman G. Prevalence of Diabetes in the Malaysian National Health Morbidity

- Survey III 2006. *Med J Malaysia*. 2010;65(3).
30. Institute of Public Health. National Health and Morbidity Survey 2015. Ministry of Health Malaysia. 2015.
 31. Bommer C, Heesemann E, Sagalova V et al. The global economic burden of diabetes in adults aged 20–79 years: a cost-of-illness study. *Lancet Diabetes Endocrinol*. 2017;5:423–30.
 32. Nolte E, Bain C, McKee M. Diabetes as a Tracer Condition in International Benchmarking of Health Systems. *Diabetes Care*. 2006;29:1007–11.
 33. Institute for Health Metrics and Evaluation (IHME). Global Burden of Disease Study 2017: SR Appendix Table 4g. Percentage Change between 1990 and 2007 and 1990 and 2017 for 195 countries and territories, all causes, both sexes. Global Health Data Exchange. 2020.
 34. Gottret P, Schieber G. Health Financing Revisited [Internet]. The World Bank. 2006. 336 p. Available from: http://dx.doi.org/10.1596/978-0-8213-6585-4%5Cnhttp://siteresources.worldbank.org/INTHSD/Resources/topics/Health-Financing/HFR_SAOOverview.pdf
 35. World Bank. Adjusting to a Changing World. World Bank. 2015.
 36. Atun R. MHSR Report on Health Service Delivery. Ministry of Health Malaysia. 2016.
 37. Barnett K, Mercer SW, Norbury M et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet*. 2012;380:37–43.
 38. World Health Organisation. Noncommunicable Disease: country profiles 2018. Noncommunicable diseases country profiles 2018. World Health Organization; 2018.
 39. Marmot M, Wilkinson J. Social Determinants of Health. Oxford University Press. Oxford: Oxford University Press; 2005.
 40. NCD Countdown 2030 Collaboration. NCD Countdown 2030: worldwide trends in non-communicable disease mortality and progress towards Sustainable Development Goal target 3.4. *Lancet*. 2018;392:1072–88.
 41. Oni T, Youngblood E, Boule A, McGrath N, Wilkinson R, Levitt N. Patterns of HIV, TB, and non-communicable disease multi-morbidity in peri-urban South Africa – a cross sectional study. *BMC Infect Dis*. 2015;15(20).
 42. Di Cesare M, Bennett JE, Best N et al. The contributions of risk factor trends to cardiometabolic mortality decline in 26 industrialized countries. *Int J Epidemiol*.

- 2013;42:838–48.
43. Ezzati M, Obermeyer Z, Tzoulaki I et al. Contributions of risk factors and medical care to cardiovascular mortality trends. *Nat Rev Cardiol*. 2015;12:508–30.
 44. Jamison DT, Summers LH, Alleyne G et al. Global health 2035: a world converging within a generation. *Lancet*. 2013;382:1898–955.
 45. Zaki M, Robaayah Z, Chan SP et al. Malaysia Shape of the Nation (MySoN): a primary care based study of abdominal obesity in Malaysia. *Med J Malaysia*. 2010;65:143–9.
 46. World Health Organisation. It's time to deliver: Report of the WHO independent high-level commission on noncommunicable diseases [Internet]. World Health Organization. 2018. Available from: <http://apps.who.int/iris/bitstream/handle/10665/272710/9789241514163-eng.pdf?ua=1>
 47. United Nations. United Nations Decade of Action on Nutrition. United Nations. 2020.
 48. Horton R, Sargent J. 2018 must be the year for action against NCDs. *Lancet*. 2018;391:1971–73.
 49. International Monetary Fund. World economic outlook: The global demographic transition. International Monetary Fund. Washington DC; 2004.
 50. World Bank. Sri Lanka: Addressing the needs of an aging population. World Bank. Washington DC; 2008.
 51. Muka T, Imo D, Jaspers L et. al. The global impact of non-communicable diseases on healthcare spending and national income: a systematic review. *Eur J Epidemiol*. 2015;30(4):251–77.
 52. Garg C, Evans D. What is the impact of non-communicable diseases on National Health Expenditures: a synthesis of available data. Vol. Discussion, World Health Organization. 2011.
 53. Leal J, Luengo-Fernandez R, Gray A et al. Economic burden of cardiovascular diseases in the enlarged European Union. *Eur Hear J*. 2006;27(13):1610–9.
 54. Nichols GA, Bell TJ, Pedula KL et al. Medical care costs among patients with established cardiovascular disease. *Am J Manag Care*. 2010;16(3):86–93.
 55. Bradley CJ, Lansdorp-Vogelaar I, Yabroff et al. Productivity savings from colorectal cancer prevention and control. *Am J Prev Med*. 2011;41(2):5–14.
 56. Goss J. Projection of Australian health care expenditure by disease, 2003 to 2033. AIHW. 2008.
 57. Aaron H. What drives the health care spending? Can we know whether population

- ageing is a “red herring”? Center for Retirement Research. Boston; 2009.
58. Xu K, Evan D, Carrin G et al. Protecting households from catastrophic health spending. *Health Aff.* 2007;26(4):972–83.
 59. World Bank. Driving Sustainable, Inclusive Growth in the 21st Century [Internet]. World Bank. 2019. Available from:
<http://documents.worldbank.org/curated/en/641451561043585615/Driving-Sustainable-Inclusive-Growth-in-the-21st-Century>
 60. Russell S. Illuminating cases: understanding the economic burden of illness through case study household research. *Heal Policy Plan.* 2005;20(277–89).
 61. Wagner AK, Graves AJ, Reiss SK et al. Access to care and medicines, burden of health care expenditures, and risk protection: Results from the World Health Survey. *Health Policy (New York)* [Internet]. 2011;100(2–3):151–8. Available from:
<http://dx.doi.org/10.1016/j.healthpol.2010.08.004>
 62. Kankeu HT, Saksena P, Xu K et al. The financial burden from non-communicable diseases in low- and middle-income countries: A literature review. *Heal Res Policy Syst.* 2013;11(1):1–12.
 63. Xu K, Evans DB, Kawabata K et al. Household catastrophic health expenditure: a multicountry analysis. *Lancet* [Internet]. 2003;362(9378):111–7. Available from:
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medc&AN=12867110>
 64. van Doorslaer E, O'Donnell O, Rannan-Eliya RP et al. Effect of payments for health care on poverty estimates in 11 countries in Asia: an analysis of household survey data. *Lancet.* 2006;368(9544):1357–64.
 65. Saksena P, Xu K, Durairaj V. The drivers of catastrophic expenditure: outpatient services, hospitalization or medicines? [Internet]. World health organisation. 2010. Available from:
<http://www.who.int/healthsystems/topics/financing/healthreport/21whr-bp.pdf>
 66. Ng CS, Lee JYC, Toh MPHS et al. Cost-of-illness studies of diabetes mellitus: A systematic review. *Diabetes Res Clin Pract.* 2014;105(2):151–63.
 67. Russell S. The economic burden of illness for households in developing countries: A review of studies focusing on malaria, tuberculosis, and human immunodeficiency virus/acquired immunodeficiency syndrome. *Am J Trop Med Hyg.* 2004;71(Supp 2):147–55.
 68. Wirtz VJ, Kaplan WA, Tellez YSA et al. Affordable, quality, long-term care and

- pharmacotherapy of chronic diseases: a framework for low and middle income countries. *World Heal Organ*. 2011;
69. Abegunde DO, Mathers CD, Adam T et al. The burden and costs of chronic diseases in low-income and middle-income countries. *Lancet*. 2007;370(9603):1929–38.
 70. Chatterjee S, Riewpaiboon A, Piyathakit P et al. Cost of diabetes and its complications in Thailand: A complete picture of economic burden. *Heal Soc Care Community*. 2011;19(3):289–98.
 71. Song X, Zhao Z, Barber B et al. Cost of illness in patients with metastatic colorectal cancer. *J Med Econ*. 2011;14(1):1–9.
 72. Ray GT, Collin F, Lieu T et al. The cost of health conditions in a health maintenance organization. *Med Care Res*. 2000;57(1):92–109.
 73. Schneider K, O'Donnell B, Dean D. Prevalence of multiple chronic conditions in the United States' Medicare population. *Heal Qual Life Outcomes*. 2009;7(82).
 74. Nielsen R, Johannessen A, Omenaas ER et al. Excessive costs of COPD in ever-smokers. A longitudinal community study. *Respir Med*. 2011;105(3):485–93.
 75. Le C, Lin L, Jun D et al. The economic burden of type 2 diabetes mellitus in rural southwest China. *Int J Cardiol*. 2013;165(2):273–7.
 76. Bottacchi E, Corso G, Tosi P et al. The cost of first-ever stroke in Valle d'Aosta, Italy: linking clinical registries and administrative data. *BMC Heal Serv Res*. 2012;12(372).
 77. Clerc L, Jooste V, Lejeune C et al. Cost of care of colorectal cancers according to health care patterns and stage at diagnosis in France. *Eur J Heal Econ*. 2008;9(4):361–7.
 78. Hodgson T, Meiners M. *Cost of Illness Methodology: A Guide to Current Practices and Procedures*. *Milbank Mem Fund Q*. 1982;60(3):429–62.
 79. Segel J. *Cost-of-Illness Studies—A Primer*. RTI-UNC Center of Excellence in Health Promotion Economics. 2006.
 80. Zhu T, Tam L, Li E. Cost-of-illness studies in systemic lupus erythematosus: A systematic review. *Arthritis Care Res*. 2011;63(5):751–60.
 81. Sauerborn R, Nougara A, Hien M et al. Seasonal variations of household costs of illness in Burkina Faso. *Soc Sci Med*. 1996;43(3):281–90.
 82. Asenso-Okyere W, Dzator J. Household cost of seeking malaria care. A retrospective study of two districts in Ghana. *Soc Sci Med*. 1997;45(5):659–67.
 83. Attanayake N, Fox-Rushby J, Mills A. Household costs of “malaria” morbidity: A study in Matale district, Sri Lanka. *Trop Med Int Heal*. 2000;5(9):595–606.

84. Ahmed H, Ibrahim M, Babar Z. Affordability of essential medicines used for treating chronic diseases in Malaysia: an academic perspective. *Internet J Third World Med*. 2009;8(1).
85. Rohana D, Wan Norlida WI, Nor Azwany Y et al. Economic evaluation of type 2 diabetes management at the Malaysian ministry of health primary care clinics in Machang, Kelantan. *Malays J Public Heal Med*. 2007;7(1):5–13.
86. Sharifa Ezat WP, Azimatun NA, Amrizal MN et al. Economic burden of diabetic care in government health facilities in Selangor. *J Community Heal*. 2009;5(2):17–26.
87. Ibrahim W, Aljunid S, Ismail A. Cost of type 2 diabetes mellitus in selected developing countries. *Malays J Public Heal Med*. 2010;10(2):68–71.
88. Mustapha FI, Azmi S, Manaf MR et al. What are the direct medical costs of managing type 2 diabetes mellitus in Malaysia? *Med J Malaysia*. 2017;72(5):271–7.
89. Sorensen SV, Goh JW, Pan F et al. Incidence-based cost-of- illness model for metastatic breast cancer in the United States. *Int J Technol Assess Heal*. 2012;28(1):12–21.
90. Lopez-Bastida J, Oliva Moreno J, Worbes Cerezo M et al. Alvarez F. Social and economic costs and health-related quality of life in stroke survivors in the Canary Islands, Spain. *BMC Heal Serv*. 2012;12(315).
91. Wan Y, Gao X, Mehta S et al. Indirect costs associated with metastatic breast cancer. *J Med Econ*. 2013;16(10):1169–78.
92. Biorac N, Jakovljevic M, Stefanovic D et al. Assessment of diabetes mellitus type 2 treatment costs in the Republic of Serbia. *Vojn Pregl*. 2009;66(4):271–6.
93. Nishimura S, Zaher C. Cost impact of COPD in Japan: opportunities and challenges? *Respiratory*. 2004;9(4):466–73.
94. Darkow T, Kadlubeck PJ, Shah H et al. A retrospective analysis of disability and its related costs among employees with chronic obstructive pulmonary disease. *J Occup Env Med*. 2007;49(1):22–30.
95. Adhikari S, Maskay NM, Sharma BP et al. Paying for hospital-based care of Kala-azar in Nepal: assessing catastrophic, impoverishment and economic consequences. *Heal Policy Plan*. 2009;24:129–39.
96. Van Damme W, Van Leemput L, Por I et al. Out-of-pocket health expenditure and debt in poor households: evidence from Cambodia. *Trop Med Int Heal*. 2004;9:73–80.
97. Claesson L, Gosman-Hedstrom G, Johannesson M et al. Resource utilization and costs of stroke unit care integrated in a care continuum: a 1-year controlled, prospective,

- randomized study in elderly patients - the Goteborg 70+ stroke study. *Stroke*. 2000;31(11):2569–77.
98. Luo Z, Bradley CJ, Dahman BA et al. Gardiner JC. Colon cancer treatment costs for Medicare and dually eligible beneficiaries. *Health Care Financ Rev*. 2009;31(1):35–50.
 99. Martin S, Schramm W, Schneider B et al. Epidemiology of complications and total treatment costs from diagnosis of type 2 diabetes in Germany (ROSSO 4). *Exp Clin Endocrinol Diabetes*. 2007;115(8):495–501.
 100. Legorreta AP, Brooks RJ, Leibowitz AN et al. Cost of breast cancer treatment - a 4-year longitudinal study. *Arch Intern Med*. 1996;156(19):2197–201.
 101. Dalai AA, Shah M, Lunacsek O et al. Clinical and economic burden of patients diagnosed with COPD with comorbid cardiovascular disease. *Respir Med*. 2011;105(10):1516–22.
 102. Fireman BH, Quesenberry CP, Somkin CP et al. Cost of care for cancer in a health maintenance organization. *Health Care Financ Rev*. 1997;18(4):51–76.
 103. Lang K, Lines L, Lee D. Lifetime and treatment-phase costs associated with colorectal cancer: evidence from SEER-Medicare data. *Clin Gastroenterol Hepatol Off Clin Pr J Am Gastroenterol Assoc*. 2009;7(2):198–204.
 104. Cortaredona S, Ventelou B. The extra cost of comorbidity: Multiple illnesses and the economic burden of non-communicable diseases. *BMC Med*. 2017;15(1):1–11.
 105. Rugalema G. It is not only the loss of labour: HIV/ AIDS, loss of household assets and household livelihood in Bukoba District, Tanzania. *Pap Present East South Africa Reg Conf Responding to HIV/AIDS Dev Needs African Smallhold Agric Harare* (June 8–10). 1998;
 106. Engelgau M, Rosenhouse S, El-Saharty S et al. The economic effect of noncommunicable diseases on households and nations: A review of existing evidence. *J Health Commun*. 2011;16(SUPPL. 2):75–81.
 107. World Health Organisation. *The World Health Report 2000—Health Systems: Improving Performance*. World Health Organization. 2000.
 108. Save the Children. *Universal Health Coverage: A Commitment to Close the Gap*. Save the Children. 2013.
 109. World Health Organisation. *Women and health: today's evidence, tomorrow's agenda*. World Health Organ. 2009;
 110. Cohen J, Dupas P. Free distribution or cost-sharing? Evidence from a randomized malaria prevention experiment. *Q J Econ*. 2010;125:1–45.

111. Kremer M, Miguel E. The illusion of sustainability. *Q J Econ.* 2007;122:1007–65.
112. Gilson L, McIntyre D. Removing user fees for primary care in Africa: the need for careful action. *BMJ.* 2005;331:762–5.
113. Gaal P, Cashin C, Shishkin S. Implementing health reform: lessons from countries in transition. Observatory, European Policies, on Health Systems and. 2010.
114. Kruk ME, Mbaruku G, Rockers PC et al. User fee exemptions are not enough: out-of-pocket payments for ‘free’ delivery services in rural Tanzania. *Trop Med Int Health.* 2008;13:1442–51.
115. Lewis M. Informal payments and the financing of health care in developing and transition countries. *Heal Aff.* 2007;26:984–97.
116. Jowett M, Danielyan E. Is there a role for user charges? Thoughts on health system reform in Armenia. *J World Heal Organ.* 2010;88:472–3.
117. Rossi L, Hoerz T, Thouvenot V et al. Evaluation of health, nutrition and food security programmes in a complex emergency: the case of Congo as an example of a chronic post-conflict situation. *Public Health Nutr.* 2006;9:551–6.
118. Andrews S, Mohan S. User charges in health care: some issues. *Econ Polit Wkly.* 2002;37:3793–5.
119. Akin J, Birdsall N FD. Financing health services in developing countries: an agenda for reform. The World Bank. 1987.
120. Waddington C, Enyimayew K. A price to pay, part 2: the impact of user charges in the Volta region of Ghana. *Int J Health Plann Manage.* 1990;5:287–312.
121. Mwabu G, Mwanzia J, Liambila W. User charges in government health facilities in Kenya: effect on attendance and revenue. *Health Policy Plan.* 1995;10:164–70.
122. Knippenberg R, Nafo FT, Osseni R et al. Increasing clients’ power to scale up health services for the poor: the Bamako Initiative in West Africa. World Bank. 2003;
123. van Doorslaer E, O’Donnell O, Rannan-Eliya RP et al. Catastrophic payments for health care in Asia. *Health Econ.* 2007;16:1159–84.
124. Van de Ven, W, Schut F. Should catastrophic risks be included in a regulated competitive health insurance market? *Soc Sci Med.* 1994;39:1459–72.
125. Selden T. Should the government provide catastrophic insurance? *J Public Econ.* 1993;51:241–7.
126. Berki S. A look at catastrophic medical expenses and the poor. *Heal Aff (Millwood)Aff.* 1986;5:138–45.
127. Saksena P, Hsu J ED. Financial Risk Protection and Universal Health Coverage:

- Evidence and Measurement Challenges. *PLoS Med.* 2014;11(9).
128. Xu K. Distribution of health payments and catastrophic expenditures: Methodology. World Health Organization. 2005.
 129. Li Y, Wu Q, Xu L et al. Factors affecting catastrophic health expenditure and impoverishment from medical expenses in China: policy implications of universal health insurance. *Bull World Heal Organ.* 2012;90:664–71.
 130. Gotsadze G, Zoidze A, Rukhadze N. Household catastrophic health expenditure: evidence from Georgia and its policy implications. *BMC Heal Serv Res.* 2009;9:63.
 131. Dukhan Y, Korachais C, Xu K et al. Financial burden of health payments in France: 1995–2006. World Health Organization. 2010.
 132. Somkotra T, Lagrada L. Which households are at risk of catastrophic health spending: experience in Thailand after Universal Coverage. *Heal Aff.* 2009;28:467–78.
 133. Su T, Kouyate B, Flessa S. Catastrophic household expenditure for health care in a low-income society: a study from Nouna District, Burkina Faso. *Bull World Heal Organ.* 2006;84:21–7.
 134. Cavagnero E, Carrin G, Xu K et al. Health financing in Argentina: an empirical study of health care utilization and health care expenditure. *World Heal Organ.* 2006;
 135. Xu K, Evan DB, Kadama P et al. Understanding the impact of eliminating user fees: utilization and catastrophic health expenditures in Uganda. *Soc Sci Med.* 2006;62:866–76.
 136. Habicht J, Xu K, Couffinhal A et al. Detecting changes in financial protection: creating evidence for policy in Estonia. *Health Policy Plan.* 2006;21:421–31.
 137. World Health Organisation. Health financing strategy for the Asia Pacific region (2010–2015). World Health Organization. 2009.
 138. Anuranga, C., J. Chandrasiri, Wickramasinghe R et al. The Impact of Out-of-Pocket Expenditures on Families and Barriers to Use of Maternal and Child Health Services in Cambodia: Evidence from the Cambodia Socio-Economic Survey 2007 - RETA–6515 Country Brief. Asian Development Bank. 2013.
 139. Rannan-Eliya R, Sikurajapathy L. Sri Lanka: ‘Good Practice ’ in Expanding Healthcare Coverage. World Bank. 2009.
 140. van Doorslaer E, O’Donnell O, Rannan-Eliya RP et al. Paying out-of-pocket for health care in Asia: Catastrophic and poverty impact. Equitap Project: Working Paper 2. 2005.
 141. Ramachandran A, Ramachandran S, Snehalatha C. Increasing expenditure on health

- care incurred by diabetic subjects in a developing country: a study from India. *Diabetes Care*. 2007;30:252–6.
142. Neuhaan HF, Warter-Neuhaan C, Lyaruu I et al. Diabetes care in Kilimanjaro region: clinical presentation and problems of patients of the diabetes clinic at the regional referral hospital – an inventory before structured intervention. *Diabet Med*. 2001;19:509–13.
 143. Mahal A, Koran A, Engelgau M. The economic implications of non-communicable diseases for India. World Bank. 2010;
 144. Van Olmen J, Ku GM, Bermejo R et al. The growing caseload of chronic life-long conditions calls for a move towards full self-management in low-income countries. *Global Health [Internet]*. 2011;7:38. Available from: <http://www.globalizationandhealth.com/content/7/1/38>
 145. Mendis S, Fukino K, Cameron A et al. The availability and affordability of selected essential medicines for chronic diseases in six low- and middle-income countries. *Bull World Health Organ*. 2007;85:279–88.
 146. Nolte E, McKee M. Caring for people with chronic conditions. A health system perspective. European Observatory on Health Systems and Policies. 2009.
 147. Mannava P, Abdullah A, James C. Non-communicable diseases and health systems in the Asia-Pacific region: A review of the literature. *Asia Pac J Public Heal*. 2015;27(2):1–19.
 148. Ali MK, Rabadan-Diehl C, Flanigan J et al. Systems and Capacity to Address Noncommunicable Diseases in Low- and Middle-Income Countries. *Sci Transl Med*. 2013;5(181).
 149. Rijal A, Adhikari TB, Khan JAM et al. The economic impact of non-communicable diseases among households in South Asia and their coping strategy: A systematic review. *PLoS One*. 2018;13(11).
 150. Hamid S, Ahsan S, Begum A. Disease-specific impoverishment impact of out-of-pocket payments for health care: evidence from rural Bangladesh. *Appl Heal Econ Heal Policy*. 2014;12(4):421–33.
 151. Shobhana R, Rao PR, Lavanya A et al. Expenditure on health care incurred by diabetic subjects in a developing country—a study from southern India. *Diabetes Res Clin Pract*. 2000;48:37–42.
 152. Rao K, Bhatnagar A, Murphy A. Socio-economic inequalities in the financing of cardiovascular & diabetes inpatient treatment in India. *Indian J Med Res*.

- 2011;133(1):57–63.
153. Gwatidzo S, Stewart-Williams J. Diabetes mellitus medication use and catastrophic healthcare expenditure among adults aged 50+ years in China and India: results from the WHO study on global AGEing and adult health (SAGE). *BMC Geriatr* [Internet]. 2017;17(14). Available from: <http://dx.doi.org/10.1186/s12877-016-0408-x>
 154. Smith-Spangler C, Bhattacharya J, Goldhaber-Fiebert J. Diabetes, Its Treatment, and Catastrophic Medical Spending in 35 Developing Countries. *Diabetes Care*. 2012;35:319–26.
 155. Wagstaff A, Van Doorslaer E. Catastrophe and impoverishment in paying for health care: with applications to Vietnam 1993–1998. *Heal Econ*. 2003;12:921–34.
 156. Wagstaff A. Poverty and health sector inequalities. *Bull World Heal Organ*. 2007;85:79–88.
 157. Wagstaff A. Measuring financial protection in health. World Bank. 2008.
 158. Murray C, Evans D. Health systems performance assessment: debates, methods and empiricism. *World Heal Organ*. 2003;
 159. Moreno-Serra R, Millett C, Smith P. Towards improved measurement of financial protection in health. *PLoS Med*. 2011;8:e1001087.
 160. World Bank. Tracking Universal Health Coverage: 2017 Global Monitoring Report [Internet]. World Bank. 2017. 88 p. Available from: https://www.who.int/publications/almaata_declaration_en.pdf%0Ahttp://www.who.int/gender-equity-rights/knowledge/anchoring-uhc.pdf%0Ahttp://apps.who.int/iris/bitstream/handle/10665/259817/9789241513555-eng.pdf;jsessionid=C29E21005A5692511BE2B70BD2D3C941?se
 161. World Health Organisation. WHO unveils sweeping reforms in drive towards “triple billion” targets [Internet]. World Health Organization. 2019. Available from: <https://www.who.int/news-room/detail/06-03-2019-who-unveils-sweeping-reforms-in-drive-towards-triple-billion-targets>
 162. Russell S. Ability to pay for health care: Concepts and Evidence. *Health Policy Plan*. 1996;11(3):219–37.
 163. O'Donnell O, van Doorslaer E, Wagstaff A et al. Analyzing health equity using household survey data: a guide to techniques and their implementation. World Bank. 2008;
 164. Prakongsai P, Tangcharoensathien V, Limwattananon S. The Equity Impact of the Universal Coverage Policy: Lessons from Thailand. *Adv Heal Econ Heal Serv Res*.

- 2009;21:57–81.
165. Ataguba J-O. Reassessing catastrophic health-care payments with a Nigerian case study. *Heal Econ Policy Law*. 2011;7:309–26.
 166. Goudge J, Russell S, Gilson L et al. Household experiences of ill-health and risk protection mechanisms. *J Int Dev*. 2009;21(2):159–68.
 167. Limwattananon S, Tangcharoensathien V, Prakongsai P. Catastrophic and poverty impacts of health payments: results from national household surveys in Thailand. *Bull World Heal Organ*. 2007;85:600–6.
 168. Onoka CA, Onwujekwe OE, Hanson K et al. Examining catastrophic health expenditures at variable thresholds using household consumption expenditure diaries. *Trop Med Int Heal*. 2011;16(10):1334–41.
 169. Bhojani U, Thriveni RD, Devadasan R et al. Out-of-pocket healthcare payments on chronic conditions impoverish urban poor in Bangalore, India. *BMC Public Health*. 2012;12:990.
 170. Patcharanarumol W, Mills A, Tangcharoensathien V. Dealing with the cost of illness: the experience of four villages in Lao PDR. *J Int Dev*. 2009;21:212–30.
 171. Ravallion M. Poverty lines across the world. Social Science Research Network. 2010.
 172. Ravallion M. Poverty lines in theory and practice. World Bank. 1998.
 173. World Bank Development Group. A common vision for the World Bank Group. World Bank. 2013;
 174. Allotey P, Reidpath DD, Yasin S et al. Rethinking health-care systems: a focus on chronicity. *Lancet*. 2011;377(9764):450–1.
 175. Briggs C, Garner P. Strategies for integrating primary health services in middle- and lowincome countries at the point of delivery. *Cochrane Database Syst Rev*. 2006;2:CD003318.
 176. Hanratty B, Holland P, Jacoby A et al. Financial stress and strain associated with terminal cancer—a review of the evidence. *Palliat Med*. 2007;21:595–607.
 177. Engelgau M, Karan A, Mahal A. The economic impact of non-communicable Diseases on households in India. *Glob Heal*. 2012;8(9).
 178. World Health Organisation. Global action plan for the prevention and control of noncommunicable diseases 2013–2020. World Health Organization. 2013.
 179. World Health Organisation. Assessing national capacity for the prevention and control of noncommunicable diseases: report of the 2017 global survey. World Health Organization. 2018.

