EXPLORATIVE RESEARCH ON HEALTH LITERACY AND SELF-CARE MANAGEMENT OF TYPE 2 DIABETES MELLITUS IN MALAYSIA

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Thesis submitted to the University of Nottingham
for the degree of Doctor of Philosophy

July 2023

Abstract

Type 2 diabetes is a chronic metabolic disorder which affects 3.9 million people in Malaysia in 2019. The prevalence of diabetes in the country is expected to rise as a result of unhealthy diet and sedentary lifestyle. As a complex disease, effective pharmacological management is key, in addition to the adoption of healthy self-care behaviours by patients. However, many patients with type 2 diabetes struggled to maintain their glycaemic control and adopt self-care measures due to various reasons which include low health literacy. Low health literacy among diabetes patients may result in poor self-care management and diabetes outcome. Pharmacists play a major role in patient education especially on medication adherence and diabetes self-care as they are easily accessible to the public. The accessibility of pharmacy services to the public may aid diabetes patients with health literacy challenges getting advice and support they need in empowering self-care.

This qualitative study aims to explore newly diagnosed patients' and pharmacists' perceptions of the knowledge of diabetes and its management, and what empowers pre-diabetes and newly diagnosed type 2 diabetes patients to practise self-care and how pharmacists interact and communicate with individual patients to promote self-care behaviours in preventing disease progression. A total of 36 participants (22 patients and 14 pharmacists) were recruited online and from two public health clinics. Data were collected using semi-structured interview and focus group discussion via Microsoft Teams and Zoom as well as via telephone calls. NVivo® software was used for data analysis and data obtained were coded and categorised into themes using reflexive thematic analysis. The Health Literacy Questionnaire (HLQ) was used in this study to identify the patients' strengths and limitations in health literacy. Results from both groups and the HLQ were used to provide a better understanding on patient empowerment to self-care.

This study found that having sufficient access to reliable resources, continuous support from family, peers, and healthcare providers and a good understanding of the condition is important in empowering self-care behaviours. However, most patients in this study lacked the necessary support and access to reliable diabetes information. To address these challenges, pharmacists, being easily accessible and reliable, serve as a valuable source of information and can provide different diabetes services like blood glucose monitoring and patient education using literacy-sensitive techniques. Working together with other healthcare providers is also crucial to offer patients direct care and address the complex needs of diabetes management. Additionally, this study also found that continuing pharmacist's education on diabetes management and health literacy is essential to enhance communication strategies used for diabetes patients with different levels of health literacy.

This study emphasises the importance of supporting newly diagnosed T2DM and pre-diabetes patients to self-care, highlighting the significant role pharmacists play in assisting these individuals. The findings indicate that with sufficient access to health services, information and support, diabetes patients were empowered to practise self-care. Given the accessibility of pharmacists, especially in the community settings, they could be the big players in supporting other healthcare providers to deliver effective self-care education.

Publications and Conferences

Published papers

Ahmad Azhari, A., Chai, J., & Anderson, C. (2022). Reflections of Conducting Online Interviews During the Pandemic: Benefits, Challenges and Practical Solutions. *The Malaysian Journal of Qualitative Research, 8*(1), 24-31.

Ahmad Azhari, A., Chai, J., & Anderson, C. (2021). Explorative Research on Health Literacy and Self-care Management in Patients with Type 2 Diabetes Mellitus. *The Malaysian Journal of Qualitative Research, 7*(1), 40-52.

Published abstracts

Oral presentation

28th Federation of Asian Pharmaceutical Associations (FAPA) Congress and National Pharmacists Convention 2022, Kuala Lumpur, Malaysia

Ahmad Azhari, A., Chai, J., & Anderson, C. (2022). Assessing Health Literacy Among the Newly Diagnosed Type 2 Diabetes Mellitus and Pre-diabetes Patients in Malaysia. *Malaysian Journal of Pharmacy, 8*(2), 84.

Oral presentation (online)

10th International Qualitative Research Conference 2022

Ahmad Azhari, A., Chai, J., & Anderson, C. (2021). Reflections of Conducting Online Interviews: Benefits, Challenges and Practical Solutions. *The Malaysian Journal of Qualitative Research Special Edition,* 12.

Poster presentation

2022 FIP Pharmacy Practice Research summer meeting for PhD students, postdoctoral fellows and supervisors, Utrecht, Netherlands

Ahmad Azhari, A., Chai, J., & Anderson, C. (2022). Health Literacy and Self-care Among Malaysians with Type 2 Diabetes: Patients' and Pharmacists' Perspectives. *Pharmacy Education, 22*(5), 25.

Conferences

Oral presentation

The 2nd Joint SWU-UNM Postgraduate Symposium 2022, Bangkok, Thailand

Ahmad Azhari, A., Chai, J., & Anderson, C. (2022). Relationship Between Health Literacy and Self-care Behaviours Among the Newly Diagnosed Type 2 Diabetes and Pre-diabetes Patients in Malaysia.

International Social Pharmacy Workshop 2022, Basel, Switzerland

Ahmad Azhari, A., Chai, J., & Anderson, C. (2022). Explorative Research on Health Literacy and Self-care Empowerment Among Malaysians Type 2 Diabetes Patients.

9th International Qualitative Research Conference 2019, Bangi, Malaysia

Ahmad Azhari, A., Chai, J., & Anderson, C. (2019). Relationship of Health Literacy to Self-care Behaviours Among Malaysians in Managing Type 2 Diabetes Mellitus.

Awards

Awarded 2nd Runner Up in 1-Minute Rapid Fire Competition at the FOSE Postgraduate Research Showcase 2021/2022.

Awarded 1st Runner Up at the Graduate School Postgraduate Showcase 2021.

Awarded the Best Poster Presenter at the 2021 UNM Pharm/Biomed 6th Annual Postgraduate Research Symposium.

Acknowledgements

I would like to express my deepest gratitude to everyone who has helped me throughout my PhD journey. Your contributions have been instrumental in my success, and I could not have done it without you.

First and foremost, I want to extend my heartfelt thanks to all the participants who willingly participated in my study during the challenging times of the pandemic. Without your participation and cooperation, this study would not have been possible. I would also like to extend my sincere thanks to the hardworking staffs at the public health clinics for their assistance during the recruitment process of my study. Your dedication to public health is commendable, and I am grateful for the opportunity to work alongside all of you.

My amazing supervisors, Dr Jim Chai and Professor Claire Anderson, I could not have made it without your guidance, support and invaluable feedback throughout my PhD studies. Your expertise and insights have been instrumental in shaping my research work and your feedback has helped me to improve and grow as a researcher.

To my husband, Najmi, and my children, Al-Ghazali and Amina, I cannot thank you enough for your endless love, support and understanding throughout this journey. Your encouragement and sacrifices have been my source of strength and motivation. To my parents, Papa and Mama, and my parents in law, Abah and Mak, I am forever grateful for your unwavering prayers, support and encouragement.

I am also grateful to my family for looking after my children while I attended conferences and focused on my PhD work and thesis. As they say, it takes a village to raise a child, and you all have been that village for me. I remember every single

time each one of you stepped in to help me, and your kindness and generosity have touched my heart. I am truly blessed to have such a wonderful family who cares for me and my children.

To my friends, Aziah, Izzati, Erlyna, Farah, Val, Firra, Jessica, Zeety, Fatimah, Aisyah, Giorgia, and Nadiah, thank you for being there to cheer me up and keep me motivated during this journey. I could always count on you to make me laugh when I needed it the most.

And finally, I would like to thank Allah, the Almighty, for the guidance, support and blessings that have kept me going through this journey. I am deeply grateful for all the opportunities that have come my way and for the strength to keep moving forward.

List of Abbreviations

CPD	Continuing professional development
DMTAC	Diabetes Medication Therapy Adherence Clinic
FPG	Fasting plasma glucose
GDM	Gestational diabetes mellitus
GPs	General practitioners
HbA1c	Haemoglobin A1C
HLS-EU-Q47	The European Health Literacy Survey Questionnaire
HLS-M-Q18	The Malaysian Health Literacy Survey Questionnaire
HLQ	Health Literacy Questionnaire
IDF	International Diabetes Federation
IFT	Impaired fasting tolerance
IGT	Impaired glucose tolerance
ISF	International Self-care Foundation
KDHC	Studied public health clinic
LPHO	Lembah Pantai Health Office
MCO	Movement control order
MDT	Multidisciplinary team
MNT	Medical nutrition therapy
MODY	Maturity onset diabetes of the young
MOH	Ministry of Health
MREC	Medical Research and Ethics Committee
MTAC	Medication Therapy Adherence Clinic
NADI	National Diabetes Malaysia
NCDs	Non-communicable diseases
NDM	Neonatal diabetes mellitus
NHMS	National Health and Morbidity Survey

NIH	National Institutes of Health
NMRR	National Medical Research Registry
NVS	Newest Vital Sign
OGTT	Oral glucose tolerance test
PHO	Petaling Health Office
PIC	Person in charge
QCAS	Qualitative data analysis software
QR	Quick response
REALM	Rapid Estimate of Adult Literacy in Medicine
RMCO	Recovery movement control order
SARS-Cov-2	Severe acute respiratory syndrome coronavirus 2 which caused COVID-19
SEREC	Science & Engineering Research Ethics Committee
SHD	Selangor Health Department
SMBG	Self-monitoring blood glucose
SOP	Standard operating procedure
T1DM	Type 1 diabetes mellitus
T2DM	Type 2 diabetes mellitus
TA	Thematic analysis
THC	Studied public health clinic
TOFHLA	Test of Functional Health Literacy in Adults
UHC	Universal health coverage
UK	United Kingdom
USA	United State of America
WPKL&PHD	Wilayah Persekutuan Kuala Lumpur & Putrajaya Health Department

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CHAPTER 1 INTRODUCTION

1.1 Background

Diabetes is a long-term metabolic disorder that is characterised by high blood sugar, insulin resistance and relative lack of insulin. There are four types of diabetes which are type 1, type 2, gestational diabetes and monogenic diabetes (neonatal diabetes mellitus and maturity onset diabetes of the young) (NIDDK, 2016). Type 1 diabetes mellitus (T1DM) is characterised by insufficient production of insulin and usually treated by daily administration of insulin. Type 2 diabetes mellitus (T2DM) is the most common type of diabetes and is primarily due to insulin resistance as well as deficiency. Gestational diabetes (GDM) is characterised by increased blood glucose during pregnancy, and women who are diagnosed with GDM are at increased risk of complications during pregnancy and at delivery. GDM usually disappear after delivery, but women affected, and their children are at higher risk of developing T2DM later in life. Neonatal diabetes mellitus (NDM) and maturity onset diabetes of the young (MODY) are a rare form of diabetes which is caused by gene mutations (NIDDK, 2017). NDM usually occurs in the first 6 to 12 months of life where not enough insulin is produced resulting in increase of blood glucose, whereas MODY occurs during adolescence or early adulthood that limits the ability of the pancreas to produce insulin (NIDDK, 2017).