180. Ramesh M, Wu X. Realigning public and private healthcare in Southeast Asia. *Pac Rev.* 2008;21(2):171–87.
181. Phua K. Comparative healthcare financing systems, with special reference to East Asian countries. *Res Heal Financ Manag.* 1999;5:113–33.
182. Phua K, Chew A. Towards a comparative analysis of health systems reforms in the Asia-Pacific region. *Asia Pac J Public Heal.* 2002;14:9–16.
183. Preker A, Harding S. Innovations in health service delivery: the corporatization of public hospitals. World Bank. 2003.
184. PEMANDU. Economic Transformation Programme. PEMANDU. 2010.
185. Chee H. Current healthcare financing issues in Malaysia. Asia Research Institute. 2004.
186. Chanda R. Trade in Health Services. *Bull World Heal Organ.* 2002;80:158–63.
187. Pocock N, Phua K. Medical tourism and policy implications for health systems: a conceptual framework from a comparative study of Thailand, Singapore and Malaysia. *Glob Heal.* 2011;7(12).
188. Hopkins L, Labonte R, Runnels V et al. Medical tourism today: what is the state of existing knowledge? *J Public Heal Policy.* 2010;31(2):185–98.
189. NCD Alliance. Universal health coverage and non-communicable disease: A mutually reinforcing agenda [Internet]. NCD Alliance. 2014. Available from: https://ncdalliance.org/sites/default/files/rfiles/UHC and NCDs 2014_A4_final_web.pdf
190. Tangcharoensathien V, Pitayarangarit S, Patcharanarumol W et al. Promoting universal financial protection: how the Thai universal coverage scheme was designed to ensure equity. *Heal Res Policy Syst.* 2013;11(25).
191. Frenk J. Bridging the divide: Global lessons from evidence-based health policy in Mexico. *Lancet.* 2006;368:954–61.
192. Chongsuvivatwong V, Phua HK, Yap MT et al. Health and health-care systems in southeast Asia: diversity and transitions. *Lancet.* 2011;377:429–37.
193. Ministry of Health. Health Facts 2019. Ministry of Health Malaysia. 2019.
194. Knaul FM, Gonzalez-Pier E, Gomez-Dantes O et al. The quest for universal health coverage: achieving social protection for all in Mexico. *Lancet.* 2012;380:1259–79.
195. Meng Q, Xu K. Progress and challenges of the rural cooperative medical scheme in China. *Bull World Heal Organ.* 2014;92:447–51.
196. Giedion U, Andrés Alfonso E, Díaz Y. The impact of universal coverage schemes in

- the developing world: a review of the existing evidence. World Bank. 2013.
197. Perera M, Gunatilleke G, Bird P. Falling into the medical poverty trap in Sri Lanka: what can be done? *Int J Heal Serv*. 2007;37:379–89.
 198. Twagirimukiza M, Cosijns A, Pringels E et al. Influence of tropical climate conditions on the quality of antihypertensive drugs from Rwandan pharmacies. *Am J Trop Med Hyg*. 2009;81:776–81.
 199. International Union Against Tuberculosis and Lung Disease and World Health Organization. Collaborative Framework for Care and Control of Tuberculosis and Diabetes. International Union Against Tuberculosis and Lung Disease and World Health Organization. 2011.
 200. Dmytraczenko T, Almeida G. Toward universal health coverage and equity in Latin America and the Caribbean: evidence from selected countries. World Bank. 2015.
 201. Atun R, Jaffar S, Nishtar S et al. Improving responsiveness of health systems to non-communicable disease. *Lancet*. 2013;381:690–7.
 202. Chan M. Making fair choices on the path to universal health coverage. *Heal Sys Ref*. 2016;2:5–7.
 203. Afroz A, Mohammed JA, Hossain MN et al. Cost-of-illness of type 2 diabetes mellitus in low and lower-middle income countries: a systematic review. *BMC Health Serv Res*. 2018;18(972).
 204. Jaspers L, Colpani V, Chaker L et al. The global impact of non-communicable diseases on households and impoverishment: a systematic review. *Eur J Epidemiol*. 2014;30:163–88.
 205. Mirelman AJ, Trujillo AJ, Niessen LW et al. Household coping strategies after an adult noncommunicable disease death in Bangladesh. *Int J Health Plann Manage*. 2018;34:e203–18.
 206. Okoronkwo IL, Ekpemiro JN, Onwujekwe OE et al. Socioeconomic inequities and payment coping mechanisms used in the treatment of type 2 diabetes mellitus in Nigeria. *Niger J Clin Pract*. 2016;19:104–9.
 207. Reddy SR, Ross-Degnan D, Zaslavsky AM et al. Healthcare payments in the Asia Pacific: validation of five survey measures of economic burden. *Int J Heal Equity Heal*. 2013;12:49.
 208. Allotey P, Reidpath DD, Devarajan N et al. Cohorts and community: A case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. *Glob Health Action*. 2014;7:23176.

209. Jahan NK, Allotey P, Arunachalam D et al. The rural bite in population pyramids: What are the implications for responsiveness of health systems in middle income countries? BMC Public Health [Internet]. 2014;14(SUPPL. 2):S8. Available from: <http://www.biomedcentral.com/1471-2458/14/S2/S8>
210. Creswell J PC V. Designing and conducting mixed methods research. Sage. 2007.
211. Creswell J. A concise introduction to mixed methods research. Sage. 2014.
212. Rossman G, Wilson B. Numbers and words: Combining quantitative and qualitative methods in a single large-scale evaluation study. Eval Rev. 1985;9(5):627–43.
213. Morgan D. Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. J Mix Methods Res. 2007;1(1):48–76.
214. Patton M. Qualitative research and evaluation methods (3rd ed.). Sage. 2002.
215. Tashakkori A, Teddlie C. SAGE handbook of mixed methods in social and behavioral research (2nd ed.). Sage. 2010.
216. Changik J. Cost-of-illness studies: concepts, scopes, and methods. Clin Mol Hepatol. 2014;20(4):327–37.
217. Rice D. Cost-of-illness studies: fact or fiction? Lancet. 1994;355(8936):1519–20.
218. Murray C, Lopez A. Global comparative assessments in the health sector: disease burden, expenditures and intervention packages. World Heal Organ. 1994;
219. Mutyambizi C, Pavlova M, Chola L et al. Cost of diabetes mellitus in Africa: A systematic review of existing literature. Global Health. 2018;14(3).
220. Bloom BS, Bruno DJ, Maman DY et al. Usefulness of US cost-of-illness studies in healthcare decision making. Pharmacoeconomics. 2011;19(2):207–13.
221. Molinier L, Bauvin E, Combescure C et al. Methodological considerations in cost of prostate cancer studies: a systematic review. Value Heal. 2008;11(5):878–85.
222. Ettaro L, Songer TJ, Zhang P et al. Cost-of-illness studies in diabetes mellitus. Pharmacoeconomics. 2004;22(3):149–64.
223. Ministry of Health. Management of Type 2 Diabetes Mellitus. Ministry of Health Malaysia. 2015.
224. Tran BX, Duong AT, Nguyen LT et al. Financial burden of health care for HIV/AIDS patients in Vietnam. Trop Med Int Heal. 2013;18(2):212–8.
225. Kirigia JM, Sambo HB, Sambo LG et al. Economic burden of diabetes mellitus in the WHO African region. BMC Int Health Hum Rights. 2009;9(6).
226. Ching S, Zakaria Z, Paimin F, Jalalian M. Complementary alternative medicine use among patients with type 2 diabetes mellitus in the primary care setting: a cross-

- sectional study in Malaysia. *BMC Complement Altern Med*. 2013;13:148.
227. Byford S, Torgerson D, Raftery J. Cost of illness studies. *BMJ*. 2000;320:1335.
 228. Khazanah Research Institute. The State of Households II. Khazanah Research Institute. 2016.
 229. Ferguson BD, Tandon A, Gakidou E et al. Estimating permanent income using indicator variables. *Health systems performance assessment: debates, methods and empiricism*. World Health Organization. 2003.
 230. Drummond M. Cost-of-Illness Studies: A Major Headache? *Pharmacoeconomics*. 1992;2(1):1–4.
 231. Hodgson TA. Costs of illness in cost-effectiveness analysis: A review methodology. *Pharmacoeconomics*. 1994;6(6):536–52.
 232. Torój A, Mela A. Indirect costs of diabetes and its impact on the public finance: the case of Poland. *Expert Rev Pharmacoecon Outcomes Res*. 2018;18(1):93–105.
 233. Lindgren P, Glader E, Jonsson B. Utility loss and indirect costs after stroke in Sweden. *Eur J Cardiovasc Prev Rehabil*. 2008;15:230–3.
 234. Pagano E, Brunetti M, Tediosi F et al. Costs of Diabetes: A Methodological Analysis of the Literature. *Pharmacoeconomics*. 1999;15(6):583–95.
 235. Tharkar S, Devarajan A, Kumpatla S et al. The socioeconomics of diabetes from a developing country: a population based cost of illness study. *Diabetes Res Clin Pr*. 2010;89(3):334–40.
 236. Hennick M, Hutter I, Bailey A. Qualitative research methods. *Crit Public Health*. 2011;22(1):111–2.
 237. Howe LD, Galobardes B, Matijasevich A et al. Measuring socio-economic position for epidemiological studies in low-and middle-income countries: A methods of measurement in epidemiology paper. *Int J Epidemiol*. 2012;41:871–86.
 238. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77–101.
 239. Gibbs G. Analyzing qualitative data. The Sage qualitative research kit. 2007.
 240. Sweeney S, Vassal A, Foster N et al. Methodological issues to consider when collecting data to estimate poverty impact in economic evaluations in low-income and middle-income countries. *Heal Econ*. 2016;25(Supp 1):42–52.
 241. Lu CL, Chin B, Li GH et al. Limitations of methods for measuring out-of-pocket and catastrophic private health expenditures. *Bull World Heal Organ*. 2009;87:238–44.
 242. Barter DM, Agboola SO, Murray MB et al. Tuberculosis and poverty: the contribution

- of patient costs in sub-Saharan Africa – a systematic review. *BMC Public Health*. 2012;12(980).
243. Tanimura T, Jaramillo E, Weil D et al. Financial burden for tuberculosis patients in low- and middle-income countries: a systematic review. *Eur Respir J*. 2014;43(6):1763–76.
 244. Alam K, Mahal A. Economic impacts of health shocks on households in low and middle income countries: a review of the literature. *Global Health*. 2014;10(21).
 245. Drummond M, Jefferson T. Guidelines for authors and peer reviewers of economic submissions to the BMJ. *BMJ*. 1996;313(7052):275–83.
 246. Husereau D, Drummond M, Petrou S et al. Consolidated health economic evaluation reporting standards (cheers) statement. *Int J Technol Assess Health Care*. 2013;11(6).
 247. Noben CY, De Rijk A, Nijhuis F et al. The exchangeability of self-reports and administrative health care resource use measurements: Assessment of the methodological reporting quality. *J Clin Epidemiol* [Internet]. 2016;74:93–106. Available from: <http://dx.doi.org/10.1016/j.jclinepi.2015.09.019>
 248. Ridyard C, Hughes D, Team D. Taxonomy for methods of resource use measurement. *Health Econ*. 2015;24:372–8.
 249. Ruger J. An Alternative Framework for Analyzing Financial Protection in Health. *PLoS Med*. 2012;9(8):e1001294.
 250. Kruk M, Goldmann E, Galea S. Borrowing And Selling To Pay For Health Care In Low- And Middle-Income Countries. *Health Aff*. 2009;28(4):1056–66.
 251. Minh H, Tran B. Assessing the household financial burden associated with the chronic non-communicable diseases in a rural district of Vietnam. *Glob Health Action*. 2012;5:18892.
 252. Haque MA, Budi A, Azam Malik A et al. Health coping strategies of the people vulnerable to climate change in a resource-poor rural setting in Bangladesh. *BMC Public Health*. 2013;13(565).
 253. Deaton A. *The Analysis of Household Surveys: A Microeconomic Approach to Development Policy*. John Hopkins University Press. 1997.
 254. Lwanga S, Lemeshow S. *Sample size determination in health studies: a practical manual*. World Health Organization. 1991.
 255. United Nations Statistical Division. *Designing Household Survey Samples: Practical Guidelines*. United Nations Publication. 2008.
 256. Phung TD, Hardeweg B, Praneetvatakul S et al. Non-Sampling Error and Data

- Quality: What Can We Learn from Surveys to Collect Data for Vulnerability Measurements? *World Dev.* 2015;71:25–35.
257. Wiseman V, Conteh L, Matovu F. Using diaries to collect data in resource-poor settings: questions on design and implementation. *Heal Policy Plan.* 2005;20(6):394–404.
 258. Beegle K, De Weerd J, Friedman J. Methods of household consumption measurement through surveys: experimental results from Tanzania. *J Dev Econ.* 2012;98:3–18.
 259. Goossens MEJB, Mølken MPMHR Van VJ et al. The cost diary: a method to measure direct and indirect costs in cost-effectiveness research. *J Clin Epidemiol.* 2000;53:688–95.
 260. Marino R, Minichiello V, Browne J. Reporting of events using diaries. *Handbook for research in health sciences.* Sydney: Addison-Wesley; 1999.
 261. Partap U, Young EH, Allotey P et al. HDSS Profile: The South East Asia Community Observatory Health and Demographic Surveillance System (SEACO HDSS). *Int J Epidemiol.* 2017;46(5):1370–1.
 262. Kufa T, Hippner P, Charalambous S et al. A cluster randomised trial to evaluate the effect of optimising TB/HIV integration on patient level outcomes: the ‘MERGE’ trial protocol. *Contemp Clin Trials.* 2014;39:380–7.
 263. Lievesley D. Unit non-response in interview surveys. *Social and Community Planning Research.* London; 1986.
 264. Couper M, Groves R. The role of the interviewer in survey participation. *Surv Methodol.* 1992;18(2):263–77.
 265. Walther B, Hossin S, Townend J et al. Comparison of Electronic Data Capture (EDC) with the Standard Data Capture Method for Clinical Trial Data. *PLoS One.* 2011;6(9):e25348.
 266. Glewwe P, Dang H. The impact of decentralized data entry on the quality of household survey data in developing countries: Evidence from a randomized experiment in Vietnam. *World Bank Econ Rev.* 2008;22(1):165–85.
 267. Department of Statistics Malaysia. Household income and basic amenity report 2016. *Dep Stat Malaysia.* 2017;
 268. Akari S, Mateti U, Kunduru B. Health-care cost of diabetes in South India: a cost of illness study. *J Res Pharm Pract.* 2013;2(3):114.
 269. Khowaja L, Khuwaja A, Cosgrove P. Cost of diabetes care in out-patient clinics of Karachi, Pakistan. *BMC Heal Serv Res.* 2007;7(1).

270. Suleiman I, Festus J. Cost of illness among diabetes mellitus patients in Niger Delta, Nigeria. *J Pharm Heal Serv Res*. 2015;6(1):53–60.
271. Gillani AH, Aziz MM, Masood I, Saqib A, Yang CJ, Chang J et al. Direct and indirect cost of diabetes care among patients with type 2 diabetes in private clinics: a multicenter study in Punjab, Pakistan. *Expert Rev Pharmacoecon Outcomes Res*. 2018;18(6):647–53.
272. Ng C, Toh M, Ko Y, Lee J. Direct medical cost of type 2 diabetes in Singapore. *PLoS One*. 2015;10:e0122795.
273. American Diabetes Association. Economic costs of diabetes in the US in 2012. *Diabetes Care*. 2013;36:1033–46.
274. Bächle C, Icks A, Straßburger K, Flechtner-Mors M, Hungele A, Beyer P et al. Direct diabetes-related costs in young patients with early-onset, long lasting type 1 diabetes. *PLoS One*. 2013;8(8):e70567.
275. Park Y, Canaway R. Integrating Traditional and Complementary Medicine with National Healthcare Systems for Universal Health Coverage in Asia and the Western Pacific Integrating Traditional and Complementary Medicine with National Healthcare Systems for Universal Health Cove. *Heal Syst Reform [Internet]*. 2019;5(1):24–31. Available from: <https://doi.org/10.1080/23288604.2018.1539058>
276. Hutch R. Health and Healing: Spiritual, Pharmaceutical and Mechanical Medicine. *J Reli Heal*. 2011;27:1–11.
277. Chang H, Wallis M, Tiralongo E. Use of complementary and alternative medicine among people with type 2 diabetes in Taiwan: a crosssectional survey. *Evid Based Complement Altern Med*. 2011;2010:1–8.
278. Argáez-López N, Wachter N, Kumate-Rodríguez J, Cruz M, Talavera J, Rivera-Arce E, et al. The use of complementary and alternative medicine therapies in type 2 diabetic patients in Mexico. *Diabetes Care*. 2013;26:2470–1.
279. Kumar D, Bajaj S, Mehrotra R. Knowledge, attitude and practice of complementary and alternative medicines for diabetes. *Public Health*. 2006;120:705–11.
280. Bell R, Suerken C, Grzywacz J, Lang W, Quandt S, Arcury T. Complementary and alternative medicine use among adults with diabetes in the United States. *Altern Ther Heal Med*. 2006;12:16–22.
281. Png M, Yoong J, Phan T, Wee H. Current and future economic burden of diabetes among working-age adults in Asia: conservative estimates for Singapore from 2010–2050. *BMC Public Health*. 2016;16:153.

282. Peters M, Huisman E, Schoonen M, Wolffenbuttel B. The current total economic burden of diabetes mellitus in the Netherlands. *Neth J Med*. 2017;75(7).
283. Bermudez-Tamayo C, Besancon S, Johri M, Assa S, Brown J, Ramaiya K. Direct and indirect costs of diabetes mellitus in Mali: A case-control study. *PLoS One*. 2017;12(5):e0176128.
284. Ghaffar A, Reddy K, Singhi M. Burden of non-communicable diseases in South Asia. *BMJ*. 2004;328(7443):807–10.
285. Binnendijk E, Koren R, Dror D. Can rural poor in India afford to treat NCD? *Trop Med Int Heal*. 2012;17(11):1376–85.
286. Dugee O, Palam E, Dorjsuren B, Mahal A. Who is bearing the financial burden of non-communicable diseases in Mongolia? *J Glob Health*. 2018;8(1):e010415.
287. Valtorta N, Hanratty B. Socioeconomic variation in the financial consequences of ill health for older people with chronic diseases: A systematic review. *Maturitas*. 2013;74:313–33.
288. Loganathan T, Lee W, Lee K, Jit M, Ng C. Household Catastrophic Healthcare Expenditure and Impoverishment Due to Rotavirus Gastroenteritis Requiring Hospitalization in Malaysia. *PLoS One*. 2015;10(5):e0125878.
289. Planning Division M of H. Mesyuarat jawatankuasa pemandu MNHA 2018: SHA 2011 migration. Ministry of Health Malaysia. 2018.
290. Niëns LM, Cameron A van de PE, Ewen et al. Quantifying the impoverishing effects of purchasing medicines: A cross-country comparison of the affordability of medicines in the developing world. *PLoS Med*. 2010;7(8):e1000333.
291. Datta BK, Husain MJ, Husain MM et al. Noncommunicable disease-attributable medical expenditures, household financial stress and impoverishment in Bangladesh. *SSM - Popul Heal* [Internet]. 2018;6:252–8. Available from: <https://doi.org/10.1016/j.ssmph.2018.10.001>
292. Vu DK, Hoang VM, Nguyen BN et al. Inequalities in Household Catastrophic Health Expenditure and Impoverishment Associated with Noncommunicable Diseases in Chi Linh, Hai Duong, Vietnam. *Asia-Pacific J Public Heal*. 2017;29(5_suppl):35S-44S.
293. Swe KT, Rahman MM, Rahman MS et al. Cost and economic burden of illness over 15 years in Nepal: A comparative analysis. *PLoS One*. 2018;13(4):e0194564.
294. Tomini S, Packard T, Tomini F. Catastrophic and impoverishing effects of out-of-pocket payments for health care in Albania : evidence from Albania Living Standards Measurement Surveys 2002 , 2005 and 2008. *Health Policy Plan*. 2013;28:419–28.

295. Tan M, Kamaruzzaman S, Poi P. An Analysis of Geriatric Medicine in Malaysia-Riding the Wave of Political Change. *Geriatrics*. 2018;3(80).
296. Poi P, Forsyth D, Chan D. Services for older people in Malaysia: Issues and challenges. *Age Ageing*. 2004;33:444–6.
297. Ariff K, Teng C. Rural health care in Malaysia. *Aust J Rural Health*. 2002;10:99–103.
298. Michael E, Chuen E. Education and Health Awareness Among Indigenous People : A Study. *ARPJ Sci Technol*. 2012;2(8):745–9.
299. Rahman MM, Gilmour S, Saito E et al. Health-Related Financial Catastrophe, Inequality and Chronic Illness in Bangladesh. Vol. 8, *PLoS ONE*. 2013.
300. Kusi A, Hansen KS, Asante FA et al. Does the National Health Insurance Scheme provide financial protection to households in Ghana? *BMC Health Serv Res* [Internet]. 2015;15(331). Available from: <http://dx.doi.org/10.1186/s12913-015-0996-8>
301. Moghadam MN, Banshi M, Javar MA et al. Iranian household financial protection against catastrophic health care expenditures. *Iran J Public Health*. 2012;41(9):62–70.
302. Sun Q, Liu XY, Meng QY et al. Evaluating the financial protection of patients with chronic disease by health insurance in rural China. *Int J Equity Health*. 2009;8(42).
303. Allen L, Williams J, Townsend N et al. Socioeconomic status and non-communicable disease behavioural risk factors in low-income and lower-middle-income countries: a systematic review. *Lancet Glob Heal* [Internet]. 2017;5:e277–89. Available from: [http://dx.doi.org/10.1016/S2214-109X\(17\)30058-X](http://dx.doi.org/10.1016/S2214-109X(17)30058-X)
304. Golics CJ, Khurshid M, Basra A et al. The impact of patients' chronic disease on family quality of life: An experience from 26 specialties. *Int J Gen Med*. 2013;6:787–98.
305. Schulz R, Sherwood P. Physical and mental health effects of family caregiving. *J Soc Work Educ*. 2008;44(SUPPL. 3):105–13.
306. Biegel D, Sales E, Schulz R. Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke. Sage. 1991.
307. Haley WE, Levine EG, Brown SL et al. Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychol Aging*. 1987;2(4):323–30.
308. Vitaliano P, Zhang J, Scanlan J. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull*. 2003;129(6):946–72.
309. Lim J, Zebrack B. Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health Qual Life Outcomes*. 2004;2(50).

310. Arredondo A, Azar A, Recamán A. Diabetes, a global public health challenge with a high epidemiological and economic burden on health systems in Latin America. *Glob Public Health*. 2018;13(7):780–7.
311. Han B, Haley W. Family caregiving for patients with stroke: review and analysis. *Stroke*. 1999;30:1478–85.
312. Miaskowski C. Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. *Pain*. 1997;72:217–26.
313. Nijboer C, Triemstra M, Tempelaar R et al. Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer*. 1999;86:577–88.
314. Leive A, Xu K. Coping with out-of-pocket health payments: Empirical evidence from 15 African countries. *Bull World Health Organ*. 2008;86:849–56.
315. Chuma J, Gilson L, Molyneux C. Treatment-seeking behaviour, cost burdens and coping strategies among rural and urban households in Coastal Kenya: An equity analysis. *Trop Med Int Heal*. 2007;12:673–86.
316. Powell-Jackson T, Hoque M. Economic consequences of maternal illness in rural Bangladesh. *Heal Econ*. 2012;21(7):796–810.
317. Tangcharoensathien V, Witthayapipopsakul W, Panichkriangkrai W et al. Health systems development in Thailand: a solid platform for successful implementation of universal health coverage. *Lancet* [Internet]. 2018;391:1205–23. Available from: [http://dx.doi.org/10.1016/S0140-6736\(18\)30198-3](http://dx.doi.org/10.1016/S0140-6736(18)30198-3)
318. Oyakale T, Yusuf S. Multi-dimensional poverty of shock-exposed households and coping mechanism in rural Nigeria. *Soc Sci*. 2010;5:254–63.
319. Lopera M, Einarson T, Iván Bula J. Out-of-pocket expenditures and coping strategies for people living with HIV: Bogotá , Colombia, 2009. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV*. 2011;23(12):1602–8.
320. Kapur A. Economic analysis of diabetes care. *Indian J Med Res*. 2007;125:473–82.
321. Dhanaraj S. Health shocks and coping strategies. Vol. 8, WIDER working paper. 2014.
322. Fernando N. Understanding and Dealing with High Interest Rates on Microcredit. A Note to Policy Makers in the Asia and Pacific Region. Asian Development Bank. 2006.
323. Flores G, Krishnakumar J, O'Donnell O et al. Coping with healthcare costs: implications for the measurement of catastrophic expenditures and poverty. *Heal Econ*. 2008;17:1393–412.

324. Acharya A, Vellakkal S, Taylor F et al. The impact of health insurance schemes for the informal sector in low and middle-income countries. World Bank. 2013.
325. Roodman D MJ. The impact of microcredit on the poor in Bangladesh: revisiting the evidence. *J Dev Stud.* 2014;50(4):583–604.
326. Islam A, Maitra P. Health shocks and consumption smoothing in rural households: does microcredit have a role to play? *J Dev Econ.* 2012;97(2):232–43.
327. Khandker S, Samad H. Dynamic effects of microcredit in Bangladesh. Vol. 50, World Bank. 2014.
328. Kinsey B, Burger K, Gunning J. Coping with drought in Zimbabwe: survey evidence on responses of rural households to risk. *World Dev.* 1998;26(1):89–110.
329. Lundberg M, Over M, Mujinja P. Sources of financial assistance for households suffering an adult death in Kagera, Tanzania. *South African J Econ.* 2000;68(5):948–84.
330. Yamano T, Jayne T. Measuring the impacts of working-age adult mortality on small-scale farm households in Kenya. *World Dev.* 2004;32(1):91–119.
331. Yu C, Whynes D, Sach T. Reform towards National Health Insurance in Malaysia: The equity Implications. *Health Policy (New York).* 2011;100:256–63.
332. International Labour Organisation. World Social Security Report 2010/11: providing coverage in times of crisis and beyond. International Labour Organisation. 2010.
333. Lönnroth K, Glaziou P, Weil D et al. Beyond UHC: Monitoring Health and Social Protection Coverage in the Context of Tuberculosis Care and Prevention. *PLoS Med.* 2014;11(9):e1001693.
334. MySalam. Skim perlindungan kesihatan nasional MySalam. 2019.
335. Central Bank Malaysia. Financial Stability and Payment Systems Report 2018. Central Bank of Malaysia. 2018.
336. PeKA. Skim Peduli Sihat untuk Kumpulan B40 (PeKA) [Internet]. PekA Scheme. 2019. Available from: <https://www.pekab40.com.my/>
337. The Star Newspaper. More than public-private partnership efforts needed. Star Media Group Berhad [Internet]. 2019 Jun 23; Available from: <https://www.thestar.com.my/news/nation/2019/06/23/more-than-publicprivate-partnership-efforts-needed/>
338. Bloom G. Service delivery transformation for UHC in Asia and the Pacific. *Heal Syst Reform.* 2019;5(1):7–17.

339. Yiengprugsawan V, Healy J, Kendig H et al. Reorienting Health Services to People with Chronic Health Conditions: Diabetes and Stroke Services in Malaysia, Sri Lanka and Thailand. *Heal Syst Reform*. 2017;3(171–81).
340. World Bank. Delivering quality health services: a global imperative for universal health coverage. World Bank. 2018.
341. PAHO. Innovative Care for Chronic Conditions: Organizing and Delivering High Quality Care for Chronic Non-communicable Diseases in the Americas. PAHO. 2013.
342. Aryani FMY, Lee SWH, Chua SS et al. Chronic Care Model in primary care: can it improve health-related quality of life? *Integr Pharm Res Pract*. 2016;5:11–7.
343. Gretchen P, Orchard T, Emerson S et al. Translating the Chronic Care Model Into the Community. *Diabetes Care*. 2006;29(4):811–7.
344. World Health Organisation. 2008-2013 action plan for the global strategy for the prevention and control of non-communicable diseases: prevent and control cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. World Heal Organ. 2008;
345. World Health Organisation. WHO traditional medicine strategy: 2014-2023. World Health Organization. Geneva; 2013.
346. World Health Organisation. Beijing Declaration: WHO Congress in Traditional Medicine (7-9 November 2008) [Internet]. World Health Organization. 2008. Available from:
<http://www.who.int/medicines/areas/traditional/congress/en/index.html>
347. Allotey P, Tan DT, Kirby T et al. Community engagement in support of moving toward universal health coverage. *Heal Syst Reform* [Internet]. 2019;5(1):66–77. Available from: <https://doi.org/10.1080/23288604.2018.1541497>
348. Hunt P, Backman G. Accountability and the right to the highest attainable standard of health. *Health Hum Rights* [Internet]. 2008;10(1):81–92. Available from:
<http://www.comminit.com/democracy-governance/content/accountability-and-right-highest-attainable-standard-health>.
349. Goryakin Y, Suhrcke M. The prevalence and determinants of catastrophic health expenditures attributable to non-communicable diseases in low- and middle-income countries: A methodological commentary. *Int J Equity Health*. 2014;13(107).
350. Zhang Y, Dall TM, Mann SE et al. The economic costs of undiagnosed diabetes. *Popul Heal Manag*. 2009;12(2):95–101.
351. Schmidt H, Gostin L, Emanuel E. Public health, universal health coverage, and

- Sustainable Development Goals: can they coexist? *Lancet*. 2015;386:928–30.
352. Volmink J, Garner P. Systematic review of randomised controlled trials of strategies to promote adherence to tuberculosis treatment. *BMJ*. 1997;315:1403–6.
 353. Moverman Y, Daftary A, Franks J et al. Adherence to treatment for latent tuberculosis infection: systematic review of studies in the US and Canada. *Int J Tuberc Lung Dis*. 2008;12:1235–54.
 354. Rocha C, Montoya R, Zevallos K et al. The Innovative Socio-economic Interventions Against Tuberculosis (ISIAT) project: an operational assessment. *Int J Tuberc Lung Dis*. 2011;15:s50-57.
 355. Walker IF, Garbe F, Wright J et al. The Economic Costs of Cardiovascular Disease, Diabetes Mellitus, and Associated Complications in South Asia: A Systematic Review. *Value Heal*. 2018;15:12–26.
 356. Barton P, Andronis L, Briggs A et al. Effectiveness and cost effectiveness of cardiovascular disease prevention in whole populations: modelling study. *BMJ*. 2011;343:d4044.