Another condition which is associated with T2DM, and early detection could prevent the risk of developing T2DM is pre-diabetes. Pre-diabetes is a term used to describe people with impaired glucose tolerance (IGT) and/or impaired fasting tolerance (IFT) and individuals with pre-diabetes are at high risk to develop T2DM (Beulens et al., 2019). According to the National Diabetes Registry Report 2020 which was published in 2021, it is reported that 99.33% of patients enrolled in the registry were diagnosed with T2DM, while 0.59% and 0.06% were diagnosed with T1DM and other forms of diabetes respectively (Ministry of Health Malaysia, 2021). This shows that majority of diabetes patients in Malaysia are T2DM patients.

Poor glycaemic control can lead to macrovascular and microvascular complications and can contribute to a significant rate of mortality and morbidity. The increasing complications and hospitalisation due to poor glycaemic control has also put a burden on the government and healthcare resources. Therefore, good glycaemic control is very critical to prevent the development of complications associated with diabetes such as cardiovascular disease, retinopathy, neuropathy and nephropathy. To achieve a good glycaemic control, patients with diabetes should undergo lifestyle modification, which consists of dietary therapy and increased physical activity. When lifestyle modification failed, oral medications may be introduced. Insulin therapy may be added on if glycaemic control is still poor even after oral medications have been introduced. Nevertheless, the effectiveness of these interventions can be significantly influenced by an individual’s health literacy level. Comprehensive understanding of treatment plans and adherence to medications is crucial for better diabetes outcome.

Moreover, health literacy has an impact on the day-to-day self-care management of T2DM. With adequate or high health literacy levels, patients with diabetes are more likely to be empowered to practise self-care. Based on the National Health and Morbidity Survey (NHMS) 2019, 35.1% of Malaysian adults possessed low health literacy level (Institute for Public Health (IPH), 2020). Low health literacy could lead to poor management of non-communicable diseases (NCDs) such as diabetes and increased the risk of developing diabetes complications and poor diabetes outcomes (UCL Institute of Health Equity, 2015).

1.2 Literature review

1.2.1 Epidemiology of diabetes

Diabetes is a major public health concern not just in Malaysia but also globally. According to the International Diabetes Federation (IDF)'s 10th edition of Diabetes Atlas (2021), there are approximately 537 million adults living with diabetes worldwide. They predicted by 2045, the number of people diagnosed with diabetes will rise to 784 million. The report also stated that 81% of people with diabetes live in low- and middle-income countries such as Malaysia. In 2021, Malaysia is ranked the top 5 countries in the Western Pacific region for the number of people with diabetes aged 20 to 79 years old with 4.4 million people diagnosed with diabetes, and it has come to no surprise that Malaysia was given the title the "Sweetest Nation in Asia" (IIDF, 2021).

Based on the National Health and Morbidity Survey (NHMS) 2019, the prevalence of known diabetes in Malaysia has increased from 7.2% in 2011 and 8.3% in 2015 to 9.4% in 2019 (see Figure 1.1) (Institute for Public Health (IPH), 2020). The survey stated there was a general increasing trend in prevalence of known diabetes with age from 4.5% among those aged 35 – 39 years to 34.3% among the 65 – 69 years age group (Institute for Public Health (IPH), 2020). Among adults above the age of 18 years old, the prevalence was highest in Indians (18.5%), followed by Malays (11.0%), Chinese (8.5%), and Bumiputera Sarawak (7.9%). The high prevalence of diabetes among the Indians emphasises the importance of targeted interventions and strategies to address the challenges within this population. The prevalence of undiagnosed diabetes has also increased from 4.0% in 2011 and 5.1% in 2015 to 8.9% in 2019 (see Figure 1.1). It is found that there is a higher prevalence of undiagnosed diabetes among the young adults aged 18 to 29 years old at 5.3% (n = 345401) compared to those aged 60 years and above (n =

202740) (see Figure 1.2) (Institute for Public Health (IPH), 2020). This indicates that there is a potential gap in awareness, screening and early detection among the younger population. Furthermore, the prevalence of undiagnosed diabetes is also found to be higher in rural areas (10.2%) compared to the urban areas (8.5%) which highlights the needs to improve health initiatives and awareness campaigns in rural settings to address the challenges associated with undiagnosed diabetes.

The overall trend or prevalence of diabetes in Malaysia is most likely to increase further in the coming years if people do not start to adopt self-care activities such as eating healthy diet and exercising regularly. Moreover, with the increasing prevalence of diabetes and other NCDs such as hypertension and hypercholesterolaemia among Malaysians, it is expected that the costs of treating patients with NCDs, and their related complications will continue to increase.

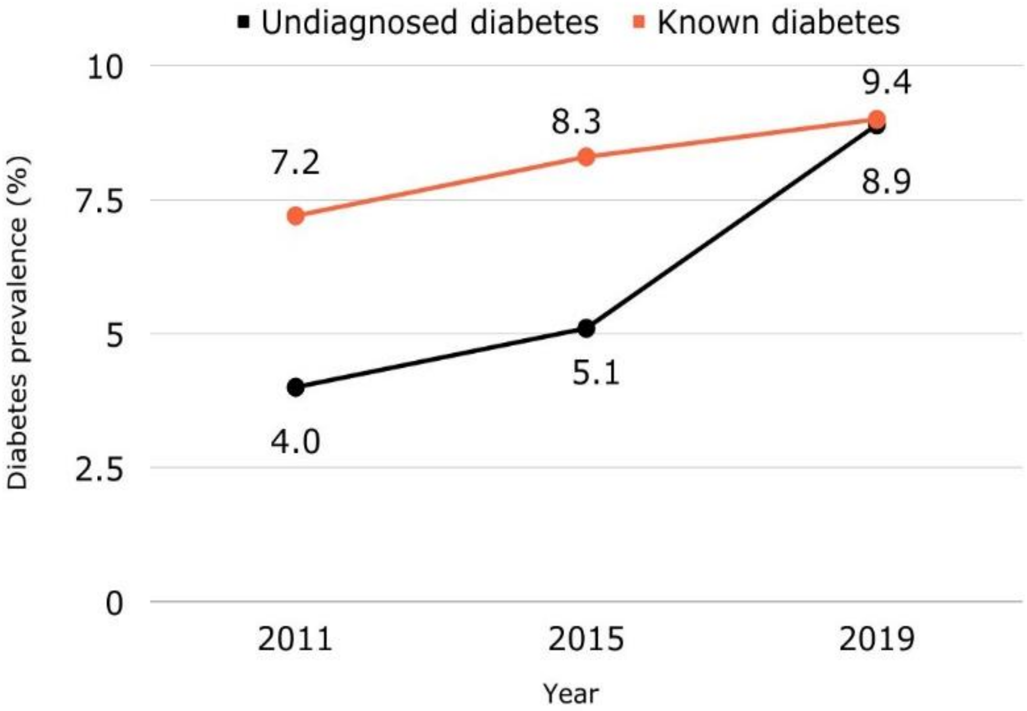


Figure 1.1: The prevalence of undiagnosed and known diabetes in Malaysia in the last 10 years (NHMS 2019)

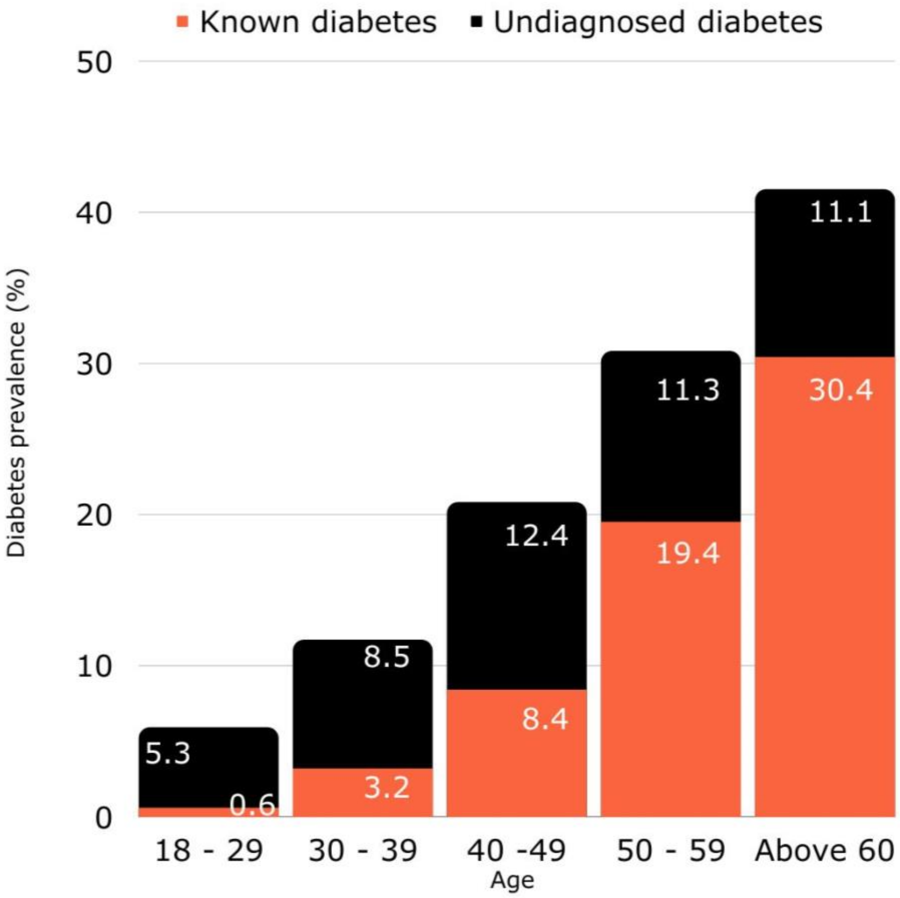


Figure 1.2: The prevalence of diabetes by age group (NHMS 2019)

1.2.2 Pre-diabetes

Based on the Ministry of Health (MOH)’s Clinical Practice Guidelines (CPG) Management of T2DM, individuals with IFG and/or IGT and/or HbA1c of 5.7% to 6.2% are considered as having pre-diabetes (Ministry of Health Malaysia, 2020a). The prevalence of undiagnosed diabetes is increasing each year in Malaysia due to unhealthy diet and physical inactivity (see Figure 1.1). In 2019, it is estimated that approximately 5 million individuals in Malaysia have probable pre-diabetes which increase the risk of developing T2DM in the future (Institute for Public Health (IPH), 2020). In addition, various studies indicated that pre-diabetes is associated with an increased risk of cardiovascular disease and all-cause mortality (Cai et al., 2020; Ford et al., 2010; Huang et al., 2016). Early detection and treatment of pre-diabetes may reduce the progression to T2DM and may also contribute to primary and secondary prevention of cardiovascular disease (Cai et al., 2020). Lifestyle interventions such as dietary change, weight management, exercise and smoking cessation is found to be effective in reducing diabetes progression (Kosaka et al., 2005; Ramachandran et al., 2006; Tuomilehto et al., 2001). Therefore, urgent measures are needed to address the increasing prevalence of undiagnosed diabetes in Malaysia, especially among younger populations. The importance of early screening, detection as well as lifestyle intervention may help reduce the risk of developing T2DM and, consequently, minimise associated complications.

1.2.3 Newly diagnosed diabetes

As noted earlier, early detection and management of pre-diabetes and T2DM is important as it can delay the progression of the disease and development of microvascular and macrovascular complications (Ahmad et al., 2022; Cai et al., 2020). However, due to the multifactorial nature of diabetes, and other modifiable risk factors such as hypertension and dyslipidaemia, the development of diabetes complications can be further increased (Ahmad et al., 2022). In the recent years, there is a trend of the rising number of children and young adults (up to age of 40 years) diagnosed with T2DM (Lascar et al., 2018). This is also observed in Malaysia as mentioned in section 1.2.1, where there is an increasing prevalence of both known and undiagnosed diabetes among younger populations. An earlier onset of diabetes could increase lifetime exposure to hyperglycaemia, contributing to the development of cardiovascular disease, which, in turn, may lead to medication burden due to multimorbidity and polypharmacy (Black et al., 2015; Hillier & Pedula, 2003; Lascar et al., 2018). One study found that multifactorial risk reduction targeting glycaemic, blood pressure and lipid control among those with T2DM and microalbuminuria reduces the risk of cardiovascular and microvascular complication by about 50% through target-driven, long-term and intensified intervention (Gaede et al., 2003). Therefore, this highlights the importance of early detection and management of T2DM to prevent or delay the development of diabetes complications and overall mortality rate.

As per Malaysia's 6th edition of Clinical Practice Guidelines (CPG): Management of T2DM, the term "newly diagnosed" is used for patients who are diagnosed with T2DM for less than a year and the term "recently diagnosed" is used for patients who are diagnosed less than 5 years (Ministry of Health Malaysia, 2020a). In this study, to ease the readability and to avoid confusion, the term "newly diagnosed" will be used for patients who are diagnosed with T2DM up to 5 years. Given to this context, there is a need to focus on self-care management among the newly diagnosed patients, empowering them during the early stages of their diagnosis to achieve better health outcomes and improve their quality of life.

1.2.4 Health literacy

Health literacy has been defined as the personal knowledge, competencies and social resources needed for individuals and communities to access, understand, appraise and use health information and health services to make informed decisions about health (Geneva: World Health Organization, 2021). Individual capacities within the main components of health literacy are viewed as cultural and conceptual knowledge, listening, speaking, arithmetical, writing and reading skills (Sørensen et al., 2012). Health literacy is important as people with high health literacy skills tend to enjoy better health and wellbeing. This allows the individual to interpret information about health, to find and use own sources of health information as well as understand when the information is poor or misleading. In simple terms, health literacy refers to the ability of a patient to understand information not only given to them by healthcare providers, but also the ability to understand the information they received or gained from personal experiences, family and friends as well as from the internet.

Based on NHMS 2019, 35.1% of Malaysian adults possessed low health literacy level (Institute for Public Health (IPH), 2020). The survey was conducted to determine the health literacy among Malaysian adults by using the HLS-M-Q18 questionnaire, which was compressed and adapted from the European Health Literacy Survey, HLS-EU-Q47 (Institute for Public Health (IPH), 2020). The questionnaire consisted of 18 items covering 9 sub-dimensions such as obtaining, understanding or appraising the information and application relevant to healthcare, disease prevention and health promotion (Institute for Public Health (IPH), 2020). From the survey, it is reported that 28.0% of Malaysian adults have low health literacy in managing medical issues, 32.3% have low health literacy related with disease prevention activities and 27.0% have low health literacy in health promotion and healthy lifestyle practices (Institute for Public Health (IPH), 2020).

There are several publications which provide different conceptual models of health literacy. One framework which is proposed by Lee et. al (2004) links health literacy to health status and health service utilisation, where the framework incorporates four interrelated intermediate factors which are disease knowledge and self-care, health risk behaviour, preventive care and routine physician visits and compliance with medications (Lee et al., 2004). Another model is that of Nutbeam (2008) where he differentiates between three typologies of health literacy. According to his conceptual model, there are three different "types" of health literacy which are related to the practical application to everyday life. They are functional, interactive and critical health literacy which represent levels of knowledge and skills. Functional health literacy is the ability to read and write, and it is the foundation for health literacy on which a range of complementary skills can be built (Nutbeam, 2008). With adequate functional skills, more advanced cognitive and literacy skills may be applied actively to participate in decision on one's health and care over time (UCL Institute of Health Equity, 2015). Through interactive skills, it enables people to critically analyse information and use this information to exert greater control over life events and situations (Nutbeam, 2008).

An integrated conceptual model of health literacy has been developed by Sørensen et al. (2012) through an extensive systematic review of different definitions and models of health literacy, which is shown in Figure 1.3. The model combines the qualities of a conceptual model outlining the four main dimensions (access, understand, appraise and apply) of health literacy which are represented in the concentric oval shape in the middle of Figure 1.3, and of a logical model showing the proximal and distal factors which impact on health literacy, and also the pathways linking health literacy to health outcomes (Sørensen et al., 2012). The core of the model shows the competencies related to the process of accessing, understanding, appraising and applying health related information which then generates knowledge and skills to enable a person to navigate the three domains of health continuity (healthcare, disease prevention and health promotion) (Sørensen et al., 2012).

There are several health literacy measurement tools that have been developed and are widely used to assess the level of patient’s health literacy, for example, the Rapid Estimate of Adult Literacy in Medicine (REALM) which tests reading ability and pronunciation; the Test of Functional Health Literacy in Adults (TOFHLA) which tests reading comprehension and numeracy; and the Newest Vital Sign (NVS) which assesses reading comprehension and numeracy using a nutritional label of an ice cream (Mayer & Villaire, 2007; Osborne et al., 2013). The tools such as REALM is quick and easy to administer and required minimal training for the healthcare providers, while the NVS is quick to administer and due to it being a nutritional label, it is viewed as less obvious which can help to alleviate patients’ anxiety on feeling shame about their lack of literacy skills (Mayer & Villaire, 2007). However, the limitation some of these tools has that they only focus on a single dimension of health literacy, for example, reading or numeracy skills, which may not capture the full range of competencies needed to access, understand, appraise and use health information. In order to address this limitation, a multidimensional tool for measuring health literacy which is called Health Literacy Questionnaire (HLQ), was developed to identify specific health literacy strengths and limitations of people and communities, where it offers the potential for practitioners, organisations and government to identify and understand the health literacy of individuals or populations as a basis of intervention development (Osborne et al., 2013). The HLQ examines nine areas of health literacy which is shown in Figure 1.4. The data collected from the HLQ allows the development and selection of effective strategies and opportunities to improve equity in health outcomes and access (Dodson et al., 2014).

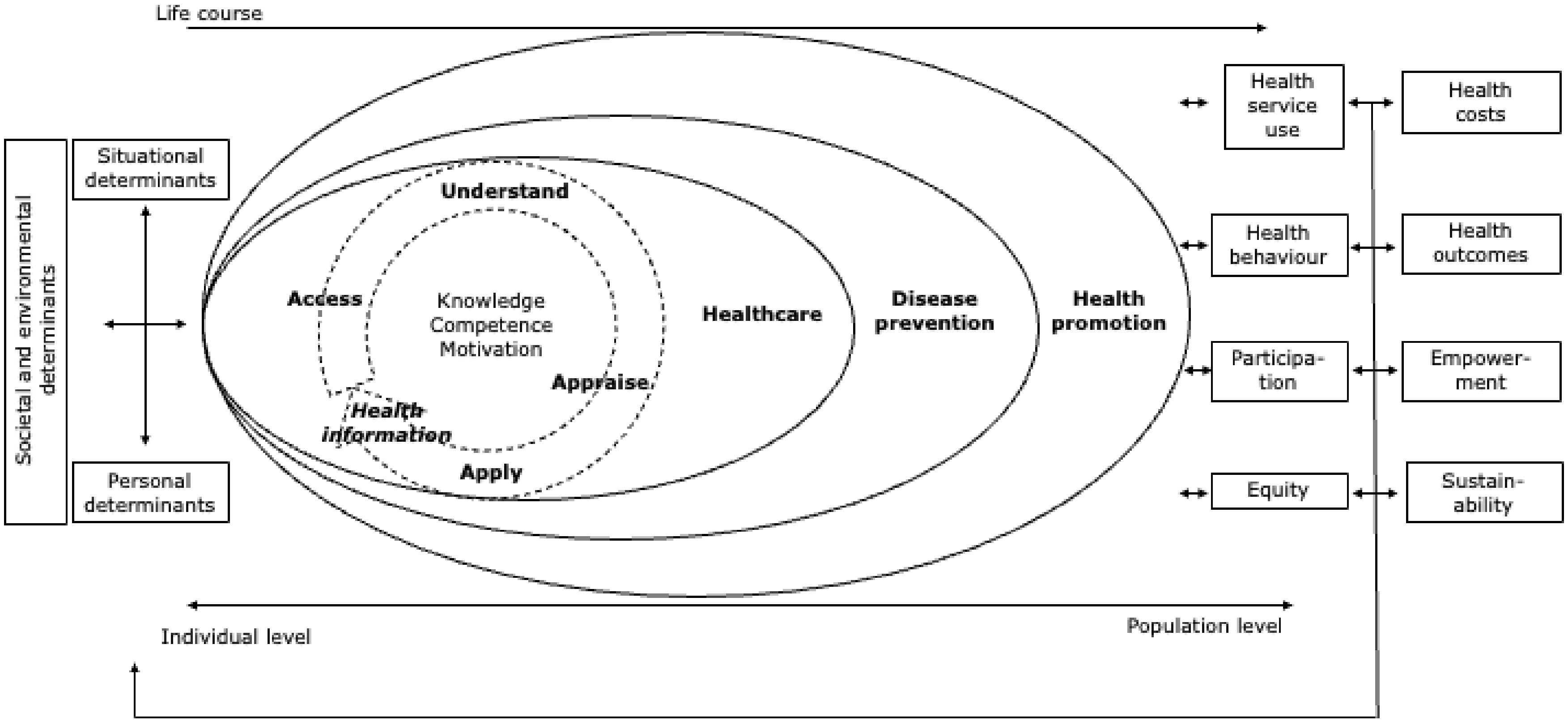


Figure 1.3: Integrated model of health literacy (Sørensen et al. 2012)

The importance of health literacy measurement allows strategic planning and delivery of interventions that help improve health outcomes and strengthen the health systems (Osborne et al., 2015). It will also help in improving the communication between healthcare providers and patients as it will alert healthcare providers to potential problems with literacy among patients, and this will assist them to change the way they communicate information appropriately (Mayer & Villaire, 2007). Therefore, to assess patient's health literacy in a given setting, the most appropriate measurement tool to use depends on the purpose of the data collection and aims of the project (Osborne et al., 2015).