Appendix 1 – E-questionnaire syntax

type	name	label	hint
start	starttime		
today	startdate		
end	endtime		
imei	deviceid		
barcode	HouseDetails_ID	Try to record the barcode with the camera	
text	HouseDetails_ID_manual	The barcode was not recorded. Manually enter it.	
integer	diabetic_number	How many diabetics in the household?	
select_one yes_no	seek_treatment	Do you seek treatment for your diabetes condition?	
select_multiple reason_no_treatment	reason_no_treatment	Why do you not seek treatment for your condition?	END INTERVIEW
text	reason_no_treatment_other	Others please specify	
integer	diabetes_history	How long have you had diabetes?	In months If male respondent, mark no and proceed to A1, if yes then end interview
select_one yes_no	pregnant	Are you currently pregnant?	
note	consent_note1	Under the Personal Data Protection Act PDPA 2010, SEACO needs to obtain explicit permission from respondents to collect personal data	
begin group	Consent	BASIC INFORMATION ABOUT THE INTERVIEW AND THE RESPONDENT	
text	consent_name	FULL Name of respondent	
select_one id_available	nric_available	You need to see \${consent_name}'s NRIC (MyKAD, MyPR, MyTentera, etc.) if they are Malaysian, or other ID if they are non-Malaysian?	
select_one nric_id_type	id_type	What type of ID is \${consent_name} using	
text	id_type_other	Enter the type of ID \${consent_name} using	
text	nric1	Enter \${consent_name}'s NRIC (MyKAD, MyKID, MyPolis, MyTentera, MyPR, etc.)	
text	nric2	Re-enter \${consent_name}'s NRIC (MyKAD, MyKID, MyPolis, MyTentera, MyPR, etc.)	
text	nric_foreign	Enter the ID Number (include letters in UPPERCASE)	
trigger	nric_empty	Go Back! The participant must provide some identification, or the consent to participate is not valid	

begin group	Ethics	
note	consent_note2	I, \${consent_name}, confirm the following:
select_one yes_no	consent_1	I have received an information sheet and a copy of the privacy statement
select_one yes_no	consent_2	Any questions I had about participation have been satisfactorily answered
select_one yes_no	consent_3	I am going to be interviewed about my expenditure in managing diabetes and household expenditure
select_one yes_no	consent_4	My responses will be stored securely on a computer
select_one yes_no	consent_5	My responses will only be made available to researchers, and only in a de-identified form for data analysis
select_one yes_no	consent_6	Summary results combining many household's responses, including mine, may be published in a de-identified form
select_one yes_no	consent_7	The responses I provide may be used by researchers in future research projects in a de-identified form
select_one yes_no	consent_8	The responses I provide may be linked to other SEACO data or administrative data in the future
select_one yes_no	consent_9	The data will only be released for a non-research purpose with explicit consent from each participant
select_one yes_no	consent_10	Participation is voluntary and I may be withdraw at any time without penalty
select_one yes_no	consent_11	I agree to being interviewed by the researcher for the first round of the questionnaire
select_one yes_no	consent_12	I agree to being interviewed by the researcher for the second round of the questionnaire
select_one yes_no	consent_13	I agree to being interviewed by the researcher for the in-depth interview session
select_one yes_no	consent_14	I agree to allowing the interviews to be audio-recorded
end group		
image	consent_15	\${consent_name}'s signature
select_one yes_no	signed	Did \${consent_name} sign the consent?
calculate	consented	
end group		
acknowledge	consent_heading	We do not have consent to continue. Save and Close the form.

begin group	Consenting_Households	ONLY FOR CONSENTING HOUSEHOLDS	
note	note_start	start the interview	
begin group	DISEASE_INFORMATION	**DISEASE INFORMATION**	
text	JDS_ID	Enter JDS ID of respondent	
select_one male_female	gender	A1.1 Gender	
integer	age	A1.2 Age	
select_one ethnicity	ethnicity	A1.3 Ethnicity	
select_one diabetes_type	diabetes_type	A1.4 What type of diabetes do you have?	
select_multiple treatment_type	treatment_type	A1.5 How do you currently treat diabetes?	
text	treatment_type_other	Others please specify	
select_one yes_no	diabetes_complications	A1.6 Do you have any medical complications related to diabetes?	
select_multiple complications	complications	A1.6.1 What diabetes related complications do you have?	
select_multiple treatment_place	treatment_place	A1.7 Did you seek treatment or advice for diabetes at any of the following places?	
text	treatment_place_other	Others please specify	
		A1.8 Did you go to the public health facility, such as government clinic or hospital when you first realized you have diabetes?	
select_one yes_no	first_treatment_place		
select_multiple reason_avoiding_public_healthcare	reason_avoiding_public_healthcare	A1.8.1 If no, why not?	
text	reason_avoiding_public_healthcare_other	Others please specify	
end group			
begin group	OUTPATIENT_CARE	**OUTPATIENT CARE**	
select_multiple outpatient	outpatient	A2.1 Where do you go for your outpatient treatment for diabetes?	
text	outpatient_other	Others please specify	
select_multiple outpatient_facility	outpatient_facility	A2.2 What kind of healthcare facility did you visit for your outpatient treatment for diabetes?	
text	outpatient_facility_other	Others please specify	
integer	outpatient_visit	A2.3 How many visits did you made in the PAST 3 MONTHS?	
text	outpatient_travel	A2.4 How long does it take you to get there (one way)	in minutes
integer	outpatient_spending_medicine	A2.5.1 How much did you spent in the PAST ONE MONTH for diabetes outpatient treatment for medicine?	If no cost, then put 0
integer	outpatient_spending_consultation	A2.5.2 How much did you spent in the PAST ONE MONTH for diabetes outpatient treatment for consultation?	If no cost, then put 0
integer	outpatient_spending_lab_test	A2.5.3 How much did you spent in the PAST ONE MONTH for diabetes outpatient treatment for lab tests?	If no cost, then put 0
integer	outpatient_spending_food	A2.5.4 How much did you spent in the PAST ONE MONTH for diabetes outpatient treatment for food?	If no cost, then put 0
integer	outpatient_spending_transportation	A2.5.5 How much did you spent in the PAST ONE MONTH for diabetes outpatient treatment for transportation?	If no cost, then put 0
integer	outpatient_spending_accommodation	A2.5.6 How much did you spent in the PAST ONE MONTH for diabetes outpatient treatment for accommodation?	If no cost, then put 0
integer	outpatient_spending_other	A2.5.7 How much did you spent in the PAST ONE MONTH for diabetes outpatient treatment for other items?	If no cost, then put 0
integer	outpatient_waiting_time	A2.6 How long is the average waiting time spent at the healthcare facility to get your treatment/medicine?	in minutes
end group			

begin group	INPATIENT_CARE	**INPATIENT CARE**	
select_one yes_no	hospitalisation	A2.9 Have you been hospitalised before PAST ONE YEAR on conditions related to diabetes?	At least one night stay at the hospital
integer	hospitalisation_frequency	A2.9.1 How many times have you been hospitalised in the PAST ONE YEAR due to diabetes?	
integer	hospitalisation_days	A2.9.2 How many days in total did you stay at the hospital in the PAST ONE YEAR due to diabetes?	
select_multiple complications	complications	A2.10 What diabetes related complications were you hospitalised for in the PAST ONE YEAR?	
select_multiple inpatient_care_place	inpatient_care_place	A2.11 Where do you go for your diabetes inpatient care?	in minutes
text	inpatient_care_place_others	Others please specify	
integer	inpatient_travel	A2.12 How long does it take you to get there (one way)	
select_multiple inpatient_payment	inpatient_payment	A2.13 How do you pay for your hospitalisation in the PAST ONE YEAR due to diabetes?	
begin group	inpatient_hospitalisation_oop	A 2.13.1 How much did you pay out of pocket during your entire stay?	If no cost, then put 0
begin repeat	inpatient_hospitalisation_times	Inpatient hospitalisation	
text	complication_type	Type of complications admitted for	
text	healthcare_facility_type	Type of healthcare facility admitted to	
integer	inpatient_food	Cost of food not provided by the hospital	
integer	inpatient_transport	Cost of travelling to hospital	
integer	inpatient_medicine	Cost of medicine	
integer	inpatient_lab_tests	Cost of lab test and diagnosis	
integer	inpatient_surgical_procedures	Cost of surgical procedures	
integer	inpatient_other_charges	Other hospitalisation costs	
end repeat			
end group			
end group			

begin group	GUARDIAN_COST	**GUARDIAN COST**	
select_one yes_no	employing_caretaker	A2.16 Do you employ someone to care for you after you have diabetes?	
integer	personal_caretaker_salary	A2.16.1 If yes, how much do you pay him/her per month?	If no cost, then put 0
select_one yes_no	employing_domestic_worker	A2.17 Do you employ someone to do the housework for your household after you have diabetes?	
integer	worker_caretaker_salary	A2.17.1 If yes, how much do you pay him/her per month?	If no cost, then put 0
select_one yes_no	hshold_member_care	A2.18 Does any household member quit their income-earning job to stay home and care for you?	
integer	hshold_member_care_duration	A2.18.1 How long has he/she been taking care of you?	In months
text	hshold_member_job	A2.18.2 What does he/she do for a living?	
integer	hshold_member_salary	A2.18.3 How much does he/she earn per month?	
select_one yes_no	outpatient_company	A2.19 Does any family member in the household take time off from work to accompany you on any visits or go in your place to collect your diabetes drugs?	
begin_group	family_company	A2.19.1 How many visits has your household member accompanied you or gone in your place for the PAST 3 MONTHS?	
begin_repeat	family_company_times	Outpatient - accompanying household members	
text	family_member	Family member	Note down name of person
select_one male_female	gender	Gender of accompanying household member	
integer	age	Age of accompanying household member	
integer	times	Number of times	
integer	duration	Duration taken	in minutes
text	occupation	Occupation of accompanying household member	
end_repeat			
end_group			
select_multiple reason_for_company	reason_for_company	A2.19.2 Why did someone accompany you?	
text	reason_for_company_others	Others please specify	
select_one yes_no	inpatient_company	A2.20 Did any family member of the household stay with you while you were in the hospital for the PAST ONE YEAR?	
begin_group	family_company_details	Details of accompanying household member	
begin_repeat	family_company_number	Inpatient - accompanying household member	
text	family_member	Family member	Note down name of person
select_one male_female	gender	Gender of accompanying household member	
integer	age	Age of accompanying household member	
integer	days_stayed	Days stayed at hospital or nearby places	
integer	times	Number of times accompanying	
integer	accommodation_cost	Cost for accommodation to accompany diabetic	If no cost, then put 0
integer	transport_cost	Cost for transport to accompany diabetic	If no cost, then put 0
integer	food_cost	Cost of meals taken to accompany diabetic	If no cost, then put 0
text	occupation	Occupation of accompanying household member	
end_repeat			
end_group			
end_group			

begin group	COPING_STRATEGIES	**COPING STRATEGIES**
select_one yes_no	borrow_money	A2.21 Did you borrow any money to cover the costs due to the diabetes illness?
integer	amount_borrowed	A2.21.1 If yes, how much did you borrow in the PAST ONE YEAR?
select_multiple lender	lender	A2.21.2 From whom did you borrow from?
text	lender_others	Others please specify
select_one yes_no	assets_sold	A2.22 Have you sold any of your assets to finance the cost of the diabetes illness in the PAST ONE YEAR?
select_multiple asset	asset	A2.22.1 If yes, what did you sell?
text	asset_others	Others please specify
integer	asset_value	A2.22.2 How much did you sell it for?
end group		
begin group	OTHER_COSTS	**OTHER COSTS**
select_one yes_no	supplement	A2.23 Do you buy any supplements for your diet because of the diabetes illness, for example vitamins, special foods for diabetics?
select_multiple supplement_type	supplement_type	A2.23.1 What did you buy?
text	supplement_type_other	Others please specify
integer	supplement_spending	A2.23.2 How much did you spend on these items in the PAST 3 MONTHS? If no cost, then put 0
select_one yes_no	glucose_monitoring	A2.24 Do you do monitor your blood glucose levels at home?
integer	glucose_monitoring_spending	A2.24.1 If yes, how much do you spend on glucose self monitoring(e.g. glucose strips) PER MONTH? If no cost, then put 0
select_one yes_no	medical_equipment	A2.25 Do you buy any medical equipment such as wheelchair, crutches, etc. to support and manage your diabetes condition?
integer	medical_equipment_spending	A2.25.1 If yes, how much do you spend on these items? If no cost, then put 0
end group		
begin group	OTHER_HEALTHCARE_EXPENDITURE	**OTHER HEALTHCARE EXPENDITURE**
select_one yes_no	other_chronic_illness	A3.1 Do you have any other chronic illness for which you are receiving treatment?
select_multiple chronic_illness	chronic_illness	A3.1.1 If yes, what other chronic disease do you have?
integer	chronic_illness_cost	A3.1.2 How much are these additional costs on average PER MONTH? If no cost, then put 0
end group		

begin group	INDIVIDUAL_SES	**INDIVIDUAL SOCIAL ECONOMIC STATUS**
select_one education	education	A5.1 What is your level of education?
text	education_others	Others please specify
integer	individual_income	A5.2 What is your estimated personal take home earning PER MONTH?
select_one yes_no	social_impact	A5.3 Has the diabetes illness affected your social or private life in any way?
select_one yes_no	financial_burden	A5.4 Has this resulted in a financial burden?
end group		
begin group	HOUSEHOLD_INCOME_AND_EXPENDITURE	**HOUSEHOLD_INCOME_AND_EXPENDITURE**
integer	people_in_house	B1.1 How many people are there in your household?
integer	food_expenditure	B1.2 How much does your household spend on food EVERY MONTH on average (excluding alcohol beverages and tobacco)?
select_one yes_no	food_production	B1.3 Do you grow/produce food at home for consumption?
text	food_type_produced	B1.3.1 What kind of foods do you grow/produce?
select_one food_expenditure_changes	food_expenditure_changes	B1.4 Did your household food expenditure change due to having diabetes?
select_one food_expenditure_difference	difference_in_food_expenditure	B1.4.1 Has the food expenditure increased or decreased?
integer	overall_household_spending	B1.5 What is your estimated overall household spending PER MONTH now?
select_one overall_household_spending_changes	overall_household_spending_changes	B1.6 Did your overall household spending change due to having diabetes?
select_one household_spending_difference	difference_in_household_spending	B1.6.1 Has the household spending increased or decreased?
integer	health_spending	B1.7 What is your estimated household expenditure on health PER MONTH now?
select_one primary_earner	primary_earner	B1.8 Who is the primary income earner in the household?
text	primary_earner_others	Others please specify
integer	overall_household_income	B1.9 How much do you estimate was the average income of your household PER MONTH?
select_one overall_household_income_changes	overall_household_income_changes	B1.10 Did your household income change due to having diabetes?
select_one overall_household_income_difference	difference_in_overall_household_income	B1.10.1 Has the household income increased or decreased?
end group		
end group		

Includes welfare payments,
government assistance or
other social support

Appendix 2 – In-depth interview guide

Opening questions

1. Can you tell me some background of your diabetes condition? For example, how long have you had diabetes, and how have you been managing it so far?

Bolehkah anda berkongsikan sedikit latar belakang tentang penyakit diabetes anda? Contohnya, berapa lamakah anda telah menghidapi diabetes dan bagaimana anda menguruskan ia selama ni?

Impact on individual and family

1. How has having diabetes affected your financial situation and wellbeing?
Bagaimana diabetes telah menjejaskan kesihatan anda serta keadaan kewangan anda?

2. Do you have any fears or concerns regarding the economic burden due to diabetes care? What are they?

Adakah anda merasa bimbang tentang bebanan kewangan disebabkan penjagaan diabetes? Apakah mereka?

3. How did the economic burden impact upon the family?

Bagaimanakah bebanan kewangan menjejaskan keluarga anda?

Coping

1. How do you cope with the significant cost that arises due to diabetes care? Do you have any contingency plans to overcome these concerns?

Bagaimana anda menangani kos-kos rawatan yang tinggi akibat dari penjagaan diabetes? Apakah pelan anda?

2. How does the household make decisions on allocating household resources? *Probe on the social, cultural and economic factors that may have influenced this decision.*

Bagaimanakah isirumah anda membuat keputusan mengenai pengagihan sumber? Misalannya bila ada kecemasan yang memerlukan wang.

3. Do you receive support from other members of the community? What social supports do you access to? (*formal, informal*)

Adakah anda menerima bantuan/sokongan dari ahli komuniti? Apakah jenis bantuan itu? (formal/tak formal)

4. Would you have any special requests/hopes for assistance or programs for people living with diabetes?

Adakah anda mempunyai permintaan khas untuk bantuan ataupun program untuk orang yang menghidap diabetes?

Closing questions

1. Thank you very much for your kind sharing. Do you have anything further to add to your earlier responses, or have any further questions about this research?

Terima kasih atas perkongsian pengalaman anda. Adakah anda mempunyai apa-apa untuk menambah, atau sebarang pertanyaan lanjut mengenai kajian ini?

-- End --

Appendix 3 – Focus group discussion guide

Focus group introduction

WELCOME

Thanks for agreeing to be part of the focus group. We appreciate your willingness to participate.

INTRODUCTIONS

Moderator

PURPOSE OF FOCUS GROUPS

The reason we are having this focus group is to find out about how you manage your diabetes and the kind of treatment you seek. We need your input and want you to share your honest and open thoughts with us.

GROUND RULES

1. WE WANT YOU TO DO THE TALKING.

We would like everyone to participate.

I may call on you if I haven't heard from you in a while.

2. THERE ARE NO RIGHT OR WRONG ANSWERS

Every person's experiences and opinions are important.

Speak up whether you agree or disagree.

We want to hear a wide range of opinions.

3. WHAT IS SAID IN THIS ROOM STAYS HERE

We want you to feel comfortable sharing when sensitive issues come up.

4. WE WILL BE TAPE RECORDING THE GROUP

We want to capture everything you have to say.

We don't identify anyone by name in our report. You will remain anonymous

Discussion question

The range of health care providers sought and underlying reasons

1. Where do you usually go for diabetes treatment?
 - Government clinic
 - Government hospital
 - Private clinic
 - Private hospital
 - Traditional and complementary medicine
 - Pharmacy
 - Direct sales products
2. Why do you prefer to go to there?
3. How often do you usually go for treatment?
4. What range of health services do you use/receive for your diabetes treatment?
 - consultation
 - condition assessment/tests
 - treatment (medication, medical procedures/surgery)
5. Did the doctor recommend these tests/procedures or do you request for them?
 - If you request for them, why so?

Factors that constitute good quality/satisfaction with each provider

6. How would you define the quality of healthcare services received for your diabetes treatment by the providers you have accessed?
 - Attitude of staffs
 - Medical experience of staffs
 - Waiting time
 - Environment (comfort, cleanliness of venue)
 - Adequacy of equipment/services
 - Distance to medical facility
 - Medical treatment process
 - Cost
 - Ease of access (including language barriers)

7. Is it affordable for you to receive/access your diabetes treatment?
8. Are you satisfied with your current blood glucose level? if not, why?
9. Do you monitor your blood sugar at home regularly?
10. Finally, if you have any other views on your diabetes treatment, please feel free to share.

-- End --

Appendix 4 – Qualitative interview respondent profiles

In-depth interview

Code	Age	Gender	Ethnicity	Sub-district
IDI-01	58	Female	Malay	Bekok
IDI-02	72	Male	Chinese	Bekok
IDI-03	68	Female	Indian	Sungai Segamat
IDI-04	65	Female	Malay	Sungai Segamat
IDI-05	53	Female	Chinese	Bekok
IDI-06	51	Male	Malay	Sungai Segamat
IDI-07	53	Female	Indian	Bekok
IDI-08	56	Male	Indian	Bekok
IDI-09	69	Female	Malay	Sungai Segamat
IDI-10	55	Female	Chinese	Sungai Segamat
IDI-11	67	Male	Indian	Bekok
IDI-12	87	Female	Chinese	Bekok
IDI-13	78	Female	Chinese	Bekok

Focus group discussion

Note: Age group categories: young = 18-35yrs old, middle age = 36-64 years old, elderly = above 64 years old

Bekok (BK)

Code	Age	Gender	Ethnicity
FGD-BK01	Young	Female	Malay
FGD-BK02	Elderly	Female	Malay
FGD-BK03	Middle age	Female	Malay
FGD-BK04	Middle age	Female	Malay
FGD-BK05	Middle age	Male	Indian
FGD-BK06	Middle age	Male	Malay
FGD-BK07	Middle age	Male	Malay
FGD-BK08	Middle age	Male	Malay
FGD-BK09	Middle age	Male	Indian

FGD-BK10	Elderly	Male	Chinese
FGD-BK11	Middle age	Male	Chinese

Sungai Segamat (SG)

Code	Age	Gender	Ethnicity
FGD-SG01	Middle age	Male	Malay
FGD-SG02	Middle age	Male	Malay
FGD-SG03	Middle age	Female	Malay
FGD-SG04	Middle age	Male	Indian
FGD-SG05	Middle age	Male	Chinese

Appendix 5 – Qualitative analysis data frame

TOPIC	THEMES	CODES	DESCRIPTION	DATA (quotes in italics were used)
Experiences of living with diabetes	Personal barriers to diabetes management	Language barrier, Ashamed of disease, Fear of doctors and treatment	Types of personal barriers preventing optimal management of diabetes	<p><i>Yes, I know, but I'm scared of injection. A lot of people here also say no to injection. 2-3 people I know were asked to start on insulin, but we keep pleading the doctor no. In the next check-up, when the doctor sees the (glucose) level is lower, then we're safe, haha. It's been a year since and we keep saying this. - [IDI-07]</i></p> <p><i>For Malays it's not a problem, but for other races like Chinese sometimes they don't understand Malay. There are those who understand and those who don't. - [FGD-BK01]</i></p> <p><i>The Chinese tend to be less proficient in Malay. Sometimes when we ask them things in Malay, they say they don't know anything. - [FGD-BK02]</i></p> <p><i>Some people are ashamed of having diabetes and don't want anyone else to know. Only until they cannot bear it, then we know.- [FGD-BK11]</i></p> <p><i>When I first know I have diabetes, my reaction was we just need to accept it as our age is old. When we reach above 60, many illnesses will come to the body. Many of my friends are like that. I had it when I was 60, and now I'm 66. Old people will have it; there's nothing much to do about it. - [FGD-SG01]</i></p> <p><i>Sometimes we see people who go to clinics to check. We ask if they have diabetes, and they say they're just there for a check-up. They're scared. Why are they scared? It's a common disease these days. Women who are pregnant also get it. - [FGD-BK06]</i></p>

				<p>I'm scared to go for clinic checkups. My check up is tomorrow, but I was scared for the past week so I went to buy meds from the pharmacy and take them before I go for check up...I see how it is, wait for 2-3 days then I go. So in the meantime I will keep a strict diet. – [IDI-07]</p> <p>She can't communicate in Malay at the clinic. So when she needs to see the doctor her children will come back and take her there. – [IDI-13]</p> <p>That is why for people at Bekok, they will go to clinic more especially when there is a Chinese doctor. They scared of going somewhere else due to communication barrier. – [IDI-05]</p> <p>I don't really understand Malay as well so it's hard to communicate with the people in the clinic. Plus I have poor hearing so I can't hear them very well too. – [IDI-02]</p> <p>That's why when it's almost time for a check up we will make sure to fast. - [FGD-BK05]</p> <p>I bought the equipment for diabetes (home screening). Before I go to the clinic, I checked at home and it was low. When I checked at the clinic afterwards, the reading is high...I didn't say anything, I just observe. - [FGD-BK03]</p>
	Impact to daily lives and activities	Self-care practices, Restricted lifestyle	Impacts of living with diabetes on daily lives	<p><i>No, my leg is in pain. I haven't been working in the past three years. This part of the foot I have problems, and then this part, and this (pointing to ankle wound). - [IDI-06]</i></p> <p><i>Yes, of course. I can work a lot more last time. Now I can't. I do a little bit of work, and then I got tired. I have not worked for a long</i></p>

				<p><i>time. - [IDI-07]</i></p> <p><i>It didn't happen last time (affecting work) before I start on insulin. The doctor told me now I might get some dizziness. - [IDI-02]</i></p> <p><i>My diabetes has more or less burdened me. For example, eating is already giving me pressure. I have to choose carefully and avoid sweet and high carb (carbohydrate) foods. - [IDI-10]</i></p> <p><i>Insulin yes, at 1030pm or 11pm. I don't eat medicines consistently. It's inconvenient, and there are many to take. If its insulin, I just adjust it to 16 and inject, wait for a few seconds, and it's in. - [FGD-SG01]</i></p> <p><i>Insulin. I take it every day. In the morning, the doctor told me to inject 40 IU/ml, but I don't want to, I'll sweat a lot, so I reduce to 30 IU/ml. 30 in the morning, 30 in the evening. But this is good because if you eat medicine, it will affect the kidney. If it's this (insulin), it goes direct to blood. - [FGD-SG04]</i></p> <p><i>Everything I will eat. A diet book was given to me but I don't really look at it and just eat. - [FGD-SG01]</i></p> <p><i>I don't control my diet at all. - [IDI-07]</i></p> <p><i>Diabetes made my legs weak. Now my son helped to manage (plantation estate). – [IDI-11]</i></p> <p><i>They (people with diabetes) were tired, felt hungry easily and wanted to eat more. They were also lazy to go to work due to weak body. – [IDI-05]</i></p> <p><i>Enough (money) or not we have to keep living. For now I can still</i></p>
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				<p>manage. I observed that if I only eat in the afternoon and not having dinner, the sugar level will drop a bit, to about 7. – [IDI-09]</p> <p>I get hungry fast. Sometimes I get numbness on my hands and legs. – [IDI-10]</p> <p>I inject (insulin) and watch my diet. Whatever it is you must take care of your diet. – [IDI-06]</p> <p>I just went for a check up. Every month, and when I feel something is not right. I don't wait anymore these days. – [IDI-06]</p> <p>I only drink sweet things in the morning, and if I eat sweet desserts, I will drink plain water. yeah, it's just like that – [IDI-09]</p> <p>Yes, I just follow the doctor's advice. I take the big and the small medicine 2 times a day. I take them even when my sugar level is normal. – [IDI-09]</p> <p>I only sometimes buy small things like ginger sugar cubes to use. It doesn't have any effect really, the key thing is to keep a strict diet. – [IDI-10]</p> <p>And when I go for my regular check up in Melaka I bring over the glucometer and the doctor can read all my glucose readings recorded in the machine. She said I'm managing my sugar levels well, but told me to not sleep so late and check my sugar in late mornings. So we can't cheat as well even if we want to on the record card because the doctor will know exactly when the test is conducted and what the readings are. – [IDI-11]</p> <p>Yes, every morning I'll do some light exercise, and pluck some grass</p>
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				<p>outside. It's not good if there's no exercise. I wake up around 6 am then do some light exercises. If not my legs cannot move well. If I move about a bit, then there is less pain. – [IDI-13]</p> <p>In the mornings usually around 5am, and in the evening around 10pm (measuring blood sugar). I bought the machine and strips and check at home – [IDI-08]</p> <p>You know why his healing is slow? I fed him porridge. Some people can't take porridge. When I stopped giving him that, his pus slowly began to clear. Some diabetic people if they take porridge for sure there will be pus. – [IDI-08]</p> <p>If I'm just quiet, my children will come help me and give me something to drink because they know. – [IDI-01]</p> <p>We must really control diet. In my earlier days I just eat whatever I want and then later I became diabetic. Now everything I control. - [FGD-BK05]</p> <p>I'm taking care to avoid amputation. I'm scared.- [FGD-BK02]</p> <p>I manage my diet, eat less rice. Eat less noodles. Just take veggies with some sauces, that's it.- [FGD-SG05]</p> <p>We have to take care of our body not to get hurt. If injured, then it will be a lot of problem. - [FGD-SG04]</p> <p>I take it once a day. From 2 times a day now I take it once a day...because I've taken the (Rama-Rama tea). We cannot drink it all the time, if we do the blood pressure will go too low. - [FGD-SG02]</p> <p>Because my sugar level was very high. Now I eat the medicines from</p>
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				<p>the hospital, 4-5 tablets, sometimes 2-3, not consistent. There are pills for morning and evening, but I just eat once a day. Now my fingers are numb. - [FGD-SG01]</p> <p>He (doctor) says but we can't follow because we can't take it. When I inject more I sweat. - [FGD-SG04]</p>
	Experiences with healthcare providers	Satisfy with public care services, Sceptical of public care services, Passive communication, Low quality public care	Experiences of accessing and utilising healthcare services for diabetes treatment	<p><i>The service is very good. The nurses are very good. When you were sleeping, they will wake you up when it's time for medication. They will say sorry for disturbing and then help you with your medication. When I hear this, I also feel happy.</i>- [FGD-BK11]</p> <p><i>Ok, it's clean and has ample space for seating</i> - [FGD-SG01]</p> <p><i>I'm worried that taking anything aside from KK (government health clinic) medicines may cause problems. In that case, it's not compatible (contraindication).</i> - [FGD-BK05]</p> <p><i>Because we believe in the medicines provided.</i> - [FGD-BK01]</p> <p><i>I just get my meds from the public clinic, my wife also goes there. I go to the clinics nearby here and also in Labis (nearest and one of the largest sub-districts).</i>- [IDI-08]</p> <p><i>I only believe in medicines provided by the KK (government health clinic), that's all I consume. Other things I don't have the money to buy even if I want to</i> - .[FGD-BK02]</p> <p><i>The public sector is full of people and not enough doctors. What can they do? The nurses just keep postponing appointment dates. For my condition, if I go to the government hospital, I think I would have been long gone (dead) already.</i> - [IDI-11]</p>