Figure 1.4: The nine scales of Health Literacy Questionnaire (Osborne et al. 2013)

A qualitative study to investigate health literacy issues among Chinese American immigrants with diabetes found that there were several issues as to why they are having difficulty obtaining, processing and understanding diabetes related information. The factors found to potentially affect different components of health literacy among these group of patients were cultural factors, structural barriers and personal barriers (Yee et al., 2014). One of the meanings or interpretations under cultural factors is to do with the perception of patients on the paternalistic behaviour of a doctor where participants felt that they need to listen to doctor’s instruction, and patient involvement in decision making in treatment regimen is limited (Yee et al., 2014). Hence, this limits the patients to obtain information and communicate with their doctors effectively. For structural barriers, one of themes identified was lack of health insurance and high cost of health care that affect access to health information and delay in getting treatment, and for personal barriers, Yee et al. found that unawareness of self-care responsibility among the patients affect their ability to obtain information, communicate with healthcare providers and their capacity to understand the choices of treatment and self-care (Yee et al., 2014).

1.2.5 Self-care

Self-care is defined as "the ability of individuals, families and communities to promote health, prevent disease, maintain health and to cope with illness and disability with or without the support of a healthcare providers" (World Health Organization, 2022). Self-care is a crucial step to improving health and quality of life as well as contributes towards universal health coverage (UHC) and health equity (International Pharmaceutical Federation (FIP), 2022). The International Self-care Foundation (ISF) has developed a framework for self-care which evolved around the seven "pillars" or "domains" (see Figure 1.5) which describes the set of activities that may be taken on to improve and preserve highest levels of health and quality of life (El-Osta et al., 2019). The first pillar focuses on the knowledge and health literacy of an individual on health, disease and self-care. Hence, health literacy and self-care are both equally important as empowering patients through increased health literacy would result in improved health outcomes.

Figure 1.5: The Seven Pillars of Self-care (ISF 2019)

There are seven essential self-care behaviours in people with diabetes which predict good outcomes (Shrivastava et al., 2013). They are healthy eating, being physically active, monitoring of blood sugar, compliance with medications, good problem-solving skills, healthy coping skills and risk-reduction behaviours (Shrivastava et al., 2013). Individuals with diabetes have been shown to make a dramatic impact on the progression and development of their disease by participating in their own care (Shrivastava et al., 2013). With strong health literacy, patients can understand information given by healthcare providers and use the resources accordingly. Poor or low health literacy among T2DM patients may affect self-care behaviour as they may misinterpret the information given or do not follow instructions, for example, diet plan that has been set up to help control good glycaemic level. Hence, addressing and improving health literacy can contribute to self-care empowerment and adherence to diabetes management.

1.2.6 Role of pharmacists

The role of pharmacists in patient care has starting to expand beyond traditional dispensing duties which involves a broader scope of active participation in patient counselling and education. The self-care readiness index which was launched by the Global Self-care Foundation highlights that pharmacists have an important role in driving the second enabler of its framework which is consumer and patient empowerment (International Pharmaceutical Federation (FIP), 2022). This is because pharmacists have daily direct contact with patients and therefore may empower patients to make better-informed health choices. They could also contribute to the provision of UHC by supporting individuals in adopting healthy lifestyle choices and behaviours by encouraging positive daily habits related to nutrition, physical activity, mental health, sleep and general health routines (International Pharmaceutical Federation (FIP), 2022). Health literacy is one of the important pillars of self-care and individuals with low health literacy may tend to abandon self-care. Thus, pharmacists can play a major role in improving individuals' health literacy levels and empowering self-care behaviours as they are seen as trusted sources of information which are accessible to everyone.

In Malaysia, we have a two-tier healthcare system which consists of public and private sectors. The public sectors are funded by the government, and most Malaysians will get their regular prescribed medicines from the public hospitals or health clinics. Whereas the private sector consists of private hospitals and general practice clinics which provide fee-for-service basis and mainly caters for people who can afford to pay for the services (Hassali et al., 2009). Currently, people who visit clinics will be seen by doctors and have medication dispensed at the same time as doctors are legally allowed to prescribe and dispense medications in their clinics under the Poison Act 1952 (Hassali et al., 2009). Community pharmacies, or also known as retail pharmacies in Malaysia are included in the private sector and they can be easily accessed by the public to obtain supplements, over the counter medicines, or health advice.

The most common services provided by Malaysian pharmacists found in a narrative review were diabetes medication therapy adherence clinic (DMTAC), home medication review, patient education programme, and pharmaceutical care involving T2DM patients (Karuppannan, 2019). The Medication Therapy Adherence Clinic (MTAC) was introduced in public hospitals in Malaysia in 2004 to increase patient medication adherence (Pharmaceutical Services Division, 2013). The service involves the collaboration of doctors and pharmacists to enhance the pharmaceutical care of patients with disease for example, diabetes and heart problems, and patients who are on certain medications, for example warfarin. In 2010, a paper on the evaluation of a pharmacist managed DMTAC was published and reported that the programme resulted in significant improvement on patients' clinical markers (HbA1c, glucose and LDL cholesterol) and medication adherence (Lim & Lim, 2010). Therefore, further exploration on the role of pharmacists, especially community pharmacists, in improving newly diabetes patients' health literacy and self-care is needed.

1.3 Study rationale

The increasing trend of overall diabetes prevalence in the last 10 years in Malaysia calls for important measures to be taken to address this issue. As the development of T2DM can be prevented or delayed by practising healthy lifestyle such as eating healthy diet, losing weight and engaging in physical activities, early intervention is required to increase Malaysian public awareness of diabetes progression by improving people's health literacy and empowering self-care behaviours. It is reported that even though the rate of screening for diabetes complication has improved over the years in Malaysia, the outcome care such as glycaemic control and proportions of patients with complications has not improved and hence, further exploration into the reasons behind this may need to be pursued (Ministry of Health Malaysia, 2020b).

Low health literacy has an impact especially on diseases which are best controlled by self-management such as T2DM, as there is a risk of possible complications, for example, severe hypoglycaemia (Osborne et al., 2015). Patients with T2DM who are, for example, taking a glucose lowering drug such as a sulphonylurea, and insulin require additional understanding to prevent admissions for hypoglycaemia and overuse of hospital resources. Lacking knowledge could lead to poor management of disease in terms of dosing, identifying side effects of medicines taken and interpreting blood glucose levels. With poor understanding, disease progression and complications that arise can affect a patient's quality of life which results from poor medicine adherence and no empowerment for self-care. In a study done by Al Sayah et al. (2013), the results indicated that low health literacy is consistently associated with poorer diabetes knowledge (Al Sayah et al., 2013). Thus, assessing and managing low health literacy is important to help patients with diabetes stay safe, informed and well controlled (Watts et al., 2017). Studies conducted by Abdullah et. al (2019, 2020) reported that the global data on limited health literacy among T2DM patients and research on health literacy in Malaysia is limited and most published studies focused on general health literacy (Abdullah et al., 2019, 2020). To understand better the factors and burden of T2DM patients to low health literacy, further studies need to be conducted to explore the contextual factors before developing and implementing interventions to improve health literacy among T2DM patients (Abdullah et al., 2019).

Currently, there is little insight from the perspective of pharmacists on the poor health literacy and self-care among T2DM patients (Kairuz et al., 2015). The accessibility of pharmacy services to the public provides a strong position for community pharmacists to assist T2DM patients with health literacy challenges. Pharmacists, especially in the community sector, can play an important role in diabetes care by screening patients who are at higher risk of developing T2DM, assessing patients’ health status and educating and empowering them about medication and self-care as well as referring the patients to other healthcare providers as appropriate (Campbell, 2002). A study which assessed the effect of community pharmacist-provided extended diabetes care on the changes in patient-reported behaviours and clinical markers showed that even though there were no significant improvements in clinical markers of intervention group compared to the control group, the study reported that patients who received the service were more engaged in healthy diabetes self-care activities (Doucette et al., 2009). Hence, it is crucial to further explore the perspectives of pharmacists on their roles to provide quality diabetes care.

A descriptive study investigating the self-care practices of Malaysian adults with diabetes showed that even after the recognition of the importance of self-care, the majority of the subjects continued to have problems understanding and practising appropriate self-care management (Tan & Magarey, 2008). The study recommended that a qualitative study should be conducted to explore the insight on the discrepancy between the perceived importance of self-care practices and the actual behaviour of these patients. Another qualitative study which investigated the goals, beliefs, knowledge and barriers for diabetes self-care in a multi-ethnic population in Malaysia found that the major theme of patient's goal is to obtain a better blood glucose control (Saunders et al., 2019). However, the exploration of what these patients are doing to achieve this goal and to understand what is important in empowering self-care practices is not thoroughly discussed.

The focus of this study is to provide the understanding of pharmacists and newly diagnosed T2DM and pre-diabetes patients views and experiences to the importance of health literacy and self-care in managing diabetes and preventing diabetes progression. Qualitative research is seen as the most appropriate approach to use in this study to enable rich and detailed exploration of patients' and pharmacists' perspectives to self-care behaviours.

1.4 Aims and objectives

The aim of this study is to explore both patients' and pharmacists' perceptions of disease knowledge and management among patients with type 2 diabetes mellitus and pre-diabetes in order to empower self-care behaviours in preventing disease progression. The objectives of the study are to:

- To explore pre-diabetes and newly diagnosed type 2 diabetes mellitus patients up to 5 years on their diabetes knowledge and its management.
- To identify what empowers these patients to practise self-care.
- To assess the health literacy level and to identify the strengths and limitations of health literacy of the patients recruited in this study.
- To explore the perspectives of pharmacists who are working in private and public healthcare facilities in Malaysia on their interactions with these group of patients to promote self-care behaviours.
- To identify how can pharmacists contribute to preventing diabetes progression.

CHAPTER 2 METHODOLOGY AND METHODS

2.1 Introduction

In this chapter, the methodology and methods of this study will be discussed in detail. The first section discusses the ontological and epistemological positions of the study followed by the rationale behind choosing qualitative approach instead of quantitative approach. I will then discuss the use of narrative research, and thematic analysis as the tools to analyse the data of this study. In section 2.3, the quality in qualitative research is discussed where I write about the steps I have taken to ensure rigour.

In section 2.4, the methods of this study are discussed. The methods section starts with the discussion of sampling and selection, followed by sample size, ethics approval, the study sites used, recruitment of participants and confidentiality. The next section focuses on data collection, transcribing as well as the translation processes. In section 2.4.10, I discuss the Health Literacy Questionnaire (HLQ). Finally, in section 2.5, the discussion on data analysis of the study takes place.

2.2 Methodology

2.2.1 Ontology and epistemology positions

There are two broad research approaches that are commonly used in health services and pharmacy practice research i.e., qualitative, and quantitative approach. They are different in terms of their essential elements on ontological and epistemological positions, theoretical perspectives, methodology and methods (Yilmaz, 2013).

Ontology is related to the nature of reality and existence or "what is out there to know about" (Grix, 2002; Holloway & Wheeler, 2010). The key ontological questions are concerned about whether that the social reality exists independently from human perceptions and interpretations or whether we think it cannot be separated from human practices and hence, knowledge is going to reflect our perspectives and interpretations (Braun & Clarke, 2013d; Ormston et al., 2014). There are two very broad terms that shaped the two ontological positions in relation to the questions, which are realism and relativism. Realism assumes a knowable world and an external reality exists independently of human beliefs and understandings. It assumes that there is only one truth out there which can be accessed by the appropriate application of research techniques (Braun & Clarke, 2013d). Realism is the ontological position which underpinning most of quantitative research and rarely it informs qualitative research. Relativism on the other hand, argues that there are multiple constructed realities, and that reality is fundamentally mind-dependent which is only knowable through the human mind and socially constructed meanings (Braun & Clarke, 2013d; Ormston et al., 2014). A relativism ontological position underpins some qualitative approaches (Braun & Clarke, 2013d). The ontological position of a researcher informs his or her epistemological position as the beliefs about the nature of reality and existence shape the beliefs about the methods and strategies of acquiring the knowledge.

Epistemology is defined as theory of knowledge and what counts as knowledge or "what and how can we know about it" (Grix, 2002; Holloway & Wheeler, 2010). When setting out a framework for research practice, methodology relies on ontology and epistemology (Braun & Clarke, 2013d). The two contrasting epistemological positions are those contained within positivism and interpretivism (Grix, 2002). In quantitative research positivism is used to guide the research methods and analysis (Urquhart, 2013). Positivism is related to objectivity where there is only a single version of what is real and the only way to find the truth and credible data is to measure and analyse causal relationships between isolated variables within *a priori* theories (Urquhart, 2013; Yilmaz, 2013). Whereas in qualitative research, interpretivist paradigm is adopted where the paradigm considers multiple and varied perspectives of what may be real (Urquhart, 2013). The point of qualitative research is to gain insight of people's perspectives and experiences as well as to understand of why people act in the way they do.

As the research questions of this study focuses on the exploration of patients' and pharmacists' perspectives on diabetes knowledge and self-care management, the relativism ontological standpoint was most appropriate because the reality, for example, the experiences of being newly diagnosed with T2DM or pre-diabetes and trying to understand the condition or the experiences of counselling a diabetes patients, is only knowable through people's experiences, feelings and perceptions, which provides us with a foundation for knowledge. The knowledge produced from the exploration and understanding of the people being studied i.e., the newly diagnosed T2DM and pre-diabetes patients as well as pharmacists, sits on the interpretivism epistemological approach where the knowledge gained were constructed for meanings and interpretations.

2.2.2 Chosen methodology and its rationale

In this study, the qualitative approach was adopted. Qualitative approach was chosen instead of quantitative because the latter emphasises in seeking to confirm hypotheses about phenomena by gathering quantifiable data and performing statistical techniques. The former focused more on exploration of the research question by exploring the views and perspective of participants on phenomena. Therefore, the main aim of qualitative research is to gain a better understanding of a phenomena through the experiences of the people that experiencing that phenomenon of interest by recognising the values of the participants' views (Castleberry & Nolen, 2018). As stated by Castleberry et al. (2018), the value of qualitative approach compared to empirical research is that it provides a richer and deeper understanding of the meanings that people place on actions, events, and relationships.

Besides the difference in their general framework, another reason why a qualitative approach was more suitable for this study is because of its flexibility compared to a quantitative approach. In quantitative studies, the content and direction of the questionnaires or surveys are pre-determined and standardised by researchers. Hence, the questions are more "closed-ended", and no further exploration of rich details can be achieved. To be able to explore and understand peoples' perspective, "open-ended" questions need to be asked for people to be free to respond in their own words rather than simply a "yes" or a "no". In this study, the following research questions, using "what" and "how" were employed to obtain rich details of peoples' perspective on T2DM and its management.

As a scientifically trained healthcare professional, pharmacists may be more familiar with the concept of quantitative approach than qualitative because they may have used methods such as surveys, questionnaires, or audits within their own practices (Austin & Sutton, 2014). Though large amount of data can be collected in a healthcare setting through a quantitative approach, they are not able to provide us with the reasons of why people have thoughts and feelings that might affect the way they respond to health care and act the way they do. Hence, conducting qualitative research in a healthcare setting is important and is complementary to quantitative approach as they can be used as a tool to understand emotions, perceptions and actions of people who suffer from a disease (Holloway, 2005). The meaning of the work done by healthcare professionals can also be uncovered through talking to them or observing their interactions with patients. By understanding people's behaviour, the development of effective health and education policies for changing health behaviours can be executed if the reasons for the behaviour are clearly understood (Holloway, 2005). Therefore, the use of qualitative approach was more suitable to answer the research questions of this study.

2.2.2.1 Narrative research

There are different research approaches within qualitative research such as grounded theory, narrative research and phenomenology, and they differ from each other based on the focus and objectives of the research studies (Creswell, 2013). Phenomenology is the reflective study of people's lived experience to understand the essence of an experience, or a phenomenon informed by philosophical assumptions (Creswell, 2013). Grounded theory on the other hand refers to a method used to develop theory grounded in the data through the core process of constant comparison to identify emerging theory throughout the research process (Creswell, 2013; Urquhart, 2013). Meanwhile, narrative approach is a systematic study of personal experience and meaning, and it is very useful for exploring people's thoughts about their experiences of health and illness (Anderson & Kirkpatrick, 2016). The emphasis is on the story, where typically "what" and "how" is narrated. Using this approach, it will help researchers to better understand people's experience and behaviours (Anderson & Kirkpatrick, 2016). As Denzin (2003: xi) suggested, he said that *"We live in narrative's moment. The narrative turn in the social sciences has been taken…Everything we study is contained within a storied, or narrative representation. Indeed, as scholars we are storytellers, telling stories about other people's stories. We call our stories theories"* (Sparkes, 2005).

There are different themes under the narrative approach, i.e., autobiographical self-reflection, biographical data, and representative constructions. In trying to understand peoples' experiences on health and illness, narrative has become a popular approach. This is because when an illness strikes a person, he or she will start to make sense of their illness in personal and social terms (Bissell et al., 2006). This triggers a process where the person will start to find answers to the questions about why the illness happened at the time it did, what it means to them and how it can be explained (Bissell et al., 2006). In other words, for people to make sense of their health and illness, it is clearly through their stories and narratives about the illness. The process of trying to find the true meaning of one’s health and illness can be seen as one of the themes of narrative approach, which is the biographical data. It can be collected using conversational approach, for example, by the interviewing the patients. Biographical data can be a useful way to create a record of experience of patient that is as true to life as it can be at a particular point in time (Bold, 2012).

For this study, a narrative approach would enable the patients to tell their stories about the experiences of being newly diagnosed with T2DM and pre-diabetes, their understanding about the knowledge of the disease and what empowers them to self-care behaviours. The experiences of pharmacists dealing with new patients can also be explored through narrative approach by understanding their personal experiences and feelings talking to diabetes patients and how they can help in empowering self-care behaviours.

2.2.2.2 Thematic analysis

One of the challenges to analysing qualitative research data is due to the open-ended nature of the data as opposed to just numbers only. Thematic analysis (TA) is a method of identifying, analysing, and reporting patterns (themes) within data (Braun & Clarke, 2006). It is known as descriptive method that reduces the data in a more flexible way compared to grounded theory. It is commonly used because a wide range of research questions and topics can be addressed using this method of data analysis (Castleberry & Nolen, 2018). The most common type of qualitative data in pharmacy is gathered from participants' interviews or conducting focus group discussions. Content that gathered from these means of data collection can easily be analysed using TA.

There are three broad "schools" of TA which Braun et al. (2019) refers as "coding reliability", "codebook" and "reflexive TA". The major difference between the three schools of TA lies on whether the research sits on a partially qualitative approach ("small q") i.e., mixed of qualitative techniques and quantitative values, for example, in controlling researcher's bias and subjectivity, or purely qualitative approach ("BIG Q") i.e., uses qualitative techniques and is underpinned by qualitative values (Braun & Clarke, 2022). Coding reliability is a type of TA that is broadly postpositivist in orientation and the coding process is designed to assume reliable and accurate coding by using fixed codebook and multiple independent coders (Braun et al., 2019; Braun & Clarke, 2022). Codebook TA on the other hand, sits in between the partially and purely qualitative approaches or as Braun & Clarke (2022) called it as "medium Q", i.e., combination of qualitative research values of reflexive TA with more structured and fixed approach to coding where some of the themes are pre-determined in advance of full analysis (Braun et al., 2019; Braun & Clarke, 2022). The third "school" of TA is reflexive TA which is located within a qualitative paradigm and involves the active role of the researchers in coding and theme development (Braun & Clarke, 2022).

In this study, the data collected from both participants' interviews and focus group discussion will be analysed using reflexive TA where each text will be analysed for meanings and coded accordingly to develop themes. I will discuss further on data analysis in section 2.5.

2.3 Quality in qualitative research

What makes a good piece of qualitative research? Unlike quantitative research, qualitative research does not have formal criteria widely agreed upon to evaluate its quality. In quantitative research, the research is considered good research when it is reliable, valid, and the results obtained are generalisable. Antirealists argued that it is not possible to judge qualitative research by using conventional criteria such reliability, validity, and generalisability (Mays & Pope, 2000). Nevertheless, there are various ways that can be taken to ensure validity in qualitative research which I will explain in the next section.