				<p><i>When they inserted the needle, it was so painful for almost an hour. I told them I had enough and then went home. I cannot take the pain anymore. They are not making people better but giving pain to people, what is this??? I told the doctor I don't want it (treatment) anymore and I want to go back. - [IDI-06]</i></p> <p><i>He (husband with diabetes) was in a lot of pain, and then we went to the hospital. The doctor kept asking me when did he get the wound, and I got angry. I just took him (husband with diabetes) to see him the other day, and he still doesn't know when. And then he (doctor) just kept quiet. - [IDI-08]</i></p> <p><i>Luckily, my son brought me to a private hospital. If I go to the government, they will surely have amputated my toe. I'm scared of public healthcare. - [IDI-10]</i></p> <p><i>When I was leaving the Segamat Hospital, the doctor actually asked me am I leaving and forgot that he had signed the discharge papers for me. You see, this also they don't remember. What kind of work are they doing there? That's why I'm scared. - [IDI-11]</i></p> <p><i>There's a time when I went for a check, and they told me my readings were 5 (blood glucose reading). I asked them, are you sure it's 5? Because if it's 5, I tend to get tired easily. Then I just go home.- [FGD-BK07]</i></p> <p><i>I bought the equipment for diabetes (home screening). Before I go to the clinic, I checked at home, and it was low. When I checked at the clinic afterward, the reading was high...I didn't say anything, I just observed. - [FGD-BK03]</i></p> <p><i>The sugar level will go down, the medicine is good but he doesn't give to everyone. The insulin they use in the ward is different. A friend of</i></p>
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			<p><i>mine went for eye surgery and has a sugar level of 17, the next morning when he was discharged it was 8. The best insulin they keep and don't simply give out. For us, they (clinic doctors) give like the second one (second best). - [FGD-SG04]</i></p> <p><i>I heard about it, but I don't go there (public clinic). All my check-ups were done in the private clinic... I'm already used to it.... for me. I just want it to be easy and fast. I don't have time as I have to work. - [FGD-SG05]</i></p> <p><i>For diabetes medication and check-up, we go to KK Bekok (public clinic). We go to Batu 8 (private clinic) when we have other illnesses like stomach ache, fever, etc. - [FGD-BK05]</i></p> <p><i>I am used to Dr. X (private GP). Treatment from government clinic here is not as good. - [IDI-12]</i></p> <p><i>Erm, I don't really quite like how they work. When we go and want a check-up on the same day they say cannot, and ask us to come back on another day. How can we wait until then? That's why my son says, don't go there (public care) and just go to private care. The money is fine. - [IDI-11]</i></p> <p><i>The biggest problem is we have to wait (in public clinics). The rest is like normal, they only give medicines, and there is no big difference.- [FGD-SG01]</i></p> <p><i>When doctors come in, they don't see you immediately. When they do see you, it could sometimes be in the afternoon, and you could have fainted. - [FGD-BK06]</i></p> <p><i>If your readings (blood glucose) are high, sometimes they (clinic doctors) will call you and give you a drip, and that can take up a</i></p>
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				<p><i>whole day. - [FGD-SG04]</i></p> <p><i>I go there (private clinic) early in the morning around 9am, then complete within 20mins. - [FGD-SG05]</i></p> <p><i>We want to complain but can't because there's only one clinic (public) and have to take it. - [FGD-BK07]</i></p> <p><i>I buy bandages and wound cleaner because I clean my wounds at home. Sometimes I go to Batu 8 clinic (private clinic established for estate workers), but not the normal (public) clinic because they usually don't have supplies for wound cleaning. - [FGD-BK06]</i></p> <p><i>Patients prefer the wound cleaning from Batu 8 (clinic) than the Bekok clinic (public) here because the wound dressing at Batu 8 is better, and sometimes nurses from the Bekok clinic refused to help and told patients to do the dressing by themselves at home instead. Nurses from the Bekok clinic also do not provide wound cleaning at home for those who cannot go to the clinic due to disability or bedridden.- [IDI-05]</i></p> <p><i>Of course it's ok though it's expensive (private care). This one (showing amputated toes) where I got it cut, and it costs RM8,000 in Melaka (an adjacent state approximately 101.3 kilometers away).- [FGD-BK06]</i></p> <p><i>They (Segamat hospital's doctors) didn't check thoroughly. Then I told my son, 'your dad has this problem now, and he has to operate, how do we do about it?' He said, 'no need mom, we go to Kluang (private hospital).' We brought him over to Kluang and he was operated on the next day.- [IDI-08]</i></p> <p><i>The public sector is full of people and not enough doctors. What can</i></p>
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				<p><i>they do? The nurses just keep postponing appointment dates. For my condition, if I go to the government hospital, I think I would have been long gone (dead) already. - [IDI-11]</i></p> <p><i>No (unavailability of a public surgeon). This is why most people will go to KPJ (private hospital) for this surgery (eye lens replacement for cataract due to diabetes) though it is a private hospital. We buy the lens by ourselves from the list of places given by the (public) hospital. - [IDI-05]</i></p> <p><i>At first, it was a small operation in Segamat hospital; on the first day, the infection wasn't that bad, but on the second day, it got worse and turned black. The doctor says need to amputate, and I asked when he said within two days. I went to Melaka straight on the same day at 7pm for the surgery, and it's cut until here (showing toes), if it's here (Segamat) then I might have to amputate till here (pointing ankle). I spent three nights over there. - [FGD-BK06]</i></p> <p><i>When I first got this foot injury, I went to Segamat hospital. After that, they send me to Muar (district hospital).- [IDI-06]</i></p> <p><i>On Thursdays, it's long (waiting time). Treatments will only start after their meeting. It's until at least 10am, I have fasted the day before, how can I bear the hunger? If they know they'll be having meetings every Thursday, then don't give patients appointments on that date. If anyone of you been there on Thursdays, you'll know. I have experienced it two times.- [FGD-BK06]</i></p> <p><i>That time when I was unconscious (due to hypoglycaemia), they sent me to Segamat Hospital. For ten days I was there. I really want to go home; I cannot take it. The doctor comes and checks me every morning, and I keep asking him when can I go back – [IDI-11]</i></p>
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				<p>If we go the private clinic here in Bekok, it can cost up to RM30, and if we go to Batu Lapan, it costs half. - [FGD-BK06]</p> <p>I go for private healthcare, mostly in Johor Baru. Because my son is there he takes me there to see a specialist. I tried taking the medicine from the Bekok government clinic here, but I find it not so suitable. I felt dizzy after taking them. After that my daughter brought me to see a specialist in Johor Baru. – [IDI-10]</p> <p>That one (private sector services) I don't have any issues. – [IDI-06]</p> <p>I stayed there (Segamat Hospital) for one night, and the next afternoon they cut off a small bit of my skin, just a little bit. But the doctor was shaking! I asked him what's wrong? I'm still new he said. Gosh, they didn't take me to the operation room but just cut it on my bed you know. After that they say I can go back. The bill then came and it amounted to over rm500. I said I don't want to pay, and they want to charge to the estate, I'm telling you they're stupid people. . – [IDI-06]</p> <p>For some of those that do not speak Malay (language), they will go to private clinics. Once private clinic is no longer affordable to them, they will come back to the clinic in Bekok. – [IDI-05]</p> <p>You see that Krishnan, for example. He has 5 children, and all of them have married, and have good jobs in Johor Baru. Can't they help their parent? They can send him for a proper check up in a private hospital. All the time they use public healthcare. If we are capable, we should at least try private care. It's expensive, but you get better faster. – [IDI-11]</p> <p>I don't buy vitamins, but I drink diabetic milk powders. But I can't</p>
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				<p>take if it's too thick. Previously in the hospital, I had one that was too thick with 7 scoops of powder and when I tried to swallow, I vomited out everything. They made me drink it again, and again I vomited everything out. It's too thick. The staff nurse then diluted it to the consistency I can take which is only 2 scoops. I feel like vomiting when I smell it. – [IDI-11]</p> <p>The biggest cost I think it's the travelling in between (healthcare premises). – [IDI-02]</p> <p>We are poor people, the private sector is expensive isn't it right? Even though we have plantations, it's not really ours we just work on it. – [IDI-04]</p> <p>Patients do not go there for treatment (private GP) because treatment is costly. – [IDI-05]</p> <p>It's expensive to go there (hospital in Johor Bahru), RM150 to hire a taxi. I only went once last year and I will never go back again. It's expensive every time RM150, how can I afford? – [IDI-07]</p> <p>No, only clinic medications. - [FGD-BK04]</p> <p>Because we believe in the medicines provided - [FGD-BK01]</p> <p>If we found that our blood pressure is higher than normal we ask the doctor if we should take higher doses or not. If he says no, then there's no need. - [FGD-BK10]</p> <p>If I have anything I'll just ask the doctor.- [FGD-BK05]</p> <p>When I went for an injection many years ago, the nurse told me my</p>
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				<p>arm was dead. When the doctor came, I complaint to him saying the nurse told me my arm was dead. - [FGD-BK10]</p> <p>Now even the chairs may not be enough sometimes (at the government clinic). - [FGD-BK11]</p> <p>Last time I went there (Segamat Hospital) for a test, they told me my blood sugar level was 7. I was eating a lot during those periods so I knew something must be off. I told them that the machine could be faulty. Then they say, ‘eh, how can you say this?’. Then we checked another person’s blood sugar, it’s the same, 7. Ok, not satisfied? Called for another one, 7 as well. Then I ask them if they have other machines to use, and they said yes. After checking with the other machines, my blood sugar level was actually 13. The nurse was telling me that I can’t say the machine was broken, but I told the nurse to check properly. – [FGD-BK08]</p> <p>If we need to do something like an X-ray, the Jalan Muar clinic doesn’t have the facility and we have to go Bandar Putra. - [FGD-SG02]</p> <p>Our clinics here there are many rooms but no doctors. There are six rooms, sometimes there are three doctors, sometimes two. - [FGD-SG02]</p> <p>The other day I was the hospital ward for injuries. The doctor was taking my blood and I asked him if it’s done then he said not yet he’s still finding the vein. The doctor is not very capable as he’s not used to do this. - [FGD-SG04]</p> <p>The main issue is just the time it takes. But we understand, it’s just one doctor. Whether a person is sick or pregnant, it’s also the same</p>
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				<p>doctor. - [FGD-BK08]</p> <p>We also understand that we are not the only people going there. The actual time spent there for me is only around 30mins, but sometimes there are 30-40 people there. - [FGD-BK05]</p> <p>All the medicines are readily available (Bekok government clinic).- [FGD-BK01]</p> <p>But only this Thursday meetings is problematic. The rest is ok, good. If you call them, they'll come quick. - [FGD-BK06]</p> <p>Other things may not be good, but the nurses (Bekok government clinic) are really good. They check you thoroughly. They are always helpful, day or night. - [FGD-BK06]</p> <p>The doctor also is very nice (Bekok government clinic). When he comes in he will say "good morning" Mr XXX. It's very good, nowadays is very good. - [FGD-BK11]</p> <p>It's satisfactory (Sungai Segamat government clinic), just the basic checkups. - [FGD-SG01]</p> <p>Doctors used to be loud but not now (Sungai Segamat government clinic). [FGD-SG04]</p>
	Supportive environments	Informal, Formal	The availability and adequacy supportive environments for households living with diabetes	<p><i>If they want to help, I mean, I'm not begging. People know my situation is difficult. So I won't go for begging; just let it be. If they come, then I receive it. If not, people will talk about it...I'm very tired of asking for help here and there. We never get any formal welfare support, like from the village chief or anything. - [IDI-01]</i></p> <p><i>No, no one came, and no one will come. I've been sick for so long, no</i></p>

				<p><i>one there (MIC) ever comes...I'm telling you, these politicians are really useless. Like my hospital fees for this while they (MIC) never offered any help. They know about my condition, but they didn't do anything. - [IDI-11]</i></p> <p><i>Now BRIM (national financial aid program for the poor) is getting hard to get, not like previously. Now you have to fill forms, they will check your details, and then 2-3 months still, you will get nothing. - [IDI-04]</i></p> <p><i>If you have a formal name registered here in FELDA when you want to seek welfare help, you won't get it. We'll die...having a plantation plot doesn't mean one is well off. - [IDI-04]</i></p> <p><i>I receive SOCSO (social security) compensation for my eye, RM300 monthly, but the payments always come late. - [IDI-03]</i></p> <p><i>MIC (Indian-based political party) is useless. They never help at all. The MCA people, though, came and visited me here. - [IDI-08]</i></p> <p><i>We have tried, and it's no use. For both Segamat hospital and in Johor Bahru, we have tried going back and forth, and eventually, there was nothing...then I said, let's forget about it and no need to burden ourselves with the back and forth to the hospital in Johor Bahru. Transportation cost is also very high, going to the Johor Bahru welfare offices. I'm very tired of asking for help here and there. We never get any formal welfare support, like from the village chief or anything. - [IDI-01]</i></p> <p><i>They seldom come back. Last time, I gave one of children about RM50,000-70,000. They are working now, but they do not give me money though they can afford to...I do not depend on my children. I gave RM40,000 to my son when he has mortgaged off his house. I</i></p>
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				<p><i>cannot see my child living on the street. – [IDI-12]</i></p> <p><i>We're tired of that...we will never get that...we are permanent residents and not citizens, so we are shut off from a lot of things. – [IDI-01]</i></p> <p><i>No, she didn't ask. No one wants to pay attention and just ignore her. – [IDI-04]</i></p>
Impact of economic burden	Impact to household welfare	Incurring debts, Exhausting savings and facing impoverishment, Cut back on daily necessities	The impacts of economic burden due to diabetes on household socioeconomic wellbeing	<p><i>We don't have the money. To me, if I have the money, I will definitely pay it back. My situation is I don't have enough for basic living. We also didn't have any additional support or whatever. - [IDI-01]</i></p> <p><i>More than RM8000. My son paid for it until now he is still paying back the debt. If I didn't do it (operation) at that time, my leg would be gone. We still owe RM4000. - [IDI-06]</i></p> <p><i>For those who do not have savings, who are unemployed, or do not have financial support from their children, but needed insulin medication, the burden is big for them. - [IDI-05]</i></p> <p><i>I'll just be direct; the expenses are really high for us. For us, our livelihood is really pressured, but we believe that we must buy them still, find ways to get the money. - [IDI-01]</i></p> <p><i>Enough or not, we have to keep living. For now, I can still manage. I observed that if I only eat in the afternoon and not having dinner, the sugar level will drop a bit, to about 7. - [IDI-09]</i></p> <p><i>When I was selling cendol I used my own money, but now all of that is gone. All my savings were used to take care of him (husband with diabetes). Now he is much better. I told him to do some exercise.-</i></p>

				<p>[IDI-08]</p> <p><i>Yes, luckily, I have my own money or else I do not know what to do. You see, they (children) only give me RM100 (USD23.5) per year, which is less than RM1 (USD0.2) per day. He (son) is still useless and is gambling still. He is over 50 years old now. - [IDI-12]</i></p> <p><i>From Bekok I used to go there (Johor Baru hospital) everyday for 3 whole months – [IDI-01]</i></p> <p><i>I sell cendol actually last time, now I just stay at home and take care of him. – [IDI-08]</i></p> <p><i>If they force me to pay, then just bring me to the police station. Just arrest me if I can't pay. You know what, it's not that we don't want to pay, but even for basic living we're facing difficulties. If I have a bit of money, I will go and pay. If the hospital forces us to pay, then they come take what it's feasible from my house. I don't have a choice. – [IDI-01]</i></p> <p>The meds is given by the government gives, but other things like needle and disposable items I need to buy – [IDI-06]</p> <p>If I buy the better one I can't take it (financially)...last time I bought from clinic but I can't take it anymore, so I go and buy outside, the antiseptic lotion – [IDI-06]</p> <p>Quite expensive as well. If I buy one strip of 10 for the big pill, its RM1 per strip. But if it's the small pill, it's over RM30. For his test strips, it's RM38. I buy 2 times a month. Sometimes if I see his blood glucose increased I will check 3 times a day. – [IDI-08]</p>
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				<p>All the expenses I pay from my pocket...10 days about RM3000 – [IDI-01]</p> <p>Sometimes from relatives yes...we still owe the hospital RM3600, we can only pay bit by bit, we need to eat and live -it's not enough. – [IDI-01]</p> <p>Like the other day when I went to the hospital, I borrowed money from him (employer) RM5000. Every month he will deduct the money from my salary, but not all. – [IDI-01]</p> <p>My earnings per month is only less than RM100, it is surely not enough. The rest of my expenses my children helped out and gave me money now and then. – [IDI-02]</p> <p>Not very, as we go to the public clinic and ask from our children. – [IDI-03]</p> <p>Now my expenses for diabetes are not really that high, as the government clinic gives out free medicine. –[IDI-02]</p> <p>They use their own income and saving to cover their diabetes cost. People here do not really spend so much money for their diabetes because they take medicine from the clinic. However, costs incurred when they are on insulin treatment. – [IDI-05]</p> <p>Now it's on my own. This medicine and bandages I bought them myself. This kind of things also cost me more than RM200 per month. – [IDI-06]</p> <p>Previously, when I just came back from the operation, I went to the</p>
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				<p>private clinic in Labis. One trip costs me RM30, and one day I have to go twice. That's already RM60 for transport. After 1 month, I can't take it anymore. After that I just go to Batu 8 clinic. One time cleaning there is only RM3. – [IDI-03]</p> <p>My friend's car. I pay RM20 to my friend to go there and come back. It is considered cheap, if it's taxi it's RM35. I can't afford the Muar trip. I can't really go far either as my son is still studying here. When he has finished studying then yes. – [IDI-07]</p> <p>There was a case of someone I know where he stayed in private sector for 5 days and the bill came to RM8000, and the medicines costs RM1000 per month. He can't take it anymore in the second month, and he just go to the government clinic. If given medication, then he takes them, and if there isn't then he goes to buy them at the pharmacy. He just doesn't have the money every month. – [IDI-11]</p> <p>Every month around RM200 (treatment). My children pay for me. After a while they noted that they have to work as well as don't have much money. And so I have to come back here (Bekok) for the medicine and treatment. I told the doctor to see me. – [IDI-13]</p> <p>Yes. I used to give money to my son. I sold off my plantation and gave the money to my children. I still have my own savings. If I do not have savings, I would already "call" them (died) – [IDI-12]</p> <p>The transportation cost is also very high, going to Johor Baru (hospital). And then you have to take the taxi to the hospital. It costs a lot. –[IDI-01]</p> <p>Treatment at the hospital there in Johor Baru is free, but the wound cleaning the cost for it is a lot, and I've been doing cleaning for 40</p>
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				days. – [IDI-02]
	Impact on diabetes management	Poor SMBG management, Seeking cheaper care options, Restricted physical access to care, Under treatment	The impacts of economic burden due to diabetes on the management of diabetes	<p><i>Now, my needles (insulin pen) have also finished. I don't have the money to buy any. - [IDI-01]</i></p> <p><i>I clean my wound two times a day. It used to be three times but now reduced. The pharmacy told me now the items are getting more expensive. I used to buy this bandage for RM8; now it's RM10.50. The medicine, plasters, everything increased. If I buy the better one, I can't take it (financially)...last time I bought (antiseptic lotion) from the clinic, but I can't take it anymore, so I go and buy outside. - [IDI-06]</i></p> <p><i>Now I buy (insulin pen needles) at the clinic here for 70cents a piece, and they told me I could use up to four times. But I don't do that. I don't throw it away until I felt pain when I inject. - [IDI-06]</i></p> <p><i>There was a case of someone I know where he stayed in the private sector (hospital) for five days, and the bill came to RM8000, and the medicines cost RM1000 per month. He can't take it anymore in the second month, and he just goes to the government clinic. If they (clinic) give medication, then he takes them, and if there isn't, then he goes to buy them at the pharmacy. He just doesn't have the money every month.- [IDI-11]</i></p> <p><i>If my sugar level drops to 2, I can't even sit up. Nowadays, I didn't check because we couldn't manage to buy any new stocks (glucose test strips).- [IDI-01]</i></p> <p><i>I also check my sugar levels regularly once a day, but sometimes only 3-4 times a week. The card (glucose strip) is expensive. I can't take it.</i></p>

			<p>- [IDI-06]</p> <p><i>I plant them (herbs). If you buy outside, it's about RM3-5 (USD0.7-1.2). There are seeds you can put in boiling water, and when you drink it your glucose level will go down, they say. When my legs were numb, after taking that, it will go away. You take those. You will be okay. - [IDI-07]</i></p> <p><i>People are saying it. And that's why I drink it (bitter gourd juice), even though not very frequently. I take that to reduce my blood sugar. But if my blood sugar is four and below, I can't take it. I get weak. And I know it's because of my diabetes. -[IDI-01]</i></p> <p><i>Yes, it (Chinese medicinal herbs) does help to control my sugar levels. My body also can feel more active, and I sweat more. - [IDI-03]</i></p> <p><i>There's this time that I wasn't aware; I was at the farm with daun ketum. The one people say with red veins that are good. So I boiled it and I was supposed to boil only 3-4 leaves, but I boiled 20-30 leaves...I keep drinking it and suddenly my eyes can't see. Then my son took me to KL (Kuala Lumpur) and admitted me to UMMC (University Malaya Medical Center). - [FGD-SG01]</i></p> <p><i>Err, no as well (on telling doctors the supplements they're taking). - [FGD-SG01]</i></p> <p><i>I don't dare to (take traditional medicine). What if something happens? I'd just take the meds the government clinic gives. - [IDI-06]</i></p> <p><i>No, I only take medicines from the clinic. Whatever sickness we have,</i></p>
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				<p><i>we just go to the clinic (government). - [IDI-03]</i></p> <p><i>Previously, when I just came back from the operation, I went to the private clinic in Labis (30 kilometers away from Segamat town). One trip costs me RM30, and one day I have to go twice. That's already RM60 for transport. After one month, I can't take it anymore. After that, I just go to Batu 8 clinic. One time cleaning, there is only RM3. - [IDI-03]</i></p> <p><i>The biggest cost I think it's the traveling in between (healthcare premises). - [IDI-02]</i></p> <p><i>The needles are expensive. One piece is already 60 cents. The most you use it two times then you throw, but we use up to 5-6 times because it's expensive. In total, it costs around RM100 per month. - [FGD-SG01]</i></p> <p><i>I clean my wound two times a day. It used to be three times but now reduced. The pharmacy told me now the items are getting more expensive. I used to buy this bandage for RM8, and now it's RM10.50. The medicine, plasters, everything increased. – [IDI-06]</i></p> <p><i>Treatment at the hospital there in Johor Bahru is free, but the wound cleaning the cost for it is a lot, and I've been doing cleaning for 40 days. – [IDI-02]</i></p> <p><i>Recently, I buy this Rama-Rama tea. I saw it in the newspaper, and then I buy it. My blood pressure went down, from over 200 to 100 something.- [FGD-SG02]</i></p> <p><i>All sorts, like calcium... I buy it on my own. I go to the shop and ask them (sales personnel). And these (a new batch of medical items) are the items he needs for wound cleaning. I bought all of them.- [IDI-08]</i></p>
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				<p><i>Yes, we buy vitamins. You see now that his (husband with diabetes) wounds have dried upright, so we have stopped buying the meds for his wounds and start buying vitamins. We buy them from the pharmacy. It's not cheap as well. Every time my purchase is about RM100.- [IDI-08]</i></p> <p><i>I buy this medicine, Sauda, it's like fish oil. And then I buy olive oil—only these two. One packet cost about RM10-12 (USD2.4-USD2.8), I eat one of these each... yes, someone told me it's good for diabetes, and so I eat. - [FGD-SG01]</i></p> <p><i>Yes, my father did. His friend recommended (traditional medicine) to him. My father paid this out from his pocket. He tries whenever someone recommends- [IDI-05]</i></p> <p><i>One more thing, if we use the machine to check our blood sugar right, the paper (glucose test strip) is expensive. One pack is more than RM40. That also I will ask for free (from health minister). - [FGD-SG01]</i></p> <p><i>I don't think it's (TCM) very useful. My eldest son has diabetes and he really likes to go to see the Chinese medicine doctor. It's not guaranteed to be effective. – [IDI-02]</i></p> <p><i>She buys those (herbal medicine) outside. But now she can't take them. She can't drink much, her kidney is damaged. There are a lot of things she can't take anymore. – [IDI-04]</i></p> <p><i>The injection is free, but the needles we need to buy. They say we need to pay RM150-200 if you want to start (insulin) injection. – IDI-</i></p>
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				<p>07</p> <p>I only buy the needles for insulin. I use it until I feel pain when injecting. - [FGD-SG04]</p>
Household coping strategies resource allocation	Financial coping mechanism	Reliance on public healthcare, Informal and formal social support, Surrendering personal assets, Borrowing money, Personal income and savings	Types of financial coping mechanisms households utilised to manage the cost burden of diabetes	<p><i>I get my medicines free from the clinic, why do I need to buy from pharmacies? - [FGD-BK11]</i></p> <p><i>No, it is all the time with the government sector. My parents' medical treatments are all coming from the government, so it is not that expensive compared to the private sector. - [IDI-05]</i></p> <p><i>No. No money, how to go to private clinics? We poor people cannot afford it; we can only go to the government clinic. Only rich people will go far for treatment. The Malays here many are poor. - [FGD-BK02]</i></p> <p><i>We don't have much bank savings. We mainly survive on my pension and dividends from some of my shares (share trading). - [IDI-03]</i></p> <p><i>We have savings. Usually, I will use my savings to overcome it because I still have savings. - [IDI-05]</i></p> <p><i>They (people with diabetes) use their income and saving to cover their diabetes cost.- [IDI-05]</i></p> <p><i>Like the other day, when I went to the hospital, I borrowed money from him (employer) RM5000. Every month he will deduct the money from my salary, but not all. - [IDI-01]</i></p> <p><i>Out-of-pocket myself. My son helped as well, and I also borrowed from friends. - [IDI-06]</i></p>