2.3.1 Reliability, validity, and generalisability

Reliability is defined as the possibility of generating consistent results when the same measures are administered by different researchers to a different participant group (Braun & Clarke, 2013c). Validity can be defined as the extent to which a concept accurately measured what the research question has aimed to measure and claimed to show (Braun & Clarke, 2013c; Heale & Twycross, 2015). The reliability and validity terms are widely used in quantitative research to measure the quality of the research (Heale & Twycross, 2015). In qualitative research, rigour is used to establish trust and confidence in the findings or results of a research study (Thomas & Magilvy, 2011).

There are different models available that can be used to assess rigour in qualitative research such as the model of trustworthiness proposed by Lincoln and Guba (1985), where the model addresses four components of trustworthiness which are relevant to qualitative research and they are credibility, transferability, dependability, and confirmability (Thomas & Magilvy, 2011). Credibility is defined as the ability to allows others to recognise the experiences contained within the study through the interpretation of participants' experiences (Thomas & Magilvy, 2011). There are various ways to establish credibility such as triangulation, member checking, reflexivity, attention to negative cases and fair dealing (Mays & Pope, 2000; Stahl & King, 2020; Thomas & Magilvy, 2011). Transferability in qualitative research which is similar to generalisability in quantitative research, is the ability to transfer research findings or methods from one group to another and this is established by providing thick description of the research study (Stahl & King, 2020; Thomas & Magilvy, 2011). The third component of trustworthiness is dependability, or the trust in trustworthiness which refers to the reliability and consistency of the research design and findings, allowing someone outside the research to follow or audit the research process (Stahl & King, 2020; Thomas &

Magilvy, 2011). Lastly, confirmability which is similar to objectivity in quantitative research occurs when credibility, transferability and dependability have been established by being reflexive and open to refutation (Thomas & Magilvy, 2011).

In this study, studying the perspectives of different target groups i.e., the patients and pharmacists can be considered as a way of triangulating the findings. Member checking was also used in this study where a transcribed interview script was returned to the participant, because of the occurrence of internet disruptions during the interview which affected the transcription process, to check for errors and generate the true data. In section 2.3.2, I will talk more about reflexivity and the steps I have taken to be reflexive throughout the study.

2.3.2 Reflexivity

Reflexivity is viewed as the process of a continual internal dialogue and critical self-evaluation of researcher's positionality, for example, age, gender, race, personal experiences and professional beliefs, as well as active acknowledgement and explicit recognition that this position may affect the research design, data collection and research findings (Berger, 2015). Hence, it is important that researchers make sure that they enter the research process with the right instrument and ignores any pre-conceived ideas about the topic under study, and the role should be prompt, probe and encourage participants' views of their experiences (Jootun et al., 2009). There are several ways that can be done to promote reflexivity, for example, keeping a diary to record what is influencing the interpretation of data and our relationship to the study and the participants (Jootun et al., 2009). We should also be open to refutation by being explicit on how we design the study, how we collect data and how we approach data analysis for people who are reading the study can make judgement about how open we are to refutation. To avoid biases as well as to promote rigour, it is important for the researchers to understand the role of their self in the creation of knowledge by carefully monitoring the impact of biases, beliefs, and personal experiences on their research (Berger, 2015).

In this section, I will discuss about myself and how my identity may influence the study. Before joining the PhD programme, I worked as a community pharmacist for 6 years in the United Kingdom (UK) and 2 years in Malaysia. In 2018, I worked as a lecturer in pharmacy for 2 years in Kuala Lumpur. Professionally, I have prior knowledge about diabetes and its management. Personally, I have had experience dealing with the condition itself when I was diagnosed with GDM when I was pregnant with my daughter. Having said that, I felt that I did not really have the true insider role or pre-conceived ideas for both patient and pharmacist participants because when I was working as a community pharmacist in Malaysia, the pharmacy I worked at is in a very busy public hospital and most of the diabetes patients that visited the pharmacy were not newly diagnosed T2DM or pre-diabetes patients. And as for my GDM, even though I understood what the participants felt when they mentioned about difficulty of having to change their diet, I felt that my personal experiences did not influence how I conducted the study because my GDM was well controlled. As a pharmacist, I felt that some of responses that I received from patients for example, on their adherence on medications, could lead me giving them advice, but I refrain myself for doing so and instead I asked why they were not taking their medications as directed to gain more in-depth answers. In terms of pharmacists, again because of my short time working in Malaysia and because I did not have any experiences working in a hospital or public health clinic, I was not familiar with most of the standard operating procedures and guidelines. Hence, there were no pre-conceived ideas beforehand.

When conducting the interview with patients, I introduced myself as a PhD pharmacy student from University of Nottingham Malaysia and that I am doing a study on type 2 diabetes and pre-diabetes where I will be looking into their experiences and perceptions of the condition and its management. I did not introduce myself as a pharmacist because I did not want participants to feel that the interview is a formal interview conducted by a healthcare provider as I want them to speak freely and truthfully as well as to feel at ease and relax during the interview. I also found that when introducing myself as a student, participants were helpful, and they were more open to talk about their experiences with doctors and pharmacists. One participant even mentioned about helping me out because she would want people to help her son if he had to conduct research or interview like this. For pharmacists, most participants knew that I am a pharmacist and a PhD pharmacy student. However, that did not hinder the rapport and the flow of the conversation.

Keeping a diary provides the opportunity for researchers to engage with their regular self-conscious reflection on one’s impact on the participants and the interviews conducted (Murphy & Dingwall, 2003). Hence, I use both notebooks and the function “Memos” under the “Notes” on the NVivo® software to include my thoughts or ‘discussions with myself’ after each interview. The memos can be linked to the particular sources for easy access.

Throughout this thesis, I will be reporting the steps that I have taken to be reflexive and to ensure rigour, for example, in section 2.4.9, I explained about sharing the same language and culture with the participants to ensure no meaning losses during translation process.

2.4 Methods

2.4.1 Sampling and selection

Sampling strategies in qualitative research differ in many ways to quantitative research and within qualitative research itself, sampling strategies are decided based on the qualitative approach used (Gill, 2020). In this study, purposive sampling was used. Purposive sampling involves the identification and selection of targeted individuals who would have the experience on the study matter with the aim of generating insight and in-depth understanding (Braun & Clarke, 2013b; Smith, 2005). Purposive sampling involves selecting information-rich data cases, for example, participants, for an in-depth understanding of the research questions (Patton, 2002). In this study, the participants were purposively selected, the newly diagnosed T2DM and pre-diabetes patients as well as pharmacists who are practising in Malaysia, to understand what empowers these groups of patients to practice self-care and what pharmacists can do to encourage self-care respectively.

Another sampling strategy that was adopted in this research is snowball sampling. It is also known as chain referral sampling and is considered a type of purposive sampling (Family Health International, 2012). In this method, the participants recruit future participants using their social contacts or refer the researchers to other people that could potentially participate in the study (Family Health International, 2012). This method of sampling was used to recruit pharmacists where some of the existing participants helped to invite more pharmacists to participate in this study. The details of the recruitment process of patients and pharmacists are discussed in section 2.4.5.1 and section 2.4.5.2 respectively.

2.4.2 Sample size

Determining sample size in quantitative research is usually guided by power calculations from the law of statistics and probability to demonstrate the effects of a certain magnitude from an intervention (Malterud et al., 2016). This is not the case in qualitative research as there are no similar standards for assessment of sample size exist (Malterud et al., 2016). One of the concepts that can help in the question of how many samples or data you need in a qualitative study is saturation which refers to the point when additional data fails to generate new information, codes, or themes (Braun & Clarke, 2013b, 2021b). However, data saturation which is evolved from theoretical saturation is a concept which is originally tied to a specific methodology developed by Glasser and Strauss (1967) as a specific element of constant comparison in Grounded Theory (Braun & Clarke, 2021a; Malterud et al., 2016). As written by Morse (2000), to reach data saturation, factors such as the scope and the nature of the study, the quality of data and the study design need to be considered (Morse, 2000). However, I am using reflexive thematic analysis to analyse my data, the term "no new" makes little sense because as stated by Braun & Clarke (2021), data saturation is not a universally useful or meaningful concept for all types of thematic analysis research (Braun & Clarke, 2021b). In a reflexive organic process, analysis can never be complete because researcher makes a situated, interpretative judgement about when to stop coding or when to stop theme generation and map thematic relationship for the final written report (Braun & Clarke, 2021b). Coding and theme development is an iterative process where researcher can move back and forth and meaning generated requires the active role of interpretation and hence, there is always the potential for new understandings or insights generated (Braun & Clarke, 2021b; Mason, 2010). Therefore, determining sample size based on data saturation as there is no new information emerging from the data cannot be regarded as the gold standard in all qualitative research.

Another concept which was proposed by Malterud et al. (2016) in guiding adequate sample size in qualitative research is to use information power. The concept of information power means the larger information power the sample holds, the lower the sample size is needed, and vice versa (Malterud et al., 2016). They suggested that the size of a sample with sufficient information power depends on the aim of the study, sample specificity, use of established theory, quality of dialogue and analysis strategy (Malterud et al., 2016). They concluded that a study would need the least number of participants when the aim of the study is narrow, if the combination of participants is highly specific for the aim of the study, if it supported by established theory, if the interview dialogue is strong and if the analysis includes longitudinal in-depth exploration of narrative or discourse detail; and if the aim of the study is broad, the combination of participants is less specific for the research questions, it is not theoretically informed, the interview dialogue is weak and the cross-case analysis is conducted then a larger number of participants is needed (Malterud et al., 2016).

Though it is difficult to determine in advance the number of participants required in qualitative research, initial approximation is sometimes needed to plan the research design and to obtain ethical approval from the ethics committee. The sample size in qualitative research is generally smaller compared to quantitative research as we are looking into in-depth understanding of participant's experience and perception of the research question and with the amount of data produced, more time is needed to analyse it. The aim of this research is neither too narrow nor too board but the specificity of the participants who belong to specified target group exhibited some variations within the experiences to be explored would suggest that perhaps the least number of participants are needed. In terms of the established theory, I am looking into new knowledge on health literacy and self-care behaviours and as there are models which have been developed within both topics, they could be used to support the level of the theoretical background of this study. However, information power is also related to the quality of the interviews conducted. Though I have been working as a community pharmacist before where I communicated with patients daily, I am still new at doing research and conducting research interviews and focus groups. Therefore, more participants might be required to build up my interview skills. Also, there were some interviews where the participants' responses were not rich and meaningful, hence, more participants need to be recruited and interviewed as I went along the data collection process. As for the analysis, because this is an explorative research where only selected patterns relevant to the research aim is to be presented, a larger number of participants are not required. With all the points stated above and the factors on information power were taken into consideration, at the end of the data collection, 36 participants were recruited and interviewed (22 patients and 14 pharmacists) in this study.

2.4.3 Ethics approval

Permission for conducting this research at the Ministry of Health (MOH) facilities in Malaysia is obtained from the National Medical Research Registry (NMRR). NMRR is a web-based service initiated by the National Institutes of Health (NIH) of the MOH to support the implementation of the NIH guidelines on the conduct of research in the MOH. All research that is conducted in MOH facilities requires registration and approval by the MOH. The registration of this research was done through NMRR website and once application is submitted, the submission was then forwarded to the Medical Research and Ethics Committee (MREC) for review and approval.

Application for this research was submitted to NMRR on 15 May 2020. Research proposal, patient information sheet and consent form both in Malay and English languages (see appendices 1, 2, 3 and 4), and all other supporting documents were submitted together with the application. The application was then passed to MREC, and a 1-year ethical approval was approved and received on 12 August 2020 (see appendix 5). Once the research is approved, permission letter to use MOH facilities must be sent to respective health clinics which I will explain in detail in the next section. Due to the COVID-19 pandemic, annual ethical renewal was submitted on 16 June 2021 to NMRR to gain permission to extend the course of the study. The request was approved by MREC on 1 July 2021 and the study gained 1-year extension of the ethical approval up to 11 August 2022 (see appendix 6).

This research also received ethics approval from the Science & Engineering Research Ethics Committee (SEREC) of the University of Nottingham Malaysia on 10 May 2020 (see appendix 7). Amendment was made on the end date of the research on 15 June 2021 and approved on 16 June 2021 (see appendix 8).

2.4.4 Study site and local state health department approval

Two public health clinics were selected as the study site. Both clinics are in the Klang Valley. Public health clinics were selected for this study because mostly newly diagnosed T2DM and pre-diabetes patients go to these clinics for their regular appointments. In Malaysia, there are two types of clinics under the MOH which are *Klinik Desa* (smaller clinics located in villages) and *Klinik Kesihatan* (public health clinic). The public health clinics are usually located in different districts under their state health department. The clinics are much bigger, and they are equipped with laboratory, x-ray machine and pharmacy as well as different healthcare personnel, for example, doctors, nurses, dietitians, and pharmacists.

Study site 1, THC, is one of the oldest healthcare facilities built in Malaysia is in Kuala Lumpur. Around 500 to 600 patients visit THC daily and the clinic offers different types of healthcare services such as screening for NCDs, smoking cessation clinic, Diabetes Medication Therapy Adherence Clinic (DMTAC) and many other services. THC runs their diabetes clinic every Tuesday, Wednesday, and Thursday.

KDHC is the second study site which is in Selangor. Like THC, KDHC offers different type of healthcare services such as *"Klinik Warga Sihat"* (Being Healthy Clinic) which includes the screening for NCDs, diet counselling as well as smoking cessation clinic. They run their diabetes clinic every Tuesday, Wednesday, and Thursday and usually pre-diabetes patients will attend their appointments in the afternoon.

Before going to the study site, permission letter to use study site must be sent to their respective state health department. Since THC is in Kuala Lumpur, it is under the jurisdiction of the Lembah Pantai Health Office (LPHO) of Wilayah Persekutuan

Kuala Lumpur & Putrajaya Health Department (WPKL&PHD). Permission letter was sent to the head of LPHO on 18 August 2020 and a copy of research proposal was sent to the WPKL&PHD in September 2020. Letter of approval from the department was received on 23 September 2020 (see appendix 9). Patient recruitment from THC started in November 2020 after a brief meeting with the deputy head of the LPHO and the head of clinic of THC. Due to social distancing rules, I was only allowed to spend two hours at the waiting area of the clinic to recruit patients.

Permission letter to use KDHC as the study site was sent to the head clinic of KDHC and the medical officer in charge of the Selangor Health Department (SHD) via email on 29 August 2020. I was invited by the SHD for a presentation to explain about my research plan on 23 September 2020. On 5 October 2020, I received the letter of approval to use KDHC as one of my study sites for patient recruitment (see appendix 10) and to contact the person in charge (PIC) of Petaling Health Office (PHO). There was a delay in getting response from the training department of PHO because the PIC was involved in the COVID-19 infection prevention and control. I started my patient recruitment in KDHC in March 2021.

2.4.5 Recruitment of participants

With the sudden emergence of the pandemic due to the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) or famously known as COVID-19 at the end of 2019, the recruitment of patient participants from the public health clinics for this study was delayed. With the restriction in movement and social distancing rules, I was not able to interact with people face-to-face and had to recruit participants virtually. In the next sections (2.4.5.1 and 2.4.5.2) I will explain in detail how recruitment of patients and pharmacists were done during the pandemic.

2.4.5.1 Patients

The patient participants in this study were patients who are newly diagnosed with T2DM up to 5 years as well as patients who have pre-diabetes. The recruitment process is designed to be inclusive where individuals from diverse racial backgrounds including Malay, Chinese, Indian, Bumiputera Sabah, Bumiputera Sarawak and others were included. The eligibility extends to individuals aged 18 years old and above, and those with co-morbidities such as hypertension or hypercholesteremia provided that they have been newly diagnosed with T2DM or pre-diabetes within the last five years.

A study examining medication burden within the first 5 years following T2DM diagnosis found that individuals diagnosed with T2DM have a high medication burden at diagnosis which increases over time, especially for those who have a higher cardiovascular risk and those who receive intensive treatment (Black et al., 2015). Furthermore, in a three-year follow-up study assessing the effectiveness of a diabetes education and self-management programme for newly diagnosed T2DM patients, improvements were observed in illness beliefs among the participants (Khunti et al., 2012). However, no significant differences were found between the intervention and control groups in clinical outcomes such as HbA1c, blood pressure and lipids (Khunti et al., 2012). It was suggested that a longer follow-up period is needed to generate a deeper understanding on the intervention effects over time (Khunti et al., 2012). Therefore, the focus of this study was to look on patients who are diagnosed up to 5 years to understand their perspectives and experiences of their diagnosis in empowering self-care behaviours.

Moreover, the study also focused on newly diagnosed T2DM and pre-diabetes patients due to the increasing trend of prevalence of known diabetes and undiagnosed diabetes among younger Malaysian adults (aged 49 years and below)

(Institute for Public Health (IPH), 2020). It is also found that younger adults (aged 18 – 45 years old) diagnosed with T2DM are more likely to develop cardiovascular disease compared to older patients (Hillier & Pedula, 2003). In addition, early treatment and lifestyle intervention of pre-diabetes is found to reduce the progression of diabetes (Cai et al., 2020; Kosaka et al., 2005; Ramachandran et al., 2006; Tuomilehto et al., 2001). Therefore, by understanding the views and experiences of newly diagnosed T2DM and pre-diabetes patients on diabetes management and self-care, it would enable us to improve the support and access new patients need to empower self-care behaviours.

According to the MOH's T2DM guideline, the screening test in MOH facilities using capillary plasma glucose can be performed using standard glucometers. If the random capillary plasma glucose is ≥7.8 mmol/l or fasting is ≥5.6 mmol/l, a confirmatory test needs to be performed using the fasting plasma glucose (FPG), oral glucose tolerance test (OGTT) or HbA1c.

Individuals with HbA1c level of more than 6.3% is considered to have diabetes and individuals with HbA1c level between 5.7% and 6.2% will be deemed as having pre-diabetes. Pre-diabetes increases the risk of progression to T2DM; therefore, it is crucial to delay or stop the progression of pre-diabetes to T2DM (Ministry of Health Malaysia, 2020a). In the guideline, it is recommended that pre-diabetes patients to undergo diet modification and increase physical activity, as these interventions has proven to reduce the conversion of impaired fasting glucose (IFG)/impaired glucose tolerance (IGT) to T2DM. Metformin can be considered for those at very high risk, in addition to lifestyle intervention. People at very high risk are those with combined IFG & IGT, IGT only and obese, IGT only and over 60 years old, previous history of GDM or those who failed lifestyle intervention after 6 months (Ministry of Health Malaysia, 2020a). The management of newly diagnosed T2DM patients depends on their HbA1c level and fasting plasma glucose (FPG) as suggested in the 6th edition of Clinical Practical Guidelines (CPG): Management of T2DM.

Patient inclusions criteria for this study were:

- Malaysian individuals who are diagnosed with pre-diabetes and T2DM up to five years.
- Aged 18 years and above.

Patient exclusion criteria for this research were:

- Individuals diagnosed with diabetes other than pre-diabetes or T2DM.
- Individuals diagnosed with pre-diabetes or T2DM more than 5 years.
- Individuals who are diagnosed with severe medical conditions or mental health problem e.g., patients with dementia or psychotic disorders, that could possibly affect their ability to give consent or answer questions.

Patient participants were recruited virtually and face-to-face. Recruitment posters both in Malay and English languages (see appendices 11 and 12) were shared on social media platforms such as Instagram, Twitter and on a Facebook group called "Malaysian Diabetes Club", as well as through instant messaging application, WhatsApp. Approval from the administrator of the Facebook group was required before the poster was broadcasted to the members of the group. The poster was also shared to the National Diabetes Malaysia (NADI) through email. A brief description of the study, my contact details, and instructions on how to participate were included in the poster. Registration link and quick response (QR) code which are linked to a Microsoft Form were also provided on the poster for interested individuals to register. Notification emails were sent to my email to notify that forms have been filled by interested individuals. I would then contact them via email or WhatsApp to check if they fitted my sampling criteria and arranged for an interview date and time.

When the Movement Control Order (MCO) was lifted, and Malaysia entered the Recovery Movement Control Order (RMCO), I was allowed to recruit participants from the public health clinics while adhering to very strict rules of social distancing. At THC, I had two hours to recruit patients in the clinic's waiting area. I approached individuals waiting for their turns to be seen by the doctors. However, since there were people with various health conditions waiting, I had to inquire first if they had diabetes. If the answer was yes, I explained about my study and checked if they met the inclusion criteria outlined above. Those who agreed to participate were provided with participant information sheet and consent form. Out of 11 diabetes patients approached, four agreed to participate, four did not meet the criteria (diagnosed more than 5 years), one could not be contacted afterward (Malay, male, T2DM) and two did not agree to participate (1 Indian, female, T2DM; 1 Indian, Male, T2DM).

At KDHC, I was provided with a room, and doctors directed patients to my room if they fit my sampling criteria. In the room, I explained about my study in more detail and assessed eligibility for participation. Once patients agreed to participate, I provided them with participant information sheet and consent form. In total 12 patients were referred by the doctors, but one did not agree to participate (Malay, female, pre-diabetes). In addition, the room was also used by medical assistants to do eye and feet assessments of diabetic patients. Hence, because of lack of privacy and the standard operating procedures (SOPs) I had to adhere to, only recruiting process was done in KDHC.