				<p><i>We don't have the money. To me, if I have the money, I will definitely pay it back (to the hospital). My situation is I don't have enough for basic living. - [IDI-01]</i></p> <p><i>If they force me to pay, then just take me to the police station. Just arrest me if I can't pay. You know what, it's not that we don't want to pay, but even for basic living, we're facing difficulties. If I have a bit of money, I will go and pay. If the hospital forces us to pay, then they can come to take what it's feasible from my house. I don't have a choice. - [IDI-01]</i></p> <p><i>We don't ask from others. We supported ourselves. - [IDI-07]</i> <i>No. we take care of it by ourselves. - [IDI-08]</i></p> <p><i>I didn't ask for anything. I don't want to. To ask for help from the government is very tedious. If you take RM10 from them, then next time they would come and ask you for donations. They always ask for donations here and there. I'm telling you, this politic is really useless. Like my hospital fees for this while they never offered any help. They know about my condition, but they didn't do anything. - [IDI-11]</i></p> <p><i>Oh no, no. I can still manage things myself. My children give me money every month.- [IDI-10]</i></p> <p><i>My husband is the sole earner. He is working in Singapore, and he comes once a month. He sends the money home monthly. - [IDI-07]</i></p> <p><i>My children supported them all (diabetes treatment cost). I do get some income myself, but now my children take care of me. Some of them come back once a month or two months once and will give me money. But for hospital costs, it's just my son here who covered it. - [IDI-11]</i></p>
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				<p><i>Every day for 95 days, I go there (Johor Bahru hospital) by train after work and then come back. [IDI-01]</i></p> <p><i>My children helped me to check and told me 'mom, 3-4' (glucometer readings), and at that time, I'll be drinking sweet drinks. My children also help with insulin injection.- [IDI-01]</i></p> <p><i>She (wife) is the one who takes care of me. If she is not around, it will be difficult. She scolds me too, but it's ok. -[IDI-08]</i></p> <p><i>My children got it (glucometer) for me, but I don't measure. Sometimes they cook for me, and sometimes I cook for myself. I use the money they gave to buy food and cook for myself. For buying groceries I ask the house opposite to help me buy. Whatever food I want to buy I will ask them.- [IDI-13]</i></p> <p><i>Now, I'm asking my grandchildren to help me (to) inject.- [IDI-02]</i></p> <p><i>If my TV is not functioning, sometimes I ask them (neighbour) to come over to help to fix it, and they're helpful. There's a lot of singleton households here. For buying groceries, I ask the house opposite to help me to buy. Whatever food I want to buy, I will ask them - .[IDI-13]</i></p> <p><i>However, the amount may be lesser if the (dialysis) center is subsidized by MCA (Chinese-based political body) or any other charity bodies. It is actually upon application approval, and we need to fill up the form stating our financial information.- [IDI-05]</i></p> <p><i>You need to inform them, so they know. They have volunteers around, and for example, if they found out who has cancer, they will take note, and sometimes the YB (state assemblymen) will visit. He typically helps those who are alone, and seldom for those who have children.</i></p>
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				<p><i>You need to give children the opportunity to be filial.- [IDI-13]</i></p> <p><i>I know they (MCA, Chinese-based political party) help, but I don't want to ask. - [IDI-11]</i></p> <p><i>I take from the welfare department RM150 per month. I've taken BRIM before, this time around many people didn't get it but I got it. [IDI-06]</i></p> <p><i>When he (person with diabetes) can go to work, my son said will buy an electric start motorbike for him. – [IDI-08]</i></p> <p><i>Yes, because we have clinics at Bekok. If there is no clinic at Bekok, there will also be transportation cost to the patients to travel to Segamat town. - [IDI-05]</i></p> <p><i>Sometimes, people at Bekok will carpool with me if we happened to visit the hospital on the same day.– [IDI-05]</i></p> <p><i>I pay for it too (taxi fare). It costs around RM6-7 per trip from Bekok to Segamat. - [IDI-12]</i></p> <p><i>My friend's car. I pay RM20 to my friend to go there and come back (from Segamat Hospital). It is considered cheap. If it's a taxi, it's RM35. I can't afford the Muar trip. I can't really go far either as my son is still studying here. When he has finished studying, then yes. – [IDI-07]</i></p> <p><i>They (her children) pay for the maid who is with me. It is about RM 1600 per month. - [IDI12]</i></p> <p><i>We got them (intraocular lens) from the government hospital. Yes, we did pay for the lens but operations are free. – [IDI-05]</i></p>
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				<p>Last time when my son fell down and broke his bone, he was charged RM500. That one we cannot pay here, pay in the account (credit basis)...If it's in the private hospital, it can run up to over RM15,000. - [FGD-SG04]</p> <p>It was ok, both Segamat (hospital) and Sultan Ismail (hospital) in Johor Baru. Waiting time is typically long if you don't get good number. – [IDI-01]</p> <p>When I first got this foot injury, I went to Segamat hospital. After that, they send me to Muar (district hospital).- [IDI-06]</p> <p>Yes, for other types of illness. For my diabetes it's all in Johor Baru. For the clinic here, I go to the doctors for things like leg pain and headache. – [IDI-03]</p> <p>The private sector is really costly. There was a time I went for a bowel surgery at Melaka, and the surgery cost RM12,000. The government hospital is much more affordable. – [IDI-04]</p> <p>I don't think so as she relies on the hospital for everything. Her condition has worsened to a bad state, and the doctor also can't do much. She can't take much water or medicine. The nurse manages and narrows down the meds she can take for her. She don't know how to take care, so the nurse can help. – [IDI-04]</p> <p>No, it is all the time with the government sector. My parents' medical treatment are all coming from government, so it is not that expensive compared to private sectors – [IDI-05]</p> <p>Either we go to Segamat or Labis dialysis centers. There is no</p>
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				<p>vacancy in Hospital Segamat. – [IDI-05]</p> <p>Yes, and if I don't feel well, I will go and check. I can go there, no problem. The clinics we don't complain much. But last time, on Thursdays, they have a problem. You see, you must attend to patients first before you have these meetings. – [IDI-06]</p> <p>All the meds I take from the government clinic here – [IDI-07]</p> <p>No, I just take the medicine from the hospital. I also never buy those (TCM products) – [IDI-09]</p> <p>Here (Bekok clinic), I don't have to wait long, not like the one in Batu Pahat. If you go at 8am, you have to wait till 12pm. It's very fast here, about 1 hour. – [IDI-13]</p> <p>I just get my meds from the public clinic, my wife also goes there. I go to the clinics nearby here and also in Labis. – [IDI-08]</p> <p>Yes, they do help out (financially) little bit. They are also struggling. – [IDI-01]</p> <p>I used to stay at Rumah Rakyat area, but people's feelings got hurt there so I move out. Here, I mind my own business. The important thing is I don't disturb them and they don't disturb me. We will help ourselves. – [IDI-01]</p> <p>I cleaned my wound for at least 40 days there in Johor Baru. I stayed outside while doing the cleaning, and came back to Bekok the day after my operation. I stayed at my son's house in Johor Baru. – [IDI-02]</p>
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				<p>My son took me there (to the hospital). I went around many places to check on my feet. – [IDI-02]</p> <p>My earnings per month is only less than RM100, it is surely not enough. The rest of my expenses my children helped out and gave me money now and then. – [IDI-02]</p> <p>We have so many children and still we ask for people to help? My children at times will buy food for me and take care of me. – [IDI-02]</p> <p>Not very (high expenses), as we go to the public clinic and ask from our children. – [IDI-03]</p> <p>Her son here goes and sees her every day. She has one son who is still schooling, and is a divorcee. She has 3 children; the youngest now stays with her. The rest has moved out and working. they are quite far away, like in Kelantan, KL.– [IDI-04]</p> <p>I am the one who support them. I will pay RM 50 to my brother for sending them to Segamat for transportation expenses. He will also send them to the Hospital at Muar because it is too far for me to travel. – [IDI-05]</p> <p>No issue (on communication), because the children are going with them. They are usually accompanied except one time when all of us were busy, it was my father. However my father can handle it himself but not my mother. – [IDI-05]</p> <p>My children will support me every month. So when they have money they will send some home. – [IDI-06]</p> <p>Not really (neighbour). They can help with transportation. When my</p>
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				<p>eyes were better I drive myself – [IDI-06]</p> <p>Yes, they do as well, a little bit. Even if we ask for more we can't as they also have many children of their own. They sometimes would pay my household bills, and give us money. – [IDI-09]</p> <p>My children supported and I also pay some myself. My husband is still working, and when it gets tough I will ask my children to help – [IDI-10]</p> <p>My sister. She just lives nearby the Rumah Rakyat area. Sometimes if I need to go somewhere I'll see if I can get a lift from my friends around. For going around the neighbourhood I just ride my motorbike – [IDI-10]</p> <p>I stayed for a month in Batu Pahat, and after that my son brought me back here. He sells vegetables here and he helps me clean my wound, after that the wound heals – [IDI-13]</p> <p>Myself, I book the taxi to go to clinic. No, they (children) do not help me and more over I have maid. – [IDI-12]</p> <p>The 3 of them will pay. All of them have cars. – [IDI-08]</p> <p>My son drives me there (Segamat Hospital). The one who works as a police. He is also the one who sends him to Kluang KPJ Hospital. – [IDI-08]</p> <p>No (in seeking welfare support). Government-wise when they give out money I will go take. – [IDI-02]</p> <p>Don't ever assume those who are staying here have it good. Even if</p>
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				<p>we have plantation plots, our situation may not be good. If we hire people to work on it, we only get back like 1/3 of the profits. I have 2 acres of palm oil and some rubber trees, but we can't eat those. – [IDI-04]</p> <p>Burden? It's to my children. Each of them contributed some money – [IDI-13]</p> <p>The food spending my children will take care it. For household utility it used to be from salary, but now that it has stopped, my children then chipped in to help out a bit. We are still paying the mortgage, we only have 4 years left. – [IDI-08]</p> <p>Now my children give me money. His EPF I didn't touch. My sons' say he doesn't need to take them out. We can help they said. – [IDI-08]</p> <p>My children pay for all the expenses. No issues for me. My children send me there once a month (private hospital in Melaka). - [FGD-BK09]</p> <p>My children accompany me. My husband can't walk well, he had stroke since 3 years ago. - [FGD-BK02]</p>
	Household resource allocation	Household decision making	Underlying factors for decision making in managing household resources	<p><i>Yes. We understand their situation like my brother; he needs to support his children's education. We are fine with supporting expenses ourselves. For example, I am staying with my sister, and we split household utility bills. - [IDI-05]</i></p> <p><i>Yes, they (their children) do as well (provide money for treatment), a little bit. Even if we want to ask for more, we can't as they also have many children of their own. They sometimes would pay my household</i></p>

				<p><i>bills, and give us money. - [IDI-09]</i></p> <p><i>No, we usually do not, because they know I have savings. As you can see, my parents' medical treatment is all coming from the government, so it is not that expensive compared to private sectors. The AVF (arteriovenous fistula) expenses in KPJ Kluang (private clinic) in 2014 (RM2600) were paid by me too. - [IDI-05]</i></p> <p><i>It's just me and my children discuss and see how to go about it. If they can help, they help. For me, good or bad times, I have my family. Because even if we ask for help, people may not help us. Typically it's more frustrating as people tend to say bad things. So in times of need, we will discuss within ourselves. I'll call the eldest and ask, 'do you have money?', and if he has we'll take a little bit. Then I'll call the second son and ask if he has money. That's it. - [IDI-01]</i></p> <p><i>Our children don't always give; sometimes if we need to use a bit more, they will help. But you see, our children have their own families and have to pay for their own expenses. - [IDI-03]</i></p> <p><i>Last time when I was working, my brother is the one (sending parents to the hospital). Since I am back in home town now, I am the one who sends them. We are not calculative among us who sends parents to the hospital. Whoever is free and at Bekok, they will send my parents to the hospital. - [IDI-05]</i></p>
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Appendix 6 – Focus group discussion consent form



MONASH University
Jeffrey Cheah School of
Medicine and Health Sciences



BORANG KEBENARAN

Pusat Kajian Komuniti Asia Tenggara (SEACO)

Nama kajian: Bebanan ekonomi isirumah dari penjagaan penyakit diabetes

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Saya telah dijemput untuk menyertai sesi perbincangan kumpulan focus untuk projek kajian Universiti Monash Malaysia seperti yang tertera di atas. Saya, _____ sahkan yang berikut:

Saya telah menerima dan memahami lembaran maklumat dan salinan kenyataan privasi	<input type="checkbox"/>
Sebarang soalan mengenai penyertaan saya telah dijawab dengan memuaskan	<input type="checkbox"/>
Saya akan ditemubual tentang perbelanjaan diabetes dan perbelanjaan isirumah saya	<input type="checkbox"/>
Jawapan saya akan disimpan dengan selamat dalam komputer	<input type="checkbox"/>
Jawapan saya hanya akan disediakan kepada penyelidik untuk analisis data dan data tidak menunjukkan maklumat peribadi	<input type="checkbox"/>
Hasil rumusan yang telah menggabungkan banyak isirumah, termasuk isirumah saya, mungkin akan diterbitkan tetapi tidak akan menunjukkan maklumat peribadi	<input type="checkbox"/>
Jawapan yang saya berikan mungkin akan digunakan oleh penyelidik dalam projek kajian pada masa akan datang, tetapi tidak akan menunjukkan maklumat peribadi	<input type="checkbox"/>
Jawapan yang saya berikan mungkin akan dikaitkan kepada data SEACO yang lain atau data pentadbiran pada masa yang akan datang.	<input type="checkbox"/>
Data hanya akan dikeluarkan untuk tujuan bukan penyelidikan dengan kebenaran yang jelas dari setiap peserta	<input type="checkbox"/>
Penyertaan ini adalah sukarela dan saya mungkin akan menarik diri pada bila-bila masa tanpa dikenakan penalti	<input type="checkbox"/>
Saya setuju untuk ditemubual saya direkodkan dalam bentuk audio	<input type="checkbox"/>

Tandatangan peserta

Nama:
Nombor kad pengenalan:
Tarikh:

Appendix 7 – MUHREC approval



MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project Number: CF14/2053 - 2014001075

Project Title: Catastrophe and impoverishment from diabetes: an exploration of the economic burden of diabetes care

Chief Investigator: Prof Pascale Allotey

Approved: **From:** 10 July 2014

To: 10 July 2019

Terms of approval - Failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must include your project number.
6. **Amendments to the approved project (including changes in personnel):** Require the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

Professor Nip Thomson
Chair, MUHREC

cc: Prof Daniel Reidpath, Mr Chee Ho Cheah

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 3831
Email muhrec@monash.edu <http://www.monash.edu.au/researchoffice/human/>
ABN 12 377 614 012 CRICOS Provider #00008C

Appendix 8 – Study information sheet (in English, Malay, Chinese languages)



MONASH University

Jeffrey Cheah School of
Medicine and Health Sciences



Southeast Asia Community Observatory (SEACO)

Project title: Catastrophe and impoverishment from diabetes: an exploration of the economic burden of diabetes care

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Background to the project

Chronic diseases such as diabetes are fast becoming an epidemic in Malaysia, with 15.9% of the adult population having diabetes. Managing chronic diseases needs long term care, which requires a lot of resources and place a heavy economic burden to both the individual and household. However, how much of this burden overall largely remains unknown, particularly of indirect costs which are often overlooked. The aim of this study is to explore the economic burden for individuals, families and communities, of managing and living with Type 2 Diabetes.

We are interested in finding out the full cost of diabetes from the individual and community perspective, and how people manage and cope with the economic burden of having diabetes.

What does participation involve?

Participation will involve the administration of two rounds of questionnaires and one interview session. The first round of questionnaire will be in the near future and then the second round another in 9 months' time. This will be followed by the interview session. The questionnaire and interview sessions will be scheduled at a time and location that you choose. Each questionnaire will take approximately 20 minutes, and interview sessions will run for approximately 45-60 minutes. The length will be determined by you and what you would like

to share with the researcher. We realise that you may get tired during this time. If you do, please advise the researcher and we can stop, and meet again at a later time. With your permission, we would like to audio-record the interview session.

When the study has completed, we will send out a summary of the project. The ethical aspects of this research have been approved by the Monash University Human Research Ethics Committee.

What are the possible benefits of participating in this study?

You can talk freely about your experiences in a safe and non-judgmental environment. Many people find it helpful to share information and their experiences with someone who is not a close friend or family member. Your information will enable us to contribute valuable information to policy makers, healthcare service providers, and scientists to develop cost-effective interventions towards reducing economic burden and providing adequate risk protection for households with chronic diseases.

Can I withdraw from the research?

Being in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part and later change your mind, you are free to withdraw from the study. However, you may only withdraw prior to the data being reported.

Confidentiality

All of the data you provide is confidential. Data will be coded and a list of codes kept in a separate locked filing cabinet in Prof Pascale's office at Monash University Malaysia. Consent forms and questionnaire data will be collected electronically through a tablet computer, data will be stored in a secured server with encrypted database that only the researcher will have access. All data files will be stored separately and will contain no identifying information. Data on computers will be password protected. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report. Pseudonyms will be used whenever a direct quote is used, so you cannot be identified, and no identifying information will be included. Only the researchers have access to the research findings. Storage of data is in accordance to the Monash University Malaysia policy of a period of 5 years in a locked and secure cabinet.

Results

If you would like to be informed of the research findings, please contact Prof Pascale using the details above.

Contact information

If you have any questions about the project, please contact:

SEACO-Monash University
Suite 601-604 Wisma Centrepont
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MONASH University

Jeffrey Cheah School of
Medicine and Health Sciences



Pusat Kajian Komuniti Asia Tenggara (SEACO)

Nama kajian: Bebanan ekonomi isi rumah dari penjagaan penyakit diabetes

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Prof Daniel Reidpath

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SEACO merupakan sebuah projek kajian hasil daripada kerjasama di antara komuniti di daerah Segamat dengan universiti-universiti di Malaysia, Australia dan juga Eropah. Tujuan utama SEACO adalah untuk meningkatkan kefahaman terhadap faktor pengekalan kesihatan dan kesejahteraan di dalam komuniti dan bagaimana faktor tersebut akan berubah mengikut perubahan masa. Justeru, projek ini diharap dapat meningkatkan taraf kesihatan individu dan keluarga yang tinggal di daerah Segamat.

LATAR BELAKANG DAN OBJEKTIF

Penyakit kronik seperti kencing manis semakin meningkat di Malaysia, merangkumi 15.9% daripada golongan populasi dewasa. Pengurusan penyakit kronik memerlukan penjagaan masa panjang dan memerlukan banyak sumber, dan ini akan meletakkan beban ekonomi yang berat kepada individu dan isirumah. Tetapi, setakat mana berat beban ini adalah tidak ketahui, terutamanya kos tidak langsung yang kebiasaannya tidak dikaji. Tujuan kajian ini adalah untuk menerokai beban ekonomi individu dan isirumah yang menghidap penyakit kencing manis.

Kami berminat untuk mengukur kos penuh penyakit kencing manis dari sudut individu dan komuniti, dan bagaimana isirumah menghadapi dan mengendalikan bebanan ekonomi yang berpunca dari penyakit kencing manis.

APA YANG DIRANGKUMI DALAM KAJIAN INI?

Penyertaan anda dalam kajian ini akan meliputi dua sesi tinjauan soal selidik dan satu sesi temuramah. Sesi kedua soal selidik akan dijalankan selepas jangka masa 6-9 bulan, dan sesi temuramah akan dijalankan pada masa di antara sesi pertama dan sesi kedua soal selidik. Setiap sesi soal selidik dan temuramah akan mengambil masa kira-kira 45-60 minit. Jangkamasa soal selidik dan temuramah adalah ditentukan oleh anda mengikut maklumat yang anda ingin berkongsi dengan pengumpul data kami. Sekiranya anda berasa penat semasa soal selidik ataupun temuramah sedang dijalankan, sila beritahu para pengumpul

data untuk berhenti, dan kami boleh membuat lawatan pada hari dan masa lain yang bersesuaian dengan anda. Kami juga berminat untuk membuat rekod audio untuk sesi temuramah.

Apabila kajian telah selesai kami akan memberikan rumusan kajian dan penemuan yang kami perolehi kepada anda. Aspek etika kajian ini telah diluluskan oleh *Monash University Human Research Ethics Committee*.

FAEDAH KAJIAN KEPADA ANDA DAN KOMUNITI

Anda boleh memberikan maklumat dan berkongsi pengalaman dengan kami dalam persekitaran yang selamat dan terbuka. Kebanyakan individu berasa ia dapat membantu jika mereka berkongsi pengalaman dengan individu yang bukan ahli keluarga ataupun rakan. Maklumat anda boleh membantu kami untuk menyalurkan penemuan-penemuan penting kepada pembuat dasar kerajaan, para doktor, dan ahli penyelidik untuk membangunkan program yang lebih berkesan untuk meringankan beban ekonomi isirumah serta memberikan perlindungan risiko kewangan yang mencukupi.

BOLEHKAN SAYA MENARIK DIRI DARI KAJIAN INI?

Kajian ini adalah secara sukarela dan tiada kewajipan untuk penyertaan. Jika anda mengubah fikiran dalam jangkamasa kajian ini, anda boleh menarik diri pada bila-bila masa. Tetapi, anda hanya boleh menarik diri sebelum hasil kajian dilaporkan dan diterbitkan.

KESULITAN MAKLUMAT

Segala maklumat yang anda berikan adalah sulit. Maklumat akan dikodkan dan senarai kod akan disimpan dalam kabinet berkunci yang asing dalam pejabat Prof Pascale di Monash University Malaysia. Borang kebenaran dan maklumat soal selidik akan dikumpulkan secara elektronik melalui komputer tablet, dan akan disimpan dalam server komputer yang mempunyai pengkalan data yang disulitkan yang hanya boleh digunakan oleh penyelidik. Semua fail maklumat akan disimpan secara berasingan dan tidak akan mempunyai maklumat yang boleh mengenalpasti anda. Maklumat dalam komputer akan dilindungi dengan kata laluan. Laporan kajian akan diterbitkan, tetapi nama dan informasi peribadi peserta tidak akan dikenalpasti. Nama samaran akan digunakan di mana petikan perbualan digunakan, dan identiti anda tidak akan dikenalpasti. Hanya penyelidik mempunyai laluan untuk maklumat kajian. Penyimpanan maklumat yang dikumpul akan berpandukan peraturan Universiti dan akan disimpan di dalam kabinet yang dikunci selama 5 tahun.

PENEMUAN KAJIAN

Sekiranya anda berminat untuk mengetahui mengenai hasil kajian ini, sila hubungi Prof Pascale melalui nombor telefon atau pun emel seperti yang tertera di bawah.

BUTIRAN UNTUK DIHUBUNGI

Jika anda mempunyai sebarang pertanyaan mengenai projek ini, sila hubungi:

SEACO-Monash University
Suite 601-604 Wisma Centrepont
146, Jalan Sia Her Yam, 85000
Segamat, Johor Darul Takzim
Tel: +607-9310240/ +6079311897
E-mail: info@seaco.asia
<http://www.seaco.asia>

Southeast Asia Community Observatory (SEACO) **东南亚社区观测站 (SEACO)**

研究项目：糖尿病治疗所带来的家庭经济负担

Prof Pascale Allotey

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项目背景

慢性疾病，例如糖尿病在马来西亚迅速的普遍化，15.9%的成年人被诊断糖尿病。管理慢性疾病需要长期护理，需耗费大量的资源，这也加重个人以及家庭的经济负担。然而，这些负担整体上都被忽视，尤其是所有间接的费用。这项研究的目的是探讨糖尿病管理对个人，家庭和社区所带来的经济负担。

我们在于糖尿病对个人和社区群体所承担的全部费用这方面感兴趣，并想了解人们如何管理和应对患上糖尿病所带来的经济负担。

参与所涵盖的事项？

参与将涉及两轮问卷回答和一个访谈环节。第一轮问卷即将开始，然后在第二轮将在9个月后。之后，将有访谈环节。问卷调查和访谈将被安排在您选择的时间和地点。每一个问卷大约需要20分钟；访谈则需要大约45-

60分钟。访谈的长短由你决定，内容都是你想和研究人员分享的。我们也了解，你可能会在这段时间会觉得累。如果你累了，请告诉研究人员，我们可以停下来，并再约。有了您的许可，我们想使用音频记录采访，但如果不允许，我们会做现场笔记。

当研究完成后，我们会发表研究项目的摘要。这项研究的伦理方面已获得莫纳什大学(Monash University)人类研究伦理委员会 (Human Research Ethics Committee) 的批准。

参与这项研究可能带来的好处？

你可以自由在安全和非审问的环境下谈论你的体验。很多人认为与别人(非好友或家人)分享患上糖尿病的经验能为他人带来帮助。您的资料将使我们能够贡献有价值信息，给予政策制定者，医疗服务提供商和科学家对减少经济负担和家庭慢性疾病所提供足够的风险保障及研发有效的对策。

我可以退出研究？

这项研究是自愿的，你没有义务同意参与。如果你决定参加，后来改变了主意，你可以自由地退出研究。但是，您只能在数据还没呈献之前退出。

保密

你所提供的数据是保密的。数据将被编码及代码方式保存在Prof Pascale在Monash University Malaysia (Sunway Campus)

办公室的文件柜。同意书和调查问卷的数据将通过平板电脑以电子方式进行资料收集。数据将被储存在安全的服务器并进行加密，也只有研究人员可使用。所有的数据文件将被匿名处理和分开储存。电脑上的数据将被密码保护。这项研究的报告可能提交出版，但个别参与者无法识别这样的报告。如果需要引用句子，将尽量使用匿名直接引用，都没有身份信息将被纳入，所以你的身份将不明确。

结果

如果您想获知的研究结果，请使用下面的方式联系Prof Pascale。

联系方式：

如果您对这个项目有任何疑问，请联系：

SEACO-Monash University
Suite 601-604 Wisma Centrepont
146, Jalan Sia Her Yam, 85000
Segamat, Johor Darul Takzim
Tel: +607-9310240/ +6079311897
E-mail: info@seaco.asia
Website: <http://www.seaco.asia>

Appendix 9 – SEACO and Personal Data Protection Act sheet



SEACO dan Akta Perlindungan Data Peribadi (APDP) 2010

SEACO adalah sebuah pusat kajian di bawah naungan Universiti Monash dan terikat di bawah Akta Perlindungan Data Peribadi (APDP) 2010. Universiti Monash Malaysia merupakan pengguna berdaftar Akta (APDP) 2010.

SEACO mengumpul data peribadi penduduk Segamat (Mukim Bekok, Chaah, Gemereh, Sungai Segamat dan Jabi) dengan tiga cara yang berbeza dan hanya berbuat demikian setelah mendapat kebenaran daripada individu itu sendiri.

- Kami mengumpul maklumat daripada setiap individu secara peribadi melalui sesi soal-jawab **setelah mendapat kebenaran daripada mereka.**
- Kami mengumpul maklumat dengan menemuramah ketua keluarga (atau pihak lain yang berkenaan) mengenai mereka yang berada di dalam isi rumah.
- Kami juga mengumpul maklumat mengenai individu daripada agensi-agensi lain, **tetapi hanya dengan kebenaran daripada individu terbabit.**

Kami hanya mengumpul data untuk tujuan penyelidikan/kajian. Buat masa ini, fokus kajian kami adalah meliputi tentang kesihatan dan kesejahteraan komuniti. Walau bagaimanapun, pada masa yang akan datang, data yang diperolehi berkemungkinan akan digunakan untuk kajian lain seperti isu sosial, alam sekitar dan ekonomi. Analisis data dilakukan secara terkumpul dan di dalam bentuk ringkasan. Kami juga tidak akan mendedahkan maklumat pengenalan individu **tanpa kebenaran individu itu sendiri.** (Lihat Teks 1) Hasil keputusan kajian yang dijalankan akan dibentangkan di mesyuarat-mesyuarat saintifik, diterbitkan sebagai artikel penyelidikan dan disebarkan kepada komuniti melalui mesyuarat, laporan dan juga surat khabar.

Kakitangan Polisi, Penyelidikan dan Kawasan di kementerian-kementerian kerajaan (seperti Kementerian Kesihatan) di Malaysia juga akan dibenarkan untuk menganalisis data SEACO selain daripada penyelidik-penyelidik dalam dan luar negara. Di dalam hampir kesemua penyelidikan, mereka yang menganalisis data tidak akan mempunyai akses tentang maklumat pengenalan dan peribadi responden. Terdapat beberapa situasi dimana mereka mempunyai akses terhadap data peribadi, tetapi hanya dengan kehadiran kakitangan SEACO dan mereka tidak akan dibenarkan menyimpan salinan data **melainkan dengan kebenaran individu terbabit itu sendiri.**

Dari semasa ke semasa, kami akan menghubungkan data peribadi yang diperolehi dengan pelbagai sumber yang berbeza **tetapi hanya dengan kebenaran individu terbabit itu sendiri**. Teks 2 dan Teks 3 merupakan contoh tentang bagaimana data tersebut akan digunakan.

Penglibatan bersama SEACO adalah sepenuhnya secara sukarela. Individu tidak perlu memberi maklumat peribadi atau akses maklumat peribadi kepada pihak ketiga. Kadangkala, kerjasama yang diberikan akan memberi manfaat secara langsung kepada individu terlibat kerana mereka akan dapat mengetahui tentang keadaan kesihatan mereka sendiri. Selain itu, sumbangan yang diberikan mereka ini dapat membantu penyelidik dalam menyelesaikan kajian mereka yang berkisar tentang kesihatan dan kesejahteraan komuniti setempat, kebangsaan dan antarabangsa.

Kami bekerja keras untuk memastikan privasi dalam semua data yang diperolehi. Data peribadi disimpan di dalam sistem komputer yang selamat dan sulit dengan akses kata laluan yang ketat. Pengguna SEACO yang berdaftar akan diberikan akses kepada data yang tidak dihubungkan semula dengan individu. Data tersebut tidak akan mengandungi maklumat pengenalan peribadi. Kami juga telah mula mengumpul sampel-bio daripada beberapa individu **tetapi hanya dengan kebenaran individu tersebut**. Seperti maklumat data, sampel-sampel ini disimpan secara sulit dan dengan pengaksesan yang ketat.

SEACO hanya akan menyimpan data peribadi selama data tersebut diperlukan untuk menjalankan penyelidikan. Setelah tidak digunakan, data tersebut akan dipadam terus secara kekal dan tidak boleh didapati semula.

Mereka yang terlibat bersama SEACO boleh menarik diri pada bila-bila masa tanpa dikenakan penalti. Maklumat pengenalan diri akan dipadamkan daripada sistem komputer, manakala maklumat yang tidak dihubungkan kepada individu akan dikekalkan. Individu boleh membuat keputusan untuk menarik diri pada waktu sekarang dan boleh melibatkan diri semula pada masa akan datang.

SEACO merupakan sebahagian daripada komuniti Segamat dan kami amat berharap anda akan terus menjadi sebahagian daripada SEACO.

Jika terdapat sebarang persoalan atau kebimbangan mengenai data peribadi anda di SEACO, anda bolehlah menghubungi:

SEACO-Monash University
Suite 601-604 Wisma Centrepont
146, Jalan Sia Her Yam, 85000
Segamat, Johor Darul Takzim
Tel: +607-9310240/ +6079311897
E-mail: info@seaco.asia
<http://www.seaco.asia>

Teks 1: Kami tidak akan mendedahkan maklumat individu tanpa kebenaran mereka.

Kadangkala, untuk tujuan berita atau untuk menarik penglibatan komuniti, kami akan bertanya kepada individu sekiranya kisah dan juga gambar mereka boleh dipaparkan atau diterbitkan. Walaubagaimanapun, kami akan berbuat demikian **hanya selepas mendapat kebenaran daripada individu tersebut.**


Teks 2: Bayi di Segamat: Peralihan Kesihatan (SI:HAT)

Harapan kami adalah untuk mengikuti perkembangan kanak-kanak sejak dari kelahiran mereka sehingga lah ke zaman persekolahan mereka. Ia bertujuan untuk menghubungkan data mengenai bayi daripada Klinik Kesihatan (sejurus selepas kelahiran) dan juga hospital; dengan kehidupan mereka apabila sudah bersekolah. Data-data ini adalah penting untuk mengetahui tahap perkembangan kesihatan mereka dan membantu ibu bapa untuk mengenal pasti dengan lebih awal tentang masalah kesihatan yang dihadapi anak mereka.

Teks 3: Peningkatan usia yang sihat

Segamat mempunyai populasi warga berusia yang lebih ramai dibandingkan dengan daerah-daerah lain seluruh Malaysia. Seringkali, apabila meningkatnya usia, masalah kesihatan kronik juga akan mula dihadapi. Dengan mengikuti perkembangan mereka melalui pemantauan kesihatan seperti pendengaran, penglihatan dan fungsi kognitif, kami berharap dapat memberikan maklumat mengenai strategi kesihatan yang efektif dalam menghadapi pertambahan usia. Ini dapat dilakukan dengan menghubungkan rekod kesihatan mereka dengan pemeriksaan yang dilakukan oleh SEACO.

Appendix 10 – Segamat District Health office permission letter for research (for non-Felda areas)



PEJABAT KESIHATAN SEGAMAT
PETI SURAT 102,
JALAN GUDANG UBAT
85000 SEGAMAT
JOHOR DARUL TAKZIM

TEL : 07 - 9313355
FAX : 07 - 9321204

Sila catatkan bilangan surat ini apabila berhubung

Ruj. Tuan:
Ruj. Kami: *PUSAH 1/1/5995*
Tarikh : *5 JUN 2013*

KEPADA SESIAPA YANG BERKENAAN

Tuan,

SURAT SOKONGAN UNTUK PROGRAM SEACO

Adalah saya dengan segala hormatnya merujuk perkara tersebut di atas.

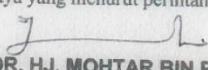
2. SEACO (Projek Kajian Kesihatan Komuniti Asia Tenggara) ialah sebuah projek kajian hasil dari kerjasama di antara komuniti di Daerah Segamat, Universiti Monash Australia dan Universiti Monash Malaysia. Tujuan utama SEACO melakukan kajian ini ialah untuk meningkatkan tahap kesihatan dan kesejahteraan komuniti serta memahami faktor-faktor yang mempengaruhi perkara ini.
3. SEACO (Projek Kajian Kesihatan Komuniti Asia Tenggara) berpusat di Segamat dan menjalankan kajian ini di mukim Bekok, Chaah, Gemereh, Jabi dan Sungai Segamat.
4. Dengan ini saya menyokong penuh pihak Universiti Monash Malaysia untuk melakukan aktiviti tersebut di daerah Segamat. Untuk makluman, Pengarah Kesihatan Negeri Johor adalah salah seorang ahli dalam Badan Pengelola SEACO di mana beliau mewakili Ketua Pengarah Kementerian Kesihatan Malaysia manakala Pengarah Institut Kesihatan Umum pula adalah salah seorang ahli dalam Badan Saintifik SEACO.
5. Di samping itu juga, pihak SEACO akan menjalankan pemeriksaan kesihatan secara percuma dari rumah ke rumah di 5 buah mukim tersebut dan surat rujukan ke klinik kesihatan terdekat akan diberikan sekiranya perlu selepas pemeriksaan tersebut. Perkara ini ialah hasil kerjasama antara SEACO dan Kementerian Kesihatan Malaysia dan diharapkan pihak tuan memberikan kerjasama kepada pihak SEACO.
6. Sehubungan itu, besarlah harapan kami sekiranya pihak tuan dapat memberikan kerjasama kepada pihak SEACO ini dan jika sekiranya terdapat sebarang kemusykilan dan pertanyaan boleh menghubungi pihak kami.

Sekian, terima kasih.

"BERKHIDMAT UNTUK NEGARA"


**"PENYAYANG, BEKERJA BERPASUKAN DAN PROFESIONALISMA
ADALAH BUDAYA KERJA KITA"**

Saya yang menurut perintah,



(DR. HJ. MOHTAR BIN PUNGUT @ HJ. AHMAD)
Pakar Kesihatan Awam
No Pendaftaran MMC : 32017
Pegawai Kesihatan Kanan
Pejabat Kesihatan Segamat.

Kami Sedia Membantu
Penyayang • Profesionalisme • Kerja Berpasukan



Appendix 11 – FELDA Kemelah permission letter for research



PEJABAT FELDA KEMELAH
Felda Kemelah, 85040 Segamat, Johor Darul Ta'zim.
Tel/ Fax: 07-9451233

Rujukan Kami : Bil (03) 3030/ 1-1-1 Pt. 4
Rujukan Tuan:

Tarikh : 08 April 2015

Pengurus SEACO
146, Jalan Sia Her Yam,
Suite 601-604, Wisma Centrepoint,
85000 Segamat,
Johor Darul Takzim.
(UP: HAJI NINGGAL BIN BABA)

Tuan/Puan,

**PER : KEBENARAN MENJALANKAN KAJIAN BEBANAN EKONOMI
TERHADAP PESAKIT DIEBETES DI FELDA KEMELAH**

Perkara di atas adalah dirujuk.

2. Sukacita dimaklumkan pihak pengurusan rancangan tiada halangan dan membenarkan wakil dari SEACO untuk menjalankan kajian di Felda Kemelah bermula dari 14.04.2015 hingga 30.09.2015.

3. Senarai nama adalah seperti berikut :-

Bil	Nama	No. Telefon
1.	HAJI NINGGAL BIN BABA	019-7487322

Sekian, terima kasih.

Yang benar,

()
ISHAK BIN HASSAN
Pengurus
Felda Kemelah
85040 Segamat, Johor.

s.k - Fail

Appendix 12 - FELDA Medoi permission letter for research



PEJABAT FELDA MEDOI
85050 SEGAMAT, JOHOR DARUL TA'ZIM.
TEL/FAX : 07-9311376

Rujukan Kami Bil : (202)3031/1-1-1 PT.3
Tarikh : 13 April 2015

Kepada,
Pengurus SEACO
146 Jalan Sia Her Yam,
Suite 601-604 Wisma Centrepont
85000 Segamat, Johor.

Tuan,

**KEBENARAN MENJALANKAN KAJIAN BEBANAN EKONOMI
TERHADAP PESAKIT DIABETES DI FELDA MEDOI**

Dengan segala hormatnya surat tuan bertarikh 6 April 2015 adalah dirujuk.

2. Pihak pengurusan merakam ucapan terima kasih diatas pemilihan Felda Medoi sebagai Projek Kajian dari pihak tuan.
3. Sukacita dimaklumkan pihak pengurusan rancangan memberi kebenaran kepada pihak SEACO menjalankan kajian bebanan ekonomi terhadap pesakit diabetes yang tinggal di Felda Medoi mulai 6 April 2015 sehingga 30 September 2015.

Sekian, terima kasih.

Saya Yang Menurut Perintah

(Hj. Mohamad Yasin bin Sardi)



PENGURUS
FELDA MEDOI
85050 SEGAMAT,
JOHOR DARUL TA'ZIM

Appendix 13 – Journal manuscript: *Collecting poverty impact-related cost data on diabetes: an experience in using health and demographic surveillance systems and electronic data capture in Malaysia* (Health Policy and Planning)

Authors : Cheah JCH^{1,2}, Reidpath DD^{1,2,3}, Jahan NK^{1,2}, Allotey PA^{1,2,4}

Name : Julius Cheah Chee Ho (JCH)*

Email : Chee.Cheah@monash.edu

Name : Daniel D Reidpath (DDR)

Email : daniel.reidpath@icddr.org

Name : Nowrozy Kamar Jahan (NKJ)

Email : nowrozy.jahan@monash.edu

Name : Pascale A Allotey (PAA)

Email : pascale.allotey@unu.edu

**Corresponding author*

Institution affiliations:

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²South East Asia Community Observatory, 6th Floor, Wisma Centrepont, Jalan Sia Her Yam, 85000 Segamat, Johor, Malaysia.

³Health Systems and Population Studies Division, icddr,b, 68, Shaheed Tajuddin Ahmed Sarani Mohakhali, Dhaka 1212, Bangladesh

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Abstract

Collecting high-quality data to estimate the impact of health expenditures on poverty can be challenging in low and middle-income countries due to the lack of standard approaches and complexities between research design and fieldwork practicalities. In this paper, reflect on our experience in collecting patient cost data in a Health and Demographic Surveillance System (HDSS) and the use of electronic data capture (EDC). We used a case study approach to systematically explore the implementation of our data collection methods and analyze the potentials and challenges encountered to inform others in future similar studies. HDSS may improve the data collection process and data quality for collecting household out-of-pocket cost data. With a longitudinal cohort and regular collection of socioeconomic data, HDSS presents a potential study site to conduct cost-of-illness, economic burden studies, and poverty impact evaluations, as well as opportunities to observe long-term effects of seasonality on expenditure, particularly in rural communities. A readily-available pool of trained data collectors with strong community relationship can potentially improve household access, response rate, and reduce responder bias. Data quality can be improved with the use of EDC through tablet computers, where data can be entered, reviewed, and analyzed in real-time to identify discrepancies.

(200 words)

Key words: poverty impact data, health and demographic surveillance system, electronic data capture

Main text

Introduction

The collection of data to measure the impact of policy shifts on catastrophic spending and impoverishing healthcare expenditure can be challenging in low-and middle-income countries (LMIC). The primary issue relates to the interaction between the research design and the pragmatics of data collection in resource-limited settings [Sweeney et al., 2016].

Macro-level surveys, such as the World Bank's Living Standards Measurement Survey, are commonly used for reporting the poverty impact of health expenditure at the national level. However, there are known limitations in capturing essential aspects of the poverty impact of illness particularly as they relate to indirect costs or income loss [Saksena et al., 2014].

Poverty impact data are also collected in intervention and economic evaluations, but the data collection method, particularly in LMIC settings lack methodological standardisation including standardisation of data sources, sampling methods, and the parcel of cost items used to measure poverty impact [Barter et al., 2012; Tanimura et al., 2014; Kankeu et al., 2013; Alam and Mahal, 2014; McIntyre et al., 2006]. The lack of standardised data collection can lead to challenges in assessing the comparability, quality, and accuracy of findings [Gibbs, 2007]. Such a mix of approaches may stem from limited practical guidance or standards for collecting patient-incurred cost data.

In economic evaluations, reporting guidelines tend to address provider perspectives and are missing poverty impact metrics. They placed considerable emphasis on measuring outcomes and the policy implications, and lack guidance when it comes to data collection constraints that require compromise, such sample size limitations or shortening questionnaire length [Alam and Mahal, 2014; Drummond and Jefferson, 1996; Husereau et al., 2013; Noben et al., 2016]. Consequently, the choice for a collection method for resource use cost data is often a matter of discretion based on convenience and practicality instead of structured methodological considerations.

Accurate and effective data capture of patient costs and income requires identifying relevant data sources, a clear protocol for survey administration, using suitable data collection tools and medium of recording, a conducive interview location, and experienced data collectors [Sweeney et al., 2016]. Numerous studies have presented empirical results [Ng et al., 2009; Wiseman et al., 2015; Phung et al., 2005; Walther et al., 2011], in contrast, the purpose of this paper is to reflect on our experience collecting patient cost data in a Health and

Demographic Surveillance Systems (HDSS) and the use of electronic data capture (EDC), and the methods for recording. We used a case study approach to explore the implementation of our data collection methods systematically, and analyze the potentials and challenges encountered in the process to inform other researchers engaging in future similar studies.

Study approach and methods

We conducted a cross-sectional, prevalence-based cost-of-illness study where cost was measured from the household perspective. The study aimed to investigate the economic burden and poverty impacts on households of managing diabetes in a rural setting in Malaysia. The study was conducted in the South East Asia Community Observatory (SEACO), a health and demographic surveillance system (HDSS) located in the Segamat district in Malaysia. SEACO captures detailed longitudinal information related to health and disease among individuals and families through a regular collection of socio-demographic and health measures among individuals, and providing a research platform for focused studies on issues related to health within the community. It enumerated 44,902 individuals living in 13,355 households in the baseline enumeration conducted over 2012–13. Our study population was selected from the SEACO database where a total of 327 households with people living with diabetes were identified [Partap et al., 2017]. We selected sub-populations from one semi-urban (Sungai Segamat sub-district) and one rural (Bekok sub-district) area as points of contrast.

We used a bottom-up costing approach to collect household out-of-pocket expenditure for the management of diabetes. The approach captured both direct and indirect costs and assessed the poverty impacts concerning catastrophic healthcare expenditure (CHE) and impoverishment. The implications of the economic burden of diabetes management on the daily lifestyle of the households and the use of coping strategies were explored qualitatively. We implemented a sequential, mixed methods approach in two phases. In phase one, we conducted a household survey to map out the cost components of out-of-pocket expenditure on diabetes. Three cost components were collected: direct medical cost (treatments sought, self-management); direct non-medical cost (travels, meals, hiring caregivers); and indirect cost (loss of income of both caregiver and person with diabetes). Households that experienced CHE formed the sample population for phase two qualitative research. Purposive sampling was used to identify respondents for in-depth interviews and focus group discussions (FGD).

Findings and discussion

Quality of data collectors

Previous studies have shown that the competency of the data collectors can substantially affect the quality of the data [Sweeney et al., 2016]. Information on personal income and expenditure, for instance, is commonly considered private and sensitive and it is commonly either under- or over-reported; and the bias is particularly likely if the purpose of the interview is not well understood by the respondents [Morris et al., 2000]. When conducting our study, we have access to a trained team of local data collectors who have strong engagement with the community, familiar with local cultural nuances, and experienced in conducting interviews with electronic tablets. In addition, data collection processes in HDSS sites such as SEACO are well-structured and established, with conformity to ISO 9001 certification [Partap et al., 2017].

The data collection team also reviewed the questionnaire and field tested it to prove community feedback prior to commencing the formal field work. The strategy helped to improve the content of the questionnaire and, more particularly, the flow of the questions. Our experience of the process was consistent with the study by Kufa et al. (2014) which showed that using trained interviewers who understand the principles and rationale for collecting patient costs significantly improved the quality of the data that are elicited. Similarly, Lievesley (1986) and Couper and Groves (1992) have also found that interviewers' survey experience is positively correlated with the response rate.

Data collection setting

There may also be differences in the data quality depending on where the data collection takes place. A formal setting such as a health facility or research office may lead to non-response bias or inaccurate answers due to pressure or stigma and lack of perceived privacy to disclose details on income and spending [Sweeney et al., 2016]. In our study, we tried to minimize non-response associated with the interview location by surveying a private setting at the respondent's home, or at community centers where respondents would feel most comfortable. Interviews were also conducted in the SEACO office, where regular community meetings and engagement activities take place. The choice of location was driven by the respondents' comfort and needs.

Data collection time frame

The appropriate timing to conduct the survey is an important aspect affecting data quality, specifically on response rate and recall bias [Phung et al., 2015]. The former was demonstrated in the study by Wiseman et al. (2005) [9] on the usage of patient cost diary, where 38% of their respondents preferred to keep their cost diaries for less than six months, citing disruptions during farming seasons. The issue of recall bias was also evident in the study by Beegle et al. (2012) [19] where the time difference between cropping period and interview sessions was a key factor leading to recall bias. Thus the interviews about health care costs should be near contemporaneous to avoid the problem of recall bias, but timed appropriately so as not to clash with other commitments.

Due to time and resource constraints, part of our questionnaire survey was inevitably conducted during the fasting month of Ramadan, and this has affected the availability and response of Muslim respondents who are the majority population. In this instance, through the DHSS site we are able to trace missed respondents accurately conduct follow up visits at a later time after Ramadan to complete the survey.

Data collection tool

We employed Electronic Data Capture (EDC) using the Open Data Kit (ODK; www.opendatakit.org) application on an Android (Google Inc.) platform in a 7-inch tablet computer (Samsung Galaxy Tab 7.0) as our primary tool for data collection. On the backend, a secured server hosted the database that allows for real-time data review and validation checks. Known issues in LMIC settings on the usage of EDC mainly relate to operational feasibility in the field, such as availability of infrastructures for internet connectivity and the more technical training required for data collectors [Walther et al., 2011].

We have had a positive experience of using EDC in our study. Without having to manually write down survey responses and embedding skip logics in the questionnaire, our data collection process was expedited. This led to shorter survey length, which could minimise survey fatigue [Sweeney et al., 2016]. The collected data was uploaded weekly at the SEACO office where internet is available, omitting the need for manual data entry from paper to the database, and lowering the risk of missing data due to missing questionnaire forms. In addition, short data entry period from the time of survey to the database was also found to improve data quality [Glewwe and Dang, 2008]. We also tried to validate income data by

cross-referencing it with expenditure data, which are considered more reliable [Xu et al., 2005] by observing any instances where expenses were reported to be higher than income. This process was greatly facilitated through the use of electronic data collection, where data can quickly be viewed and checked in the server database. Households with discrepancies in income data were identified, and the data collection team made a revisit to the particular household to do a follow-up interview and any data correction.

Internet connectivity did not pose as a major challenge, as the e-questionnaire can be conducted offline without interruption. Also, once the data has been uploaded, data checks can be immediately performed to check for completeness and detect data entry errors. If discrepancies were found, data collectors were prompted to revisit the affected households to update or redo the survey.

One notable issue we encountered using EDC was the longer preparation time needed for designing and testing the questionnaire as compared to conventional manual forms. Similar challenges are noted in other studies, in addition to the need for technical expertise in programming and database development, which may not be readily available in low-income settings [Walther et al., 2011]. Nonetheless, a well-designed EDC has the potential to be more time-effective and accurate compared to conventional paper-based data collection.

Building community trust

A critical factor in the success of collecting accurate cost data is the level of trust between the researchers and data collectors, and the community [Wiseman et al., 2015]. Trust is an essential element in HDSS sites generally to maintain and conduct numerous longitudinal studies over long periods of time. This requires consistent community engagement to build the levels of trust, which also facilitates a consistent, high response rate (above 80%) [Allotey et al., 2014]. Through extensive community engagement programs involving community leaders and members as part of their research projects [Partap et al., 2017; Allotey et al., 2014], SEACO has established a long-term presence and familiarity within the Segamat community. This supports our household access and the collection of data with minimal issues.

Conclusion

From our field experience, we found that collecting household cost data through HDSS site may improve the data collection process and data quality. With the availability of population census data, households with diabetes can be quickly and easily identified for researchers to interview whole populations or samples. With a stable longitudinal cohort and an experienced team of local data collectors, HDSS sites can also potentially provide advantages in reducing non-response and non-sampling errors, particularly concerning coverage error and responder bias as whole populations are mapped and households are regularly engaged.

Data quality can be improved with the use of EDC, where data can be entered, reviewed, and analyzed in real-time. Immediate access to the database enables households with data discrepancies to be identified and revisits to be done quickly to clarify possible data errors, in addition to providing time and cost-savings as compared to paper surveys when data checks are done after completing data entry.

Current poverty impact studies on health are mostly extensions of clinical trials or health intervention studies. As HDSS sites regularly collect socioeconomic data of income and expenditure longitudinally, it provides a potential research platform to conduct cost-of-illness or economic burden studies and poverty impact evaluations. Cost data should also ideally be collected prospectively (such as using patient cost diary) to minimize recall bias, and a longitudinal cohort in HDSS sites can help to place events in a broader social, economic and political context. For example, the ability to observe and explore the effect seasonality has on expenditure, particularly in poor rural communities.

While our study provides a snapshot of costs incurred in a particular year, incidence-based studies coupled with modeling techniques are needed to estimate lifetime costs. Such studies will give a more accurate understanding of the lifetime costs of diabetes, and the savings accrued from intervening at different disease stages. HDSS could act as platforms through which such studies are implemented as systems for following up individuals are already in place.

List of abbreviations

CHE: catastrophic healthcare expenditure

EDC: electronic data capture

HDSS: health and demographic surveillance system

LMIC: low-and middle-income countries

SEACO: South East Asia Community Observatory

Declarations

Ethics approval and consent to participate

The study was approved by Monash University Human Research Ethics Committee (MUHREC)(CF14/2053 – 2014001075). The study was embedded as a research project in the SEACO platform, which has obtained ethical clearance from MUHREC in the ways in which household in Segamat will be engaged and approach for data collection. Informed consent was sought from participants in both the qualitative and quantitative interviews in their preferred languages. The purpose of the study, the procedures involved as well as the risks and benefits of participating were explained. Respondents were aware that their participation was voluntary and that they were able to withdraw at any point during the study.

Consent for publication

Not applicable.

Availability of data and material

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

JCH, DDR, PAA designed the study. DDR, PAA, and NKJ supervised the study. JCH conducted the study and wrote the initial draft manuscript. DDR and NKJ revised the

manuscript. JCH, NKJ, DDR finalized the manuscript. All authors read and approved the final manuscript.

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References

1. Alam K, Mahal A. Economic impacts of health shocks on households in low and middle income countries: a review of the literature. *Globalization and Health*. 2014. 10:21.
2. Allotey P, Reidpath DD, Devarajan N, Rajagopal K, Yasin S, Arunachalam D, et. al. Cohorts and community: a case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. *Glob Health Action*. 2014. 7:23176.
3. Barter DM, Agboola SO, Murray MB, Barnighausen T. Tuberculosis and poverty: the contribution of patient costs in sub-Saharan Africa – a systematic review. *BMC Public Health*. 2012. 12:980.
4. Beegle K, De Weerd J, Friedman J. Methods of household consumption measurement through surveys: experimental results from Tanzania. *Journal of Development Economics*. 2012. 98: 3–18.
5. Couper M, Groves RM. The role of the interviewer in survey participation. *Survey Methodology*. 1992. 18(2), 263–277.
6. Drummond M, Jefferson T. Guidelines for authors and peer reviewers of economic submissions to the BMJ. *BMJ*. 1996;313(7052):275–83.
7. Gibbs G. Analyzing qualitative data. *The Sage qualitative research kit*. 2007
8. Glewwe P, Dang HA. The impact of decentralized data entry on the quality of household survey data in developing countries: Evidence from a randomized experiment in Vietnam. *The World Bank Economic Review*. 2008. 22(1), 165–185.
9. Husereau D, Drummond M, Petrou S et al. Consolidated health economic evaluation reporting standards (cheers) statement. *Int J Technol Assess Health Care*. 2013;11(6).

10. Institute for Public Health. National Health and Morbidity Survey 2015 (NHMS 2015). Vol. II: Non-Communicable Diseases, Risk Factors & Other Health Problems. Ministry of Health Malaysia. 2015.
11. Kankeu HT, Saksena P, Xu K, Evans DB. The financial burden from non-communicable diseases in low- and middle-income countries: a literature review. *Health Research Policy and Systems*. 2013. 11:31
12. Kufa T, Hippner P, Charalambous S, Kielmann K, Vassall A, Churchyard GJ, et. al. A cluster randomised trial to evaluate the effect of optimising TB/HIV integration on patient level outcomes: the 'MERGE' trial protocol. *Contemporary Clinical Trials*. 2014. 39: 280–7.
13. Lievesley, D. Unit non-response in interview surveys. London: SCPR. 1986.
14. McIntyre D, Thiede M, Dahlgreen G. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts? *Social Science and Medicine*. 2006. 62: 858–65.
15. Morris SS, Carletto C, Hoddinott J, Christiaensen LJM. Validity of rapid estimates of household wealth and income for health surveys in rural Africa. *Journal of Epidemiology and Community Health*. 2000. 54: 381–7.
16. Ng N, Minh HV, Juvekar S, Razzaque A, Bich TH, Kanungsukkasem U, et al. Using the INDEPTH HDSS to build capacity for chronic non-communicable disease risk factor surveillance in low and middle-income countries. *Global Health Action*. 2009. Supplement 1.
17. Noben CY, De Rijk A, Nijhuis F et al. The exchangeability of self-reports and administrative health care resource use measurements: Assessment of the methodological reporting quality. *J Clin Epidemiol* [Internet]. 2016;74:93–106.
18. Partap U, Young EH, Allotey P, Soyiri IN, Jahan N, Komahan K, et. al. HDSS Profile: The South East Asia Community Observatory Health and Demographic Surveillance System (SEACO HDSS). *International Journal of Epidemiology*. 2017, 1370–1371.
19. Phung TD, Hardeweg B, Praneetvatakul S, Waibel H. Non-Sampling Error and Data Quality: What Can We Learn from Surveys to Collect Data for Vulnerability Measurements? *World Development*. 2015. Vol. 71, pp. 25–35.
20. Saksena P, Hsu J, Evans D. Financial Risk Protection and Universal Health Coverage: Evidence and Measurement Challenges. 2014. *PLoS Med*. 11(9).
21. Sweeney S, Vassal A, Foster N, Simms V, Ilboudo P, Kimaro G, et. al. Methodological issues to consider when collecting data to estimate poverty impact in

- economic evaluations in low-income and middle-income countries. *Health Econ.* 2016. 25(Suppl. 1): 42–52.
22. Tanimura T, Jaramillo E, Weil D, Raviglione M, Lonnroth K. Financial burden for tuberculosis patients in low- and middle-income countries: a systematic review. *Eur Respir J.* 2014. June; 43(6):1763-75.
23. Walther B, Hossin S, Townend J, Abernethy N, Parker D, Jeffries D. Comparison of Electronic Data Capture (EDC) with the Standard Data Capture Method for Clinical Trial Data. *PLoS ONE.* 2011. 6(9): e25348.
24. Wiseman V, Conteh L, Matovu F. Using diaries to collect data in resource-poor settings: questions on design and implementation. *Health Policy Plan.* 2015. Nov; 20(6):394-404.
25. Xu K. Distribution of health payments and catastrophic expenditures: Methodology. World Health Organization. 2005

Appendix 14 – Journal manuscript: *Financial catastrophe from non-communicable diseases: a case study on the economic burden of diabetes on households in Malaysia*
(Journal of Public Health Policy)

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Abstract

Out-of-pocket healthcare payments can impoverish families and drive a vicious cycle of poverty and disease. Using a mixed-methods approach conducted in a demographic health surveillance site in Malaysia, we investigated the economic burden of households living with chronic diseases. Direct medical cost was found to be the largest cost component (63.4%), followed by direct non-medical cost (20.6%) and indirect cost (16.1%). Despite having a Universal Health Coverage-based healthcare system, 19.9% of Malaysian households with diabetes in the study experienced catastrophic healthcare spending. Households in higher income quintiles incurred higher catastrophic spending, driven by inadequacies in public healthcare to seek private care. Our study may provide insights to design healthcare financing systems with enhanced financial risk and social protection that can effectively manage chronic diseases in the long-term.

Keywords: non-communicable disease, economic burden, household, out-of-pocket payment, catastrophic healthcare expenditure

Introduction

Non-communicable diseases (NCD) impose substantial financial costs on the individual and households. Long-term care is resource-intensive and requires access to a wide range of health services and a continuous supply of medicines (1). The need for large out-of-pocket (OOP) health care payments can lead to catastrophic healthcare expenditures (CHE) that could impoverish families. It drives a vicious cycle that spirals families towards poverty, where poverty in turn exposes people to behavioural risk factors for NCD (2).

A substantial volume of literature exists on the economic impact of NCDs on households in high-income countries (3–5), and increasing studies are examining the implications of NCDs in low and middle-income country (LMIC) settings (6,7). At the household and individual level, studies in LMICs have shown that both direct and indirect costs of chronic conditions can be high, imposing catastrophic healthcare spending on patients and families (8–10) and reducing their capacity to spend in other areas (11). Affordability and access to NCD treatments remain as one of the key challenges facing national governments achieving Universal Health Coverage (UHC), a critical enabler for achieving good health outcomes for all, and a necessary part of the global and national health and development frameworks (12). One of the key elements of UHC is to put in place a health financing system that protects the population against the financial hardships when accessing healthcare, which can place households at risk of CHE and impoverishment from medical expenses (2).

The experience from high-income countries indicates that even in health systems that are recognised for having achieved UHC, households living with chronic conditions particularly in low socioeconomic groups still shoulder substantial economic burden (13). The worsening prevalence of NCDs in LMICs, coupled with associated high costs for treatment and long-term management (requiring preventive, curative, and supportive care) raises the critical issue of health equity and adequacy of financial risk protection. Even for health systems with universal coverage, efforts to address NCDs are hampered by developmental priorities inclined towards increasing marketization of health services and expansion of private care (14). The aim of the study was to investigate the economic burden for households living with NCD in Malaysia, a middle-income country with a UHC-based healthcare system using diabetes as a tracer disease.

Methods

Study site

The study was conducted in the South East Asia Community Observatory (SEACO), a health and demographic surveillance system (HDSS) located in the Segamat district in Malaysia. SEACO enumerated 44,902 individuals living in 13,355 households in the baseline enumeration conducted over 2012–13 (15). The study population was selected from the SEACO database where a total of 327 households with people living with diabetes were identified. We selected sub-populations from one semi-urban (Sungai Segamat sub-district) and one rural (Bekok sub-district) area as point of contrast.

Study design

We conducted a cross-sectional, prevalence-based cost-of-illness study where we measured cost from the household perspective. We used a bottom-up costing approach to collect household out-of-pocket expenditure for the management of diabetes. The approach captured both direct and indirect costs and assessed the poverty impacts concerning catastrophic healthcare expenditure (CHE) and impoverishment. The implications of the economic burden of diabetes management on the daily lifestyle of the households and the use of coping strategies were explored qualitatively.

A household survey was conducted using an electronic questionnaire to map out the cost components of out-of-pocket expenditure on diabetes. Three cost components were collected: direct medical cost which include outpatient and inpatient treatment, consumption of traditional and complementary medicine (TCM), self-monitoring of blood glucose (SMBG), and diabetes related self-care medical supplies (e.g. insulin pen needles, bandages, antiseptics, gauze); direct non-medical cost consists of transportation, meals, hiring of external caregivers); and indirect cost relates to the loss of income of both caregiver and person with diabetes).