2.4.5.2 Pharmacists

The pharmacist participants in this research were pharmacists who are working in any public or private healthcare facilities in Malaysia.

Pharmacists are considered as one of the diabetes educators in educating patients with T2DM, where they play a role in ensuring medication adherence and providing information about medication and side effects (Ministry of Health Malaysia, 2020a). Pharmacists could be a key player in improving people's health literacy and self-care behaviours due to its easy accessibility to the public.

Inclusion criteria for this study were:

- Fully registered pharmacist who are registered with the Pharmacy Board Malaysia.
- Pharmacists who are working in public health clinics, public or private hospitals or community pharmacies in Malaysia.

Exclusion criteria for this research were:

- Pharmacists who are not currently practising in their profession.
- Pharmacists who are currently working overseas.

Pharmacists were recruited virtually through the sharing of recruitment poster (see appendix 13) on "Locum Pharmacists Malaysia" group on Facebook and on WhatsApp. The "Locum Pharmacists Malaysia" group is a support group for Malaysian pharmacists practising in Malaysia who are looking for locum slots and the group is comprised of pharmacists who work full time or part time in various healthcare facilities in Malaysia. Again, approval from the group administrator was required before the poster was made available to the members of the group. And like the patient recruitment poster, brief description of this study, my contact details, and instructions on how to participate were included. Registration link and QR code which was linked to a Microsoft Form were also included on the poster for interested pharmacists to register. Notification emails were sent to my email, and I will contact them to check if they fitted my sampling criteria and arranged for the interview session.

2.4.6 Confidentiality

Participants who were recruited online and agreed to participate received the participant information sheet outlining the study and the confidentiality arrangements, together with a copy of consent form (see appendices 14, 15, 16 and 17 for pharmacists) via email or WhatsApp, while the ones who were recruited from the public health clinics and agreed to participate, the participant information sheet and consent form were given to them in person. All the participants were given adequate opportunity to consider all options, ask questions about the study and time to consider their participation before setting up the interview date and time.

All information collected from the participants is kept confidential. All field notes, transcriptions and recorded audio and video recordings were secured in a lockable cabinet and stored thereafter for six years. All electronic information collected is kept strictly confidential and stored in a database which is password protected. All attempts were made to protect the identity of the participants, and places or persons mentioned in the interviews or focus group discussion by the usage of pseudonyms. Names of hospitals, clinics and pharmacies were also disguised as well as the names of participants. Participants were also informed that all information on interview transcripts is kept confidential and maintained for six years for future reference for the purpose of publication of reports or peer reviewed publications, whereby after this period they will be professionally destroyed.

During focus group discussion, participants were briefed on the ground rules of the focus group such as to refrain from mentioning any confidential information that may identify or could potentially identify any patient (see appendix 18). They were also informed that any information from the focus group discussion must not be shared or repeated to others from outside the study.

Any personal information obtained from the participants or any study data and results from this study were not placed in the patient's medical record or used for the patient's medical care. Participants were also informed that they have the right to request access to their own personal information. However, information from the study data that could potentially identifies individuals from the study is exempted from this right of access to protect the identity of all participants in the study. Participants however can request a summary of the study if they want to.

2.4.7 Qualitative data collection

Narrative interviewing is a method that can be used to collect people's accounts, or stories, of their experiences (Ziebland et al., 2013). Due to the nature of this study being an exploratory study using the narrative approach, the following research questions, using "what" and "how" was adopted to obtain rich details of peoples' views on their understanding of T2DM or pre-diabetes and its management. The use of narrative interviews can be combined with other interview methods such as structured interviews, semi-structured interviews, or unstructured interviews (Bold, 2012). In this study, narrative interviews together with semi-structured interviews were employed to capture the patients' stories. This is particularly useful because the nature of this study is designed to explore a wide range of perspectives (Ziebland et al., 2013). Using semi-structured interviews, researcher usually have a set of questions that are used to guide the interview.

The implementation of the first MCO in Malaysia in mid-March 2020, has also significantly affected the data collection in this study. Due to the movement and social distancing rules, I was pushed to think of different ways of collecting my data without further delaying the study. Therefore, I decided to conduct the interview online. After a few interviews, I realised that not all participants have access to digital tools and data. Therefore, participants were given a choice to have the interview done virtually or via a telephone call. Almost all interviews with the pharmacists were conducted online and this probably because pharmacists are more digitally literate and hence, they have the technological competence and access to use digital tools. For patients on the other hand, not all have access to electronic devices such as smartphones or computers, for example, older patients, therefore, they prefer to have the interview done via telephone calls. In total 36 participants were interviewed in this study (see Figure 3.1).

2.4.7.1 Online interview

Microsoft Teams was chosen and mainly used to conduct the online interview because of the different features that it has such as video or audio recording function, no time limit, live transcription, and data encryption (Ahmad Azhari et al., 2022). As for the participants, they were not required to install the application as the meeting link can be accessed on the internet browser. Once the interview date and time agreed and confirmed with participant, invitation link is sent to participant's email as well as through text messages via WhatsApp. One of the interviews had to be conducted using Zoom because I was having problem with Microsoft Teams. The participant was not able to hear me clearly probably because there was a problem with my internet connection. Participant was comfortable in using Zoom hence, we decided to use it and continue the interview using it.

Before the start of the interview, participants were given the choice to have their video on or off, and most participants were comfortable having their video off. I briefly introduced myself and explained about the study and if they have any questions to ask, they can do so. Because I have already had conversations with all the participants on WhatsApp text messages, it had helped in a way to build rapport with the participants. Participants were also informed on my intention to record the interview before I clicked the "recording" button.

Participants were told that the interview is informal, and it was more on having a casual conversation to find out about their experiences being diagnosed with T2DM and pre-diabetes and their experiences in terms of accessing and understanding diabetes information and self-care practices. I started my interview with simple questions, for example, on their age, how long they have had T2DM or pre-diabetes, and any medications they are currently taking.

The interviews were conducted using languages that participants were comfortable to converse and most of the interview were conducted in Malay language, while the rest were conducted in English or a mixture of Malay and English languages. The interviews were guided using interview topic guide (see appendices 19 and 20).

2.4.7.2 Telephone call interviews

Participants who had no access to electronic devices and data were interviewed using telephone calls. Participants were asked during the recruitment process which mode of communication they would prefer to use i.e., online or telephone call. Like online interview, participants were informed about my intention to record the conversation before the interview started. They were also explained about the study and simple questions were asked at the beginning of the interview to make the participants feel at ease and relax.

When conducting interviews via telephone, determining audio recording techniques is crucial and needs to be prepared well in advance (Burke & Miller, 2001). Unlike online interviews where the recording can be done using recording function available on the online platforms without using a different equipment or device, a different equipment needs to be used to record telephone interviews. In this study, the speakerphone and tape-recording method was used where my phone was put on loudspeaker and the conversation was recorded using a tape recorder.

2.4.7.3 Online focus group

On the Microsoft Form for the pharmacist recruitment process, there was a question on whether pharmacist would like to attend a focus group discussion or individual interview. I received several responses from interested pharmacists to attend focus group discussion. However, after the arrangement of suitable date and time to conduct the online focus group was finalised, only three pharmacists agreed and were available to join the discussion.

I conducted the online focus group via Microsoft Teams and the invitation link was sent to all pharmacists via email as well as on WhatsApp. A reminder about the focus group was also sent on WhatsApp on the day of the discussion. Before the discussion started, I introduced myself as the moderator of the focus group where my role was to guide the conversation and make sure that we do not go overboard with the timing. I also introduced a Year 2 MPharm student to the participants as my note taker for the discussion. I explained about the study and that the discussion is conducted to explore their perspectives on health literacy and self-care behaviours of newly diagnosed T2DM and pre-diabetes patients. I informed the participants that the discussion will be recorded and explained to them about the group rules of the focus group. Participants were also given a choice to have their video on or off, and one pharmacist had her video on while the other two kept theirs off. The discussion was mainly conducted in English language with some mixture of Malay words and phrases.

2.4.8 Transcribing process

Majority of the patient interviews were conducted in Malay language, while the interviews and focus group discussion with pharmacists were conducted in English language with a mixed of Malay phrases and slangs. All interviews and focus group discussion were transcribed verbatim.

The slang word *"lah"* is a most frequently used Malaysian suffix. When used, it can mean an affirmation, dismissal, exasperation, or exclamation in different contexts or to soften a command or to emphasise items in a spoken list (ISKL Campus, 2021). For example, the word *"lah"* at the end of the sentence below was to soften its tone and if omitted from the transcription, it will sound more direct or formal. Meanwhile, the word *"lah"* on the second quotation expressed the strong emotion felt by the participation on the thought of losing his leg due to diabetes complication.

> *LSP: And actually, we will test on HbA1c, if the HbA1c is on the high side then we will start on supplements. If there's no harm-**lah**.*

> *SL: Because in my mind, that's the only thing that I think. I'm going to lose one of my legs. I thought, die-**lah**. Confirm, my leg will get amputated. I'm finished.*

Hence, to preserve the intended meaning of what were said by the participants, the suffix *"lah"* were not omitted during transcription. Transcribed interviews which were in Malay language were then translated into English language before they were imported to NVivo® software for data analysis.

2.4.9 Translation process

Translation involves the translating of one language to another by interpreting the texts that convey the meaning and not solely a word-to-word translation (Aloudah, 2022). In this study, the translation process happened after the interview was transcribed verbatim. Translation is an interpretive act and therefore needs to be well executed to ensure the meaning of the data is not lost during translation process (van Nes et al., 2010).

To avoid meaning losses, the transcription and translation process was done by myself. This is important because as the main translator, the active role of a translator is to ensure that the translation of the texts to the second language is done as close as possible in meaning to the original language (Chen & Boore, 2010). Also, there are factors that can affect the quality of translation such as the linguistic competence of the translator and the translator’s knowledge of the culture of the people under study (Birbili, 2000). Hence, it is important that translation is conducted by a translator who can speak the original and the target languages equally well (Chen & Boore, 2010). Most of the interviews and focus group were conducted in Malay language and a mixed of both Malay and English languages. I can speak both Malay and English languages fluently and I am familiar with the culture of people under study. Therefore, I believe that the translation process has been done extensively to avoid meaning losses. Some of the other steps that I have taken include going back to the audio recording to confirm certain interpretations of texts that I am not sure of to ensure that I have translated them correctly. For example, when asked about the importance of seeing the same doctor, a participant responded about an angry or a moody doctor, but I was not sure if the participant was talking about the doctor being angry at him or the doctor was moody