Data analysis

The cost of illness was calculated based on the reported cost items, with the mean cost for each cost item estimated based on the overall respondent population. Recall periods for outpatient and inpatient cost items were three months and twelve months respectively. Spending for traditional and complementary medicine, SMBG, self-care medical supplies,

and hired caregivers were on a monthly basis. The Human Capital Approach was used for estimating indirect costs. Forgone income due to managing diabetes for the household was captured by estimating the time absent from work times the average personal take home earning per day. The national minimum wage of RM960 per month (16) was used as the proxy measurement. Cost data expressed in US Dollars followed the currency exchange rate of Ringgit Malaysia 1 to USD0.235 (Central Bank of Malaysia, 11 June 2020).

All cost items were adjusted to a monthly figure following the World Health Organisation's (WHO) methodology for estimating the catastrophic healthcare expenditure (17). Adjustment for positively skewed cost data was done through statistical bootstrapping on the mean. The distribution of diabetes-related out-of-pocket expenditure between quintile groups was mapped out based on the household income of the study population. The formula for calculating CHE was based on WHO's methodology on the distribution of health payments and catastrophic expenditures. CHE occurs when a household's total OOP health payments equal or exceed 40% of the household's capacity to pay (17).

All statistical analyses were performed by using *R statistical package* version 3.5.1 (The R Foundation for Statistical Computing). Univariate analyses of all variables were calculated and graphed to examine the distribution of the data and check for outliers. Descriptive statistics such as frequencies, percentages, means, ranges and standard deviation were used to describe socio-demographic and healthcare utilisation data. The bootstrap was used to estimate the standard deviation to adjust for positively skewed cost data. Categorical variables are expressed in absolute numbers and percentages. We calculated the interclass correlation of patient clustering in households, and found that the statistical impact was small and non-significant, indicating that the analyses could be conducted without adjusting for a clustering effect.

For comparing baseline characteristics between CHE and non-CHE groups, independent sample t-test was used to estimate the significance difference between the two groups. The variables tested included socio-demographic (age, gender, education level, place of residence, number of household members), household economy (employment, household income, household expenditure), and disease condition (duration of diabetes, level of diabetes care, having co-morbidities, having diabetes-related complications). For non-normal distribution, the Kruskal-Wallis test was used, and the median and inter-quartile range was reported. Chi-

square test was conducted to test the significance in the difference in proportions between the two sub-districts across income quintiles. A p-value of ≤ 0.05 was regarded as statistically significant for the rejection of the null hypothesis..

Results

Socio-demographic characteristics

The mean age of the respondents was 63.4 (SD 11.1, min 29, max 87), with a majority (67%) of them over 60 years old, and a relatively few (1.8%) in the younger age category (age 18-39). Females with diabetes are more prevalent, accounting for 66%, and the population consisted mainly of Chinese and Malays (42.5% and 45.9% respectively), together with a smaller community of Indians (9.8%) and the Orang Asli (1.5%). In terms of place of residence, it was almost equally spread between rural (Bekok, 50.8%) and urban (Sg. Segamat, 49.2%). In terms of education level, most of the respondents in Sg. Segamat and Bekok (52.3%) only attended primary school, 14.7% of them reported having no formal education, and less than 3% of them attended university or obtained a professional certification. In terms of employment, slightly more than one-fifth (22.3%) has reported having current employment. The reported median monthly household income was RM1,500, and the median household spending was RM1,000.

Disease status

In terms of disease status, respondents in the two sub-districts have been living with diabetes for an average of 99 months (min 10, max 444). A total of 77 (23.5%) respondents reported having at least one diabetes-related complication. From this total, seven (9.1%) respondents reported to have one complication, five reported to have two complications (6.5%), and two reported to have three or more complications (2.6%). The remaining 63 (81.8%) were unable to specify the diabetes-related complications they have.

A total of 22 (6.7%) respondents in the study recorded seeking secondary care treatment for diabetes-related complications. These include microvascular (diabetic foot from neuropathy, retinopathy, and nephropathy) and macrovascular (cardiovascular issues) complications, as well as syncope due to hypoglycaemia. A majority of the respondents (79.3%) also reported a wide range of chronic co-morbidities, with the top three most common being hypertension (90%), vision problems (43.1%), and joint pain (34.6%). Out of those having co-morbidities,

80.3% of them have between one and three other chronic diseases, while the remaining 19.7% have more than three chronic diseases.

Household cost of diabetes

Table 1 outlined the estimated overall cost burden of diabetes. Overall, we found that households spent an average of RM93.1 (SD 14.2) (USD21.9) monthly OOP spending to manage diabetes. The largest cost component was direct medical cost, which amounted to an average of RM59.0 (SD8.5) (USD13.9) and accounted for two-thirds (63.4%) of the total monthly OOP cost. The high proportion of direct medical cost was mainly driven by spending on monthly consumable items, i.e., blood glucose monitoring and purchase of alternative care products (supplements and traditional medicine) at RM14.2 (SD1.5) (USD3.3) and RM20.8 (SD2.3) (USD4.9) respectively. Direct non-medical cost was the second-highest cost component, accounting for one-fifth (20.6%) of the total cost with an average monthly spending of RM19.1 (SD6.2) (USD4.5). Total average indirect cost was found to be the lowest, accounting for 16.1% with an average amount of RM15.0 (SD4.3) (USD3.5).

Table 1 – Estimated overall cost burden of diabetes

		Mean (RM)*	Standard Deviation	Range	Standard Error	
Direct medical cost	231	59.0	8.5	61.1	0.09	63.4
Outpatient care	159	12.7	1.7	13.07	0.02	
Inpatient care	5	11.3	7.1	45.54	0.07	
Alternative care (supplements & traditional medicine)	138	20.8	2.3	17.15	0.02	
Self monitoring of blood glucose	102	14.2	1.5	11.87	0.02	
Direct non-medical cost	175	19.1	6.2	48.38	0.06	20.6
Outpatient transportation	171	4.9	0.4	2.86	0	
Inpatient transportation	5	0.9	0.7	4.24	0.01	
Outpatient food/meals†	105	3.5	0.7	5.64	0.01	
Formal caregiver	3	9.8	5.9	41.59	0.06	
Indirect cost‡	113	15.0	4.3	31.67	0.04	16.1
<i>Diabetic loss of income</i>						
Income loss (outpatient)	73	6.7	0.9	6.56	0.01	

Income loss (inpatient)	2	5.7	4.0	31.22	0.04	
Caregiver cost						
Income loss of informal caregiver	45	2.6	0.8	6.48	0.01	
Overall patient cost per month		93.1	14.2	113.42	0.14	100

*Mean was estimated based on the total respondent of 327. Statistical bootstrap was conducted to estimate the standard deviation for positively skewed cost data

†Inpatient food was provided for by the hospital

‡Respondents who reported to have employment

In terms of the distribution of economic burden across sub-population groups (Table 2), we found that the lowest income group spent less overall (average of RM48.6, SD12.6 (USD11.4)) compared to the richest income group (average of RM214.5, SD67.9 (USD50.4)). Conversely, the lowest income group incurred the highest proportion of OOP spending from total household income (12.1%), and this proportion has a downward trend as household income increases. OOP expenditure also increases by income quintile. The richest quintile (Q5) on average spent four times more than the poorest quintile (Q1). However, as a percentage of total household income, the poorest group spent more than twice as much as on managing diabetes than the richest group.

Table 2: Mean household income and expenditure across income quintiles

	Mean spending	Standard deviation	CI (95%)	Mean income	% OOP of income
Quintile 1	48.6	12.6	45.6 - 51.6	402.4	12.1
Quintile 2	43.3	6.2	41.8 - 44.8	959	4.5
Quintile 3	98.8	26.7	92.5 - 105.1	1393	7.1
Quintile 4	102.5	27.1	96.3 - 108.7	2016.4	5.1
Quintile 5	214.5	67.9	196.0 - 232.9	3880.4	5.5

The overall prevalence of catastrophic healthcare expenditure was found to be 19.9% (65 households), with households in the lower-income group (quintile 1) incurring less catastrophic spending as compared to wealthier households (quintile 3 and 4).

In terms of association between CHE and socio-demographic variables (Table 3), the place of residence ($p < 0.001$) was found to be significantly associated with CHE; with more households are experiencing CHE in the town area of Sg. Segamat (75.4%) compared to rural Bekok (25.6%). Ethnicity was found to be significant with CHE ($p < 0.001$), and the Malay community has the highest prevalence of CHE (72.3%) compared to other ethnic groups. Households experiencing CHE tend to spend less overall for the household, given the lower capacity to pay as compared to households without CHE.

We found that respondents who received secondary care for diabetes ($p = 0.024$) were significantly associated with household having CHE. Out of the many types of diabetes treatment sought, only the consumption of supplements ($p = 0.043$) was revealed to have a significant association with CHE. In contrast, no relation was found for standard of care treatments available in the healthcare service, namely lifestyle modification, oral anti-diabetics medication, and insulin therapy (Table 3).

Table 3: Baseline characteristics of CHE and non-CHE households

Baseline characteristics	Non-CHE	CHE	p-value
Social demographic			
Overall diabetics	262	65	
Age (mean (SD))	63.08 (11.07)	64.45 (10.99)	0.373
Number of household members (median [IQR])*	3.00 [2.00, 5.00]	3.00 [2.00, 4.00]	0.79
Residence, n(%)			<0.001
Sungai Segamat (town)	112 (42.7)	49 (75.4)	
Bekok (rural village)	150 (57.3)	16 (24.6)	
Gender n(%)			1
Male	90 (34.4)	22 (33.8)	
Female	172 (65.6)	43 (66.2)	
Ethnicity, n(%)			<0.001
Malay	103 (39.3)	47 (72.3)	
Indian	25 (9.5)	7 (10.8)	
Chinese	129 (49.2)	10 (15.4)	
Orang Asli	4 (1.5)	1 (1.5)	
Others	1 (0.4)	0 (0.0)	

Education level, n(%)			0.202
Not attended	42 (16.0)	6 (9.2)	
Primary	135 (51.5)	36 (55.4)	
Secondary	79 (30.2)	20 (30.8)	
Tertiary	5 (1.9)	1 (1.5)	
Professional certification	1 (0.4)	2 (3.1)	
Having employment, n(%)			0.503
Yes	61 (23.3)	12 (18.5)	
No	201 (76.7)	53 (81.5)	
Overall household income (median [IQR])*	1300.00 [900.00, 2000.00]	1500.00 [1000.00, 1800.00]	0.654
Overall household spending (median [IQR])*	1000.00 [700.00, 1500.00]	600.00 [500.00, 800.00]	
Diabetes condition			
Years with diabetes (median [IQR])*	72.00 [36.00, 123.00]	60.00 [39.00, 130.00]	0.985
Having diabetes-related complications, n(%)			
Yes	56 (21.4)	21 (32.3)	0.09
No	206 (78.6)	44 (67.7)	
Receiving secondary care, n(%)			0.024
Yes	13 (5.0)	9 (13.8)	
No	247 (95.0)	56 (86.2)	
Having co-morbidities, n(%)			0.121
Yes	211 (80.5)	46 (70.8)	
No	51 (19.5)	19 (29.2)	

* Kruskal-Wallis test conducted for non-normal distribution. For the remaining findings T-test was performed

Table 4: Healthcare utilisation of CHE and non-CHE households

Healthcare utilisation	Non-CHE	CHE	p-value
Overall diabetics, n	262	65	
Types of diabetes treatment, n(%)			
Lifestyle modification (%)	134 (51.5)	26 (40.0)	0.127
Oral anti-diabetics (%)	238 (91.5)	56 (86.2)	0.278
Insulin therapy (%)	55 (21.2)	8 (12.3)	0.15

Traditional medicine (%)	37 (14.2)	9 (13.8)	1
Supplements (%)	35 (13.5)	16 (24.6)	0.043
Other treatments (%)	6 (2.3)	1 (1.5)	1
Place of treatment, n(%)			
Public care	233 (88.9)	57 (87.7)	0.949
Private care	33 (12.6)	11 (16.9)	0.476
Pharmacy	16 (6.1)	5 (7.7)	0.854
Traditional and complementary medicine establishments	6 (2.3)	0 (0.0)	0.475
Direct selling	6 (2.3)	3 (4.6)	0.547
Friends	1 (0.4)	1 (1.5)	0.856
Public care as first treatment place n(%)	256 (97.7)	62 (95.4)	0.547

* T-test was performed

Discussion

Our study findings revealed the magnitude of household economic burden from managing diabetes, and bring attention to the urgency to address potentially overlooked cost burdens chronic care imposes on households. Household welfare can be affected both in the short and long-term, given that OOP payments can lead to an immediate reduction in essential household items, and the borrowing of loans and sale of economically productive assets affect future household wellbeing.

Across a number of COI studies, the brunt of the cost burden was faced by those with lower incomes (18–21). However, in our study we found that households in higher income quintiles was driven to spend more OOP for care due to inadequacies of public healthcare services, which raises their risk of catastrophic health spending. From the healthcare financing perspective, this will also likely to further increase the overall proportion of OOP spending as part of national total health expenditure. This may further propagate an inequitable healthcare financing system, given that OOP is recognised a regressive resource of financing that do not achieve the benefits (both in terms of economies and financial risk protection) of pooled financing (2).

Our mapping of direct and indirect costs that households incur also highlights the critical cost components to focus on and their cost range. For managing NCDs such as diabetes, substantial costs may still incur for hospitalisation, home care (e.g. wound care, medical

equipment such as orthopaedic shoes, wheelchairs), medications (including TCM and insulin pen needles), and regular self-monitoring of blood glucose. Knowing the household consumption cost of these items may inform policy makers of the cost of implementing intervention or prevention programs that can effectively shield vulnerable populations from financial hardship, as well as avenues to reduce financial risk beyond low-income groups. Health financing strategies can also focus on these key cost components of NCDs care to minimize the cost impacts of NCDs on households.

Malaysia's existing tax-based health financing has been successful in providing universal care of a wide array of public health care services with extensive geographical coverage (14,22). However, our findings suggest that this may be insufficient to cater for the intensive resource demands of long-term care, and signals the need to explore innovative financing mechanisms to supplement existing financing sources. One potential financing mechanism is a progressive national health insurance scheme that maintains the same principle of risk pooling and prepayment as general taxation, with higher ability-to-pay groups contributing more proportionally to a ring-fenced health fund. In their modelling projections, Yu et al. (2011) (23) found that such a scheme has the potential to generate additional health funding for an enhanced healthcare package that can cater for chronic care, while preserving the equity in health care financing.

While UHC is still the health goal of many LMICs, those already with a universal or near-universal healthcare system may also consider looking beyond financial risk protection to incorporate broader social protection elements to enhance healthcare financing capacity. Even though measures towards minimization of out-of-pocket health care expenditures are essential for financial risk protection, they may not be sufficient. Social protection interventions designed to prevent or mitigate non-medical costs and income loss during the lengthy treatment may also be critical (24,25).

Our findings on poverty impact indicate a notable gap in financial risk protection for households with NCDs, which we consider to be unexpected given that Malaysia has universal health coverage provided through subsidized public provision funded by a progressive tax-based financing system (14). A similar scenario is also evident in Thailand, where despite implementing universal coverage policy, there are still poor households who persistently experienced catastrophe due to OOP spending for health care. Households with a

member who experienced chronic diseases were also found to have a greater likelihood of incurring catastrophic OOP spending on health (19). Mongolia is another example of a country that has extensive population health coverage through a combination of social insurance and subsidized public provision, but yet the population incurs a significant share of OOP spending for NCDs and faces the risk of CHE (26). These scenarios echo the findings by Saksena and Xu (2011) (11) on the impact of OOP for the treatment of NCDs in developing countries. The authors found that despite using different cut-points for defining financial catastrophe, the risks of suffering financial catastrophe as a result of OOP health payments were consistently higher for households with NCDs than other conditions. In addition, owing to the chronic nature of NCDs requiring long-term care, the households' longer-term financial status was also adversely affected through the accumulation of debt and other risk-mitigating strategies.

The main limitation of the study was the utilization of a cross-sectional study design. We are unable to determine for certain whether the catastrophic and impoverishing effects observed, and the coping strategies adopted by households occurred in a unit of time, or is it an aggregation of over a period. There has been arguments that the duration a household experiences catastrophic or impoverishing effects may be more critical than the incidence of the results in the population, particularly for NCDs which require lifelong care (27). Nonetheless, the believed that value of the evidence from cross sectional studies remains significant, as we can obtain the insights of the lived experience of people with chronic illness through the quantification of the burden across different income groups (28). In view of the number of important co-morbidities of diabetes or unobserved confounders, our estimated total costs of diabetes might overlap in part with the economic burden of other conditions causing diabetes. Our estimation of the cost of diabetes also did not take into account undiagnosed diabetes. The fact that people with diabetes already have complications at the time of diagnosis suggests that diabetes-related costs are present among the undiagnosed (29). While these individuals may not be receiving treatment for diabetes, they may be incurring additional healthcare costs compared to those without diabetes. As a result, it is highly likely that the aggregate costs associated with diabetes may have been underestimated, and the actual economic burden may have been even more substantial.

Conclusion

The demands of long-term care characteristics of NCDs place considerable strain on the healthcare system, draining healthcare resources that could affect the continuous provision of care, and undermine efforts for sustainable financing of UHC (12). At the household level, the poverty impacts of OOP payments for chronic care threaten affordability and access and directly affect household economic stability and wellbeing. Chronic diseases alongside ageing population have significant impacts on the pattern of health care needs, with implications for all aspects of a health service. It raises fundamental questions about the allocation of resources between the different levels of care, the roles of public and private health sectors, and the relative responsibilities of individuals and the formal health service in managing chronic disease (30).

NCD is threatening the core of UHC to provide equitable healthcare available for those who need it without risking financial hardship. While UHC is still very much a goal to pursue by many LMICs, middle-income countries with a readily established healthcare system with universal or near-universal coverage should begin efforts to look beyond financial risk protection to incorporate broader social protection elements. Measures towards minimizing OOP healthcare expenditures are essential for financial risk protection, but they may not be sufficient, particularly with regards to managing long-term care. Social protection interventions designed to prevent or mitigate non-medical costs and income loss during the lengthy treatment are also crucial (24).

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References

1. WHO. Global status report on noncommunicable diseases 2010. Geneva: World Health Organization; 2011.
2. World Health Organisation. The World Health Report: Health Systems Financing - the path to universal coverage. World Health Organization. 2010.

3. Lin JS, Resch SC, Brimmer DJ et al. The economic impact of chronic fatigue syndrome in Georgia: direct and indirect costs. *Cost Eff Resour Alloc.* 2011;9(1).
4. Schofield D, Passey M, Percival R et al. Retiring early with cardiovascular disease - impact on individual's financial assets. *Int J Cardiol.* 2010;9(2):125–6.
5. Langa K. Out-of-pocket health-care expenditures among older Americans with cancer. *Value Heal.* 2004;7:186–94.
6. Bloom DE, Cafiero ET, Jane-Llopis E et al. The global economic burden of noncommunicable diseases. *World Economic Forum.* Geneva; 2011.
7. Niessen LW, Mohan D, Akuoku JK et al. Tackling socioeconomic inequalities and non-communicable diseases in low-income and middle-income countries under the Sustainable Development agenda. *Lancet.* 2018;391:2036–46.
8. Barceló A1, Aedo C, Rajpathak S et al. The cost of diabetes in Latin America and the Caribbean. *Bull World Heal Organ.* 2003;8(1):19–28.
9. McIntyre D, Thiede M, Dahlgren G et al. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts? *Soc Sci Med.* 2006;62(4):858–65.
10. Seuring T, Archangelidi O, Suhrcke M. The Economic Costs of Type 2 Diabetes: A Global Systematic Review. *Pharmacoeconomics.* 2015;33(8):811–31.
11. Saksena P, Evans D, Xu K. Impact of out-of-pocket payments for treatment of non-communicable diseases in developing countries: A review of literature. Vol. Discussion, World Health Organization. 2011.
12. NCD Alliance. Ensuring health lives for all: Noncommunicable disease and Universal Health Coverage [Internet]. NCD Alliance. 2018. Available from: https://ncdalliance.org/sites/default/files/resource_files/UHC_and_NCDs_EN.pdf
13. Schoen C, Osborn R, Squires D. How health insurance design affects access to care and costs, by income, in eleven countries. *Heal Aff.* 2010;29:2323–34.
14. Chua H, Cheah J. Financing Universal Coverage in Malaysia: a case study. *BMC Public Health.* 2012;12(Supp 1).
15. Allotey P, Reidpath DD, Devarajan N et al. Cohorts and community: A case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. *Glob Health Action.* 2014;7:23176.
16. Khazanah Research Institute. The State of Households II. Khazanah Research Institute. 2016.
17. Xu K. Distribution of health payments and catastrophic expenditures: Methodology.

- World Health Organization. 2005.
18. Gillani AH, Aziz MM, Masood I, Saqib A, Yang CJ, Chang J et al. Direct and indirect cost of diabetes care among patients with type 2 diabetes in private clinics: a multicenter study in Punjab, Pakistan. *Expert Rev Pharmacoecon Outcomes Res.* 2018;18(6):647–53.
 19. Somkotra T, Lagrada L. Which households are at risk of catastrophic health spending: experience in Thailand after Universal Coverage. *Heal Aff.* 2009;28:467–78.
 20. Valtorta N, Hanratty B. Socioeconomic variation in the financial consequences of ill health for older people with chronic diseases: A systematic review. *Maturitas.* 2013;74:313–33.
 21. Loganathan T, Lee W, Lee K, Jit M, Ng C. Household Catastrophic Healthcare Expenditure and Impoverishment Due to Rotavirus Gastroenteritis Requiring Hospitalization in Malaysia. *PLoS One.* 2015;10(5):e0125878.
 22. Yasin S, Chan CKY, Reidpath DD et al. Contextualizing chronicity: A perspective from Malaysia. *Global Health [Internet].* 2012;8(4). Available from: <http://www.globalizationandhealth.com/content/8/1/4>
 23. Yu C, Whynes D, Sach T. Reform towards National Health Insurance in Malaysia: The equity Implications. *Health Policy (New York).* 2011;100:256–63.
 24. International Labour Organisation. *World Social Security Report 2010/11: providing coverage in times of crisis and beyond.* International Labour Organisation. 2010.
 25. Lönnroth K, Glaziou P, Weil D et al. Beyond UHC: Monitoring Health and Social Protection Coverage in the Context of Tuberculosis Care and Prevention. *PLoS Med.* 2014;11(9):e1001693.
 26. Dugee O, Palam E, Dorjsuren B, Mahal A. Who is bearing the financial burden of non-communicable diseases in Mongolia? *J Glob Health.* 2018;8(1):e010415.
 27. Goryakin Y, Suhrcke M. The prevalence and determinants of catastrophic health expenditures attributable to non-communicable diseases in low- and middle-income countries: A methodological commentary. *Int J Equity Health.* 2014;13(107).
 28. Jan S, Laba TL, Essue BM et al. Action to address the household economic burden of non-communicable diseases. *Lancet.* 2018;391:2047–58.
 29. Zhang Y, Dall TM, Mann SE et al. The economic costs of undiagnosed diabetes. *Popul Heal Manag.* 2009;12(2):95–101.
 30. Bloom G. Service delivery transformation for UHC in Asia and the Pacific. *Heal Syst Reform.* 2019;5(1):7–17.

Appendix 15 – Journal manuscript: *Economic burden of non-communicable disease: impacts and consequences of households living with diabetes in Malaysia* (Malaysian Journal of Medicine and Health Sciences)

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ABSTRACT

Introduction: Non-communicable diseases (NCD) impose substantial financial costs on the individual and households. Long-term care is resource-intensive and requires access to a wide range of health services and a continuous supply of medicines. Amidst the background of a universal healthcare system and a rising prevalence of NCDs in Malaysia, we aim to explore the gravity of economic impacts and consequences to various aspects of the lives of households living with diabetes. **Methods:** Through purposive sampling, we engaged thirteen (13) respondents for in-depth interviews and conducted two sessions of focus group discussions with sixteen (16) respondents; eleven (11) in Bekok sub-district (rural) and five (5) in Sungai Segamat sub-district (urban). The interview sessions were audio-recorded and transcribed verbatim. Transcribed data was analysed through Braun and Clarke's framework for thematic analysis. **Results:** Our thematic analysis revealed two emerging themes relating to the economic burden of diabetes – the impact to disease management of the person with diabetes, and consequences to the welfare of the household. We found that respondents were scaling back on home care and needed medical supplies, and also practiced self-medication without adhering to treatment regimen. The overall welfare of their families was also affected and they found themselves in debt or having to forego other household necessities to pay for diabetes treatment. **Conclusion:** Despite having a universal healthcare system, the implications of economic burden from managing chronic diseases such as diabetes in Malaysia can be far reaching to families. Our study may provide insights to develop interventions and healthcare financing systems with enhanced social and financial risk protection that can effectively manage NCDs in the long-term.

Keywords: Economic burden, Diabetes, Household Impact, Qualitative, Malaysia

INTRODUCTION

NCDs impose substantial financial costs on the individual and households. Long-term care is resource-intensive and requires access to a wide range of health services and a continuous supply of medicines. A substantial volume of literature exists on the economic impact of NCDs on households in high-income countries (1–3), and increasing studies are examining the implications of NCDs in LMIC settings (4,5). At the household and individual level, studies in LMICs have shown that both direct and indirect costs of chronic conditions can be high, imposing catastrophic healthcare spending on patients and families (6–8) and reducing their capacity to spend in other areas (9).

The International Diabetes Federation (IDF) estimated that from 2007, total healthcare expenditure on diabetes for those aged 20-79 years has grown three times from USD232 billion to USD727 billion in 2017 (10). This burden is projected to grow and even under very conservative assumptions of only factoring the demographic changes alone, and the amount could reach USD776 billion by 2045, a further 7% growth. Malaysia is a part of the Western Pacific group together with high population countries like China and Indonesia, which overall incurred an estimated expenditure of ID179 billion, 17% of the total global spending.

The economic consequences of illness and healthcare use vary across households with different socioeconomic status (SES), as do households' ability to cope with the costs. Such consequences have implications for the inter-relationship between illness and poverty. In particular, there is empirical evidence that some households (including middle-income countries) slide into poverty when faced with health care payments, especially when combined with the loss of income due to ill-health (11–13). Further compounding the issue is that the chances of a poor household ever moving out of poverty diminishes once confronted with illness-related costs (14).

Households with members living with NCDs need to reallocate household resources to cater to their additional healthcare needs, which can quickly drain household resources. There is little financial risk protection from governments or health insurance schemes in many LMICs and thus financial costs are borne mainly out-of-pocket (OOP) by households themselves rather than by governments or insurance schemes (15). The long-term cost of NCD treatments and self-monitoring can impose access barriers to lower-income groups who may not have the capacity to pay OOP for healthcare, particularly in health emergencies and

disease complications that require hospitalisation and secondary care services. This is exacerbated by the expansion of private healthcare services particularly in LMIC settings, that drives larger OOP healthcare payments that pose threats to healthcare affordability and access, and impacts household economic stability and well-being (16,17).

Experiences from high-income countries have shown that even in health systems recognised for having achieved UHC, many households still incur heavy economic burdens. The phenomenon is more pronounced in households with chronic conditions and those in low socioeconomic groups (18). The worsening prevalence of NCDs in LMICs, coupled with associated high costs for treatment and long-term management (requiring preventive, curative, and supportive care) raises the critical issue of health equity and adequacy of financial risk protection. Among developing countries, even nations that embed universal healthcare systems such as Malaysia (17) are facing new challenges in managing NCDs. The focus on a biomedical approach to the diagnosis and treatment of NCDs has mostly ignored the broader implications of the chronicity of the diseases, and lacks the integrated response to a continuum of poor health within a population (16).

Amidst the background of a universal healthcare system and a rising prevalence of NCDs in Malaysia, we aim to explore the gravity of economic impacts and consequences to various aspects of the lives of households living with diabetes. Key insights emerged from these qualitative findings would benefit towards the development of policies and intervention strategies for long-term care and enhance financial risk protection for households with chronic conditions.

METHODS

Design and respondents

In this study, we conducted in-depth interviews (IDI) and focus group discussions (FGD) with households living with diabetes in the district of Segamat in the state of Johor, Malaysia. The study was conducted at the Southeast Asia Community Observatory (SEACO), a Health and Demographic and Surveillance site in Segamat which enumerates over 44,000 individuals living in 13,355 households (19).

A voluntary, purposive sample was sought which selected adult (age 18 and above) with type 2 diabetes in the Sungai Segamat (town) and Bekok (rural) sub-districts. For the IDI, we interviewed 13 adult respondents with type 2 diabetes identified through the SEACO research platform as experiencing catastrophic healthcare expenditure from diabetes. For the FGD, two sessions were conducted among sixteen respondents (one group of five in Sungai Segamat and another group of eleven in Bekok) who were selected from a wide mix of ethnicity, both genders, and different stages of diabetes from the SEACO census database. The IDIs were conducted in the respondents' language of choice (i.e. Malay, Chinese, or English) where for the FGDs in order to facilitate meaningful and interactive conversations amongst group respondents we only select those who can converse in Malay and have a good understanding of their own diabetes condition. Both IDI and FGD interviews lasted between 1-1.5 hours each.

A discussion guide was utilized to ensure the aims of the study were met whilst allowing respondents to express views in their own way (20). The discussion guide included key questions asking respondents about their daily management regime, and how they have been impacted by the economic burden of living with a chronic disease like diabetes. All group discussions were audio recorded and transcribed verbatim.

Data analysis

Thematic analysis was chosen to analyse the dataset; whereby the dataset was searched to find repeated patterns of meaning which were then grouped as themes to provide a rich description and interpretation of the data. The approach used for thematic analysis followed the process developed by Braun and Clarke (2006)(21) that involves a six-phase process. Firstly, transcripts were read and listened to several times to familiarise with the data. Subsequently inductive and deductive codes were applied to form explicit and interpretative meanings of the data. The codes were then examined and collated to identify significant broader patterns of meaning (potential themes), and then organized into themes through a recursive process of reviewing the data at a conceptual level. Each theme were then analysed in detailed with an informative name for each being developed. Lastly, the analytic narrative and data extracts were weaved together in relation to existing literature.

Ethical considerations

The study was approved by Monash University Human Research Ethics Committee (CF14/2053 – 2014001075). Written, informed consent was sought from all respondents before the interviews begin, and respondents were aware that their participation was voluntary and they can withdraw at any point during the study. The ethical challenges incurred were more typical to FGD sessions, which included difficulty in controlling disclosure outside the group and ensuring that group dynamics did not hinder or encourage too little or excessive disclosure. To minimize the impact of these issue ground rules were stipulated at the beginning of each session to encourage confidentiality, respect of other's opinions and fairness in allowing each person to express their views and experiences. Pseudonyms were used to replace identifying details and protect respondents' autonomy.

FINDINGS

Our thematic analysis revealed two emerging themes – the impact to disease management of the person with diabetes, and consequences to the welfare of the household.

Impact on disease status and diabetes management

The economic burden of living with diabetes has impacted the way respondents manage their conditions daily. Respondents informed that they were scaling back on their home treatment in terms of frequency and usage of medical supplies, ignoring their doctor's recommendations. Though the Malaysian healthcare system provides highly affordable public healthcare services to its citizens (nominal charge of RM1 for outpatient, RM5 for secondary care), illness-associated medical supplies beyond provided medicines, namely those for home care such as insulin pen needles, bandages, antiseptics, and glucose test strips need to be purchased OOP.

“Now, my needles (insulin pen) have also finished. I don't have the money to buy any.” – [IDI-01]

“I clean my wound two times a day. It used to be three times but now reduced. The pharmacy told me now the items are getting more expensive. I used to buy this bandage for RM8; now it's RM10.50. The medicine, plasters, everything increased. If I buy the better one, I can't take it (financially)...last time I bought (antiseptic lotion) from the clinic, but I can't take it anymore, so I go and buy outside.” – [IDI-06]

“The (insulin pen) needles are expensive. One piece is already 60 cents. The most you use it two times then you throw, but we use up to 5-6 times because it’s expensive. In total, it costs around RM100 per month.” – [FGD-SG01]

“There was a case of someone I know where he stayed in the private sector (hospital) for five days, and the bill came to RM8000, and the medicines cost RM1000 per month. He can't take it anymore in the second month, and he just goes to the government clinic. If they (clinic) give medication, then he takes them, and if there isn't, then he goes to buy them at the pharmacy. He just doesn't have the money every month.” – [IDI-11]

Aside from treatment, self-monitoring of blood glucose practices was also affected due to cost barriers.

“If my sugar level drops to 2, I can't even sit up. Nowadays, I didn't check because we couldn't manage to buy any new stocks (glucose test strips).” – [IDI-01]

“I also check my sugar levels regularly once a day, but sometimes only 3-4 times a week. The card (glucose strip) is expensive. I can't take it.” – [IDI-06]

Respondents also tried out TCM care as a cheaper option to manage their disease. Even if the efficacy may not be scientifically established, respondents were attracted by the health claims and benefits purported.

“I plant them (herbs). If you buy outside, it's about RM3-5. There are seeds you can put in boiling water, and when you drink it your glucose level will go down, they say. When my legs were numb, after taking that, it will go away. You take those. You will be okay.” – [IDI-07]

“People are saying it. And that's why I drink it (bitter gourd juice), even though not very frequently. I take that to reduce my blood sugar. But if my blood sugar is four and below, I can't take it. I get weak. And I know it's because of my diabetes.” – [IDI-01]

“Yes, it (Chinese medicinal herbs) does help to control my sugar levels. My body also can feel more active, and I sweat more.” – [IDI-03]

“Recently, I buy this Rama-Rama tea. I saw it in the newspaper, and then I buy it. My blood pressure went down, from over 200 to 100 something.” – [FGD-SG02]

“I buy this medicine, Sauda, it’s like fish oil. And then I buy olive oil—only these two. One packet cost about RM10-12, I eat one of these each... yes, someone told me it’s good for diabetes, and so I eat.” – [FGD-SG01]

There were also those who were not aware of the potential side effects of the TCM care products and were reluctant to inform their doctors they are consuming it alongside clinic (modern) medication.

“There’s this time that I wasn’t aware; I was at the farm with daun ketum (kratom leaves - a traditional herb used by the Malay community to improve blood circulation and controlling blood sugar levels). The one people say with red veins that are good. So I boiled it and I was supposed to boil only 3-4 leaves, but I boiled 20-30 leaves...I keep drinking it and suddenly my eyes can’t see. Then my son took me to KL (Kuala Lumpur, 214kilometers away) and admitted me to UMMC (University Malaya Medical Center).” – [FGD-SG01]

“Err, no as well.” (on telling doctors the supplements they’re taking)” – [FGD-SG01]

The lack of services by public clinics also affected patient’s access to treatment. For patients with slow-healing open wounds such as diabetic foot ulcers who are bedridden or have difficulty in walking, they have to resort to cleaning their wounds on their own or go without care as they lack the means to go to the clinic.

“Nurses from Bekok (public clinic) also do not provide wound cleaning at home, when some patients cannot walk to the clinic due to disability or bedridden (from diabetic ulcer).” – [IDI-05]

“Previously, when I just came back from the operation, I went to the private clinic in Labis (30 kilometers away from Segamat town). One trip costs me RM30, and one day I have to go twice. That's already RM60 for transport. After one month, I can't take it anymore. After that, I just go to Batu 8 clinic. One time cleaning, there is only RM3 (USD0.3).” - [IDI-03]

“I buy bandages and wound cleaner because I clean my wounds at home. Sometimes I go to Batu 8 clinic (private clinic established for estate workers), but not the normal (public) clinic because they usually don't have supplies for wound cleaning.”– [FGD-BK06]

Similar to service gaps at public clinics, poor medical services were also reported at the hospital level which have driven those needing treatment to pay out-of-pocket to private care.

“At first, it was a small operation in Segamat hospital; on the first day, the infection wasn't that bad, but on the second day, it got worse and turned black. The doctor says need to amputate, and I asked when he said within two days. I went to Melaka (private hospital) straight on the same day at 7pm for the surgery, and it's cut until here (showing toes), if it's here (Segamat) then I might have to amputate till here (pointing ankle). I spent three nights over there.” - [FGD-BK06]

“The public sector is full of people and not enough doctors. What can they do? The nurses just keep postponing appointment dates. For my condition, if I go to the government hospital, I think I would have been long gone (dead) already.”- [IDI-11]

Impact on the welfare of the household

Respondents in the current study reported that the costs of care and management of diabetes have also impacted the overall welfare of their families. This is more apparent for those who are on insulin therapy or having related complications admitted for secondary care.

Households who cannot afford to pay for their treatment have also found themselves in debt, where family members inevitably owed money not only to lenders but also to the hospital.

“We don't have the money. To me, if I have the money, I will definitely pay it back. My situation is I don't have enough for basic living. We also didn't have any additional support or whatever.” – [IDI-01]

“More than RM8000. My son paid for it until now he is still paying back the debt. If I didn't do it (operation) at that time, my leg would be gone. We still owe RM4000”. – [IDI-06]

“For those who do not have savings, who are unemployed, or do not have financial support from their children, but needed insulin medication, the burden is big for them.” – [IDI-05]

Last time when my son fell down and broke his bone, he was charged RM500. That one we cannot pay here, pay in the account (credit basis)...If it's in the private hospital, it can run up to over RM15,000. –[FGD-SG04]

When the costs of managing diabetes are placed against other equally compelling financial demands, the decision on what needs to be spent on and what is to be put aside brings the harsh realities of chronic disease management to the surface, as described by some of the respondents;

“I'll just be direct; the expenses are really high for us. For us, our livelihood is really pressured, but we believe that we must buy them still, find ways to get the money.” – [IDI-01]

“Enough or not, we have to keep living. For now, I can still manage. I observed that if I only eat in the afternoon and not having dinner, the sugar level will drop a bit, to about 7.” – [IDI-09]

Respondents tend to cope with the long-term cost of diabetes management by themselves through their income and personal savings. For those who have retired or no longer working, personal saving was a critical source of funding.

"We don't have much bank savings. We mainly survive on my pension and dividends from some of my shares (share trading)." – [IDI-03]

"We have savings. Usually, I will use my savings to overcome it because I still have savings." – [IDI-05]

"They (people with diabetes) use their income and saving to cover their diabetes cost." – [IDI-05]

Some respondents managed their conditions without going into debt but ended up depleting their life-savings.

"Yes, luckily, I have my own money or else I do not know what to do. You see, they (children) only give me RM100 per year, which is less than RM1 per day. He (son) is still useless and is gambling still. He is over 50 years old now." – [IDI-12]

Respondents who do not have adequate savings sought to borrow money to pay for their care, particularly for high-cost inpatient treatments.

"Like the other day, when I went to the hospital, I borrowed money from him (employer) RM5000. Every month he will deduct the money from my salary, but not all." – [IDI-01]

"Out-of-pocket myself. My son helped as well, and I also borrowed from friends." – [IDI-06]

There were instances when immediate emergency treatment was required, but the household did not have sufficient money, and hence have to owe money directly to the hospital.

"We don't have the money. To me, if I have the money, I will definitely pay it back (to the hospital). My situation is I don't have enough for basic living." – [IDI-01]

Having a heavy economic burden can push households to consider selling or giving up their assets to pay for treatment costs. One respondent who owed money to the hospital can't afford to pay and was willing to surrender his household assets or even be arrested.

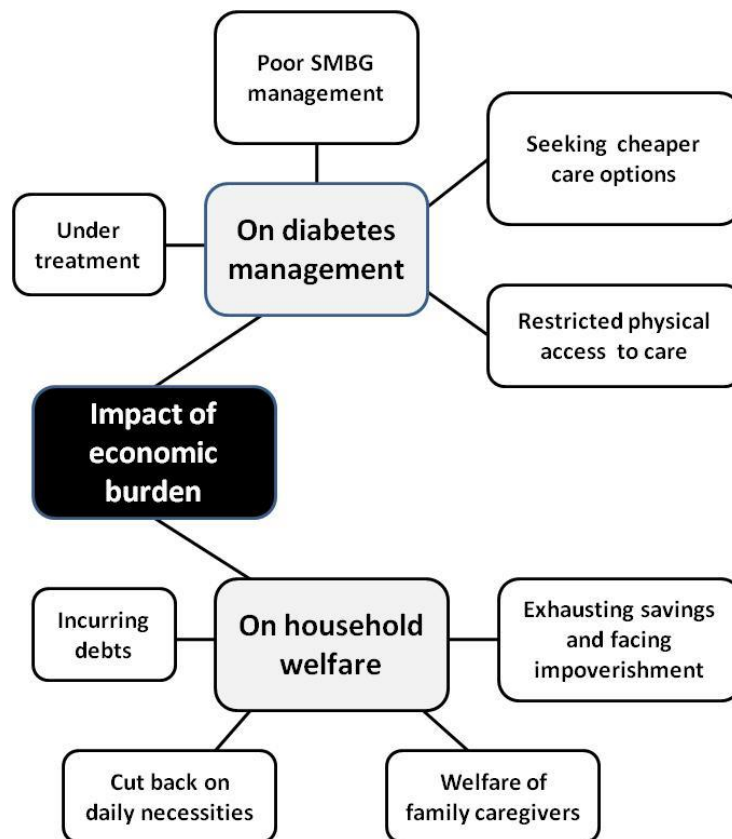
“If they force me to pay, then just take me to the police station. Just arrest me if I can't pay. You know what, it's not that we don't want to pay, but even for basic living, we're facing difficulties. If I have a bit of money, I will go and pay. If the hospital forces us to pay, then they can come to take what it's feasible from my house. I don't have a choice.” – [IDI-01]

The impact was also felt by family caregivers who have to sacrifice their time, job, and savings to care for family members with diabetes.

“When I was selling cendol I used my own money, but now all of that is gone. All my savings were used to take care of him (husband with diabetes). Now he is much better. I told him to do some exercise.” – [IDI-08]

“From Bekok I used to go there (Johor Baru hospital, 145kilometers away) everyday for 3 whole months (to care for family member with diabetes).” – [IDI-01]

Fig 1: Thematic framework of the economic impact of diabetes management



DISCUSSION

Our study showed that the implications of economic burden from managing chronic diseases such as diabetes can be far reaching to families. In terms of disease management, we found that households in our studies were scaling back on home care and needed medical supplies, and also practiced self-medication and dosage adjustments without adhering to doctor's instructions. This also extends to self-monitoring of blood glucose practices, which also requires OOP spending for glucometers and test strips. Such cost-prevention strategies were also observed in West African countries and were found to be a significant factor in the study by Okoronkwo et al. (2015)(22). The direct implication of this is poor control of their health conditions, which can likely worsen their disease progression in the long run and imposes a high risk of having acute complications of diabetes that entail high cost burdens.

Increasing support for home-based care and family caregivers

Household members play an important role in managing chronic illness. With experience and knowledge in home-based disease management over time, household caregivers are recognised as a critical resource to support many health systems that are unable to provide consistent medical support to effectively manage chronic illnesses (23). Home-based care has a critical impact on the health outcomes and wellbeing of the patient, as household members with diabetes rely substantially on family support to continuously manage their conditions. Our study found that caregivers typically close family members such as the spouse or children experienced psychosocial distress and disruptions to daily activities that could affect their quality of life, similar to studies by Golics et al. (2013)(24) and Schulz (2008)(25). Clinical observation and empirical research showed that care-giving for patients could be stressful and burdensome (26,27), as considered to be a form of chronic stress (28). Care-giving, particularly for long-term care, creates physical and psychological strain over extended periods and is accompanied by high levels of unpredictability and uncontrollability. This creates secondary stress in other life domains such as work and family relationships, and constantly requires high levels of vigilance to manage (25). With limited and constrained healthcare resources, healthcare service providers are shifting the management of long-term, complex health problems such as chronic diseases to home-based care (29). This is particularly more prevalent in LMICs, where healthcare systems are still predominantly biomedical, curative, and fragmented(30).

As Han and Haley (1999) (31) noted, attending to the impacts of chronic illness on family members is critical, as the physical and emotional health of family caregivers can influence the health, welfare, and successful rehabilitation of persons with chronic illness. Structural support for family caregivers, in the form of interventions by social workers and healthcare professionals, is highly beneficial both to caregivers and the patient, as well as the family wellbeing (29). Effective intervention support includes an assessment of the caregiver and family's wellbeing status and behaviour, developing a stress management plan (29), education on effective communication for family members and basic home nursing skills for caregivers (32), heavier involvement and ongoing care from healthcare professionals with the caregiver and patient (33), and long-term counselling and early involvement of caregivers (31).

Expanding financial risk protection

Malaysia's existing tax-based health financing has been successful in providing universal care of a wide array of public health care services with extensive geographical coverage (16). However, our findings suggest that this may be insufficient to cater for the intensive resource demands of long-term care, and signals the need to explore innovative financing mechanisms to supplement existing financing sources. While Universal Health Coverage (UHC) remains the health goal of many LMICs, those already with a universal or near-universal healthcare system such as Malaysia should begin to look beyond financial risk protection to incorporate broader social protection elements to enhance healthcare financing capacity. Even though measures towards minimization of out-of-pocket health care expenditures are essential for financial risk protection, they may not be sufficient. Social protection interventions designed to prevent or mitigate non-medical costs and income loss during the lengthy treatment may also be critical. There is mounting evidence that social protection interventions can help to improve, directly and indirectly, clinical outcomes for people with chronic illness, especially among the poorest (34,35). The linkages between actions towards UHC and broader social protection are increasingly being addressed, especially when improving equity is a key aim (36). The approach is relevant for highly debilitating health conditions and health interventions that require repeated or timely interaction with health services, such as for many non-communicable diseases.

Enhancing primary care with TCM integration

Our study also illustrated that similar to countries in Africa, Asia, and Pacific nations, the use of TCM care such as traditional medicine is a form of primary care that is culturally embedded in daily health-seeking behaviours, and forms an important component of health care (37). Considering the medical pluralism of healthcare utilisation with patients accessing both traditional and modern medicine for their illness, the sustainable management of chronic care should also look at policies to integrate the two more cohesively. Global health institutions such as the WHO and many governments, including Malaysia have recognized the role of traditional medicine and developed national policies and strategies to protect public health and maximize the potential contribution of traditional practices and providers (38). Extending the availability to primary health care can hence be harnessed to advance UHC. The WHO Beijing Declaration in 2008 has prompted many governments to recognise and integrate traditional medicine into their national health systems and be part of the universal coverage provisions and services (39).

The integration of traditional medicine into key infrastructure components of national health systems (e.g., insurance coverage and care packages) may also contribute to advancing health system attributes essential to achieve UHC; i.e., quality; efficiency; equity; accountability; and sustainability and resilience (37). The active community engagement and empowerment in the process of integration will be essential to enable health systems to be more sustainable and resilient. This is especially so in low-resourced settings where traditional medicine can be a significant resource, preserving culturally-situated wisdom, promoting health, and helping to address public health challenges. Further understanding of the utilization pattern of traditional medicine may also inform policy solutions on health-seeking behaviour, and should be considered in the context of overall health services financing.

Strengthening community engagement

Beyond the family institution, the broader community environment can also form an enabling factor to manage chronic illness sustainably. Health systems that establish formal linkages with their communities leverage have the potential to tap in community resources to create facilitative environments for people living with NCDs. These linkages range from loose or sporadic collaboration to full integration between health care organizations and community services, leveraging the latter as a health care partner (40). Moreover, links to community resources can also be further strengthened to fill gaps in care for elderly or disabled patients, who often require both health and social services. Non-governmental organizations, social

enterprises, and medical care funds can also be approached to provide services that health facilities do not offer and for patients who cannot afford (41).

The aspect of community engagement is also one of the core pillars of the Chronic Care Model to enhance patient-provider interaction through more inclusive participation in community health programs and partnerships in developing healthcare interventions (42). Within the context of UHC, effective community engagement would enable communities to participate in the decision making process on the provision and delivery of healthcare services in the community (40). Communities are also empowered to hold providers accountable for the quality and outcomes of their care and be proactive in managing their healthcare (43).

The main limitation we encounter was the validation of interview transcripts. Due to varying travel distances, transportation, and related logistic limitations, we are unable to send back the transcripts of the information generated during the in-depth interviews and focus group discussions for respondents to comment and verify what was recorded, transcribed, and analysed. Instead, respondent validation was done immediately after every interview and focus group discussions. Through this process, some issues were identified, and omissions and errors were included in the interview notes. This strategy enhanced the reliability and validity of the information collected (44).

CONCLUSION

NCD is threatening the core of UHC to provide equitable healthcare available for those who need it without risking financial hardship. Our study may provide insights to develop interventions and healthcare financing systems with enhanced social and financial risk protection that can effectively manage NCDs in the long-term. With the emphasis on the future need for a public policy response to the expected rise in economic vulnerability due to NCDs, the effective measurement and monitoring of household economic burden are therefore necessary to inform healthcare policies and financing strategies. Policies that focus exclusively on measures to protect from the OOP costs of healthcare may overlook the broader economic effects of NCDs for costs of accessing care extend beyond user charges, such as transport and loss of income for patients and carers. As highlighted by Schmidt et al. (2015)(45), placing a narrow focus on population-wide coverage of clinical services and

subsidies alone could divert crucial healthcare funds from public health and preventive services that could be more cost-effective to address the burden of NCDs at a population level.

Countries with a readily established healthcare system with universal or near-universal coverage should begin efforts to look beyond financial risk protection to incorporate broader social protection elements. Measures towards minimizing OOP healthcare expenditures are essential for financial risk protection, but as highlighted by our study, they may not be sufficient, particularly with regards to managing long-term care. Social protection interventions designed to prevent or mitigate non-medical costs and income loss during the lengthy treatment are also crucial (34). Economic support, in combination with other types of social assistance, has been associated with improved service uptake (46), treatment adherence (47), and treatment outcomes of chronic diseases such as tuberculosis (48). With the long-term management of NCDs primarily home-based, interventions and policies to enhance home-based care and empower family caregivers will also be important to sustainably manage NCDs and maintain good quality of life both for the person with diabetes and the overall household.

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REFERENCES

1. Lin JS, Resch SC, Brimmer DJ et al. The economic impact of chronic fatigue syndrome in Georgia: direct and indirect costs. *Cost Eff Resour Alloc*. 2011;9(1).
2. Schofield D, Passey M, Percival R et al. Retiring early with cardiovascular disease - impact on individual's financial assets. *Int J Cardiol*. 2010;9(2):125–6.
3. Langa K. Out-of-pocket health-care expenditures among older Americans with cancer. *Value Heal*. 2004;7:186–94.

4. Bloom DE, Cafiero ET, Jane-Llopis E et al. The global economic burden of noncommunicable diseases. World Economic Forum. Geneva; 2011.
5. Niessen LW, Mohan D, Akuoku JK et al. Tackling socioeconomic inequalities and non-communicable diseases in low-income and middle-income countries under the Sustainable Development agenda. *Lancet*. 2018;391:2036–46.
6. Barceló A1, Aedo C, Rajpathak S et al. The cost of diabetes in Latin America and the Caribbean. *Bull World Heal Organ*. 2003;8(1):19–28.
7. McIntyre D, Thiede M, Dahlgren G et al. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts? *Soc Sci Med*. 2006;62(4):858–65.
8. Seuring T, Archangelidi O, Suhrcke M. The Economic Costs of Type 2 Diabetes: A Global Systematic Review. *Pharmacoeconomics*. 2015;33(8):811–31.
9. Saksena P, Evans D, Xu K. Impact of out-of-pocket payments for treatment of non-communicable diseases in developing countries: A review of literature. Vol. Discussion, World Health Organization. 2011.
10. International Diabetes Federation. IDF Diabetes Atlas, Eighth edition 2017. International Diabetes Federation. 2017.
11. Chaker L, Falla A, van der Lee SJ et al. The global impact of non-communicable diseases on macro-economic productivity: a systematic review. *Eur J Epidemiol* [Internet]. 2015;30:357–95. Available from: <http://dx.doi.org/10.1007/s10654-015-0026-5>
12. Boutayeb A, Boutayeb S. The burden of non communicable diseases in developing countries. *Int J Equity Health*. 2005;4(2).
13. Wagstaff A, Van Doorslaer E. Paying for health care: Quantifying fairness, catastrophe and impoverishment with applications to Vietnam 1993–98. World Bank. 1993.
14. Kabir MA, Rahman A, Salway S et al. Sickness among the urban poor: A barrier to livelihood security. *J Int Dev*. 2000;12:707–22.
15. Jan S, Laba TL, Essue BM et al. Action to address the household economic burden of non-communicable diseases. *Lancet*. 2018;391:2047–58.
16. Yasin S, Chan CKY, Reidpath DD et al. Contextualizing chronicity: A perspective from Malaysia. *Global Health* [Internet]. 2012;8(4). Available from: <http://www.globalizationandhealth.com/content/8/1/4>
17. Chua H, Cheah J. Financing Universal Coverage in Malaysia: a case study. *BMC Public Health*. 2012;12(Supp 1).

18. Schoen C, Osborn R, Squires D. How health insurance design affects access to care and costs, by income, in eleven countries. *Heal Aff*. 2010;29:2323–34.
19. Allotey P, Reidpath DD, Devarajan N et al. Cohorts and community: A case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. *Glob Health Action*. 2014;7:23176.
20. Hennick M, Hutter I, Bailey A. Qualitative research methods. *Crit Public Health*. 2011;22(1):111–2.
21. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77–101.
22. Okoronkwo IL, Ekpemiro JN, Onwujekwe OE et al. Socioeconomic inequities and payment coping mechanisms used in the treatment of type 2 diabetes mellitus in Nigeria. *Niger J Clin Pract*. 2016;19:104–9.
23. Van Olmen J, Ku GM, Bermejo R et al. The growing caseload of chronic life-long conditions calls for a move towards full self-management in low-income countries. *Global Health* [Internet]. 2011;7:38. Available from: <http://www.globalizationandhealth.com/content/7/1/38>
24. Golics CJ, Khurshid M, Basra A et al. The impact of patients' chronic disease on family quality of life: An experience from 26 specialties. *Int J Gen Med*. 2013;6:787–98.
25. Schulz R, Sherwood P. Physical and mental health effects of family caregiving. *J Soc Work Educ*. 2008;44(SUPPL. 3):105–13.
26. Biegel D, Sales E, Schulz R. Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke. Sage. 1991.
27. Haley WE, Levine EG, Brown SL et al. Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychol Aging*. 1987;2(4):323–30.
28. Vitaliano P, Zhang J, Scanlan J. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull*. 2003;129(6):946–72.
29. Lim J, Zebrack B. Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health Qual Life Outcomes*. 2004;2(50).
30. Arredondo A, Azar A, Recamán A. Diabetes, a global public health challenge with a high epidemiological and economic burden on health systems in Latin America. *Glob Public Health*. 2018;13(7):780–7.
31. Han B, Haley W. Family caregiving for patients with stroke: review and analysis.

- Stroke. 1999;30:1478–85.
32. Miaskowski C. Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. *Pain*. 1997;72:217–26.
 33. Nijboer C, Triemstra M, Tempelaar R et al. Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer*. 1999;86:577–88.
 34. International Labour Organisation. World Social Security Report 2010/11: providing coverage in times of crisis and beyond. International Labour Organisation. 2010.
 35. Lönnroth K, Glaziou P, Weil D et al. Beyond UHC: Monitoring Health and Social Protection Coverage in the Context of Tuberculosis Care and Prevention. *PLoS Med*. 2014;11(9):e1001693.
 36. Save the Children. Universal Health Coverage: A Commitment to Close the Gap. Save the Children. 2013.
 37. Park Y, Canaway R. Integrating Traditional and Complementary Medicine with National Healthcare Systems for Universal Health Coverage in Asia and the Western Pacific Integrating Traditional and Complementary Medicine with National Healthcare Systems for Universal Health Cove. *Heal Syst Reform* [Internet]. 2019;5(1):24–31. Available from: <https://doi.org/10.1080/23288604.2018.1539058>
 38. World Health Organisation. WHO traditional medicine strategy: 2014-2023. World Health Organization. Geneva; 2013.
 39. World Health Organisation. Beijing Declaration: WHO Congress in Traditional Medicine (7-9 November 2008) [Internet]. World Health Organization. 2008. Available from: <http://www.who.int/medicines/areas/traditional/congress/en/index.html>
 40. Allotey P, Tan DT, Kirby T et al. Community engagement in support of moving toward universal health coverage. *Heal Syst Reform* [Internet]. 2019;5(1):66–77. Available from: <https://doi.org/10.1080/23288604.2018.1541497>
 41. PAHO. Innovative Care for Chronic Conditions: Organizing and Delivering High Quality Care for Chronic Non-communicable Diseases in the Americas. PAHO. 2013.
 42. Wirtz VJ, Kaplan WA, Tellez YSA et al. Affordable, quality, long-term care and pharmacotherapy of chronic diseases: a framework for low and middle income countries. *World Heal Organ*. 2011;
 43. Hunt P, Backman G. Accountability and the right to the highest attainable standard of health. *Health Hum Rights* [Internet]. 2008;10(1):81–92. Available from: <http://www.comminit.com/democracy-governance/content/accountability-and-right->

highest-attainable-standard-health.

44. Patton M. Qualitative research and evaluation methods (3rd ed.). Sage. 2002.
45. Schmidt H, Gostin L, Emanuel E. Public health, universal health coverage, and Sustainable Development Goals: can they coexist? *Lancet*. 2015;386:928–30.
46. Volmink J, Garner P. Systematic review of randomised controlled trials of strategies to promote adherence to tuberculosis treatment. *BMJ*. 1997;315:1403–6.
47. Moverman Y, Daftary A, Franks J et al. Adherence to treatment for latent tuberculosis infection: systematic review of studies in the US and Canada. *Int J Tuberc Lung Dis*. 2008;12:1235–54.
48. Rocha C, Montoya R, Zevallos K et al. The Innovative Socio-economic Interventions Against Tuberculosis (ISIAT) project: an operational assessment. *Int J Tuberc Lung Dis*. 2011;15:s50-57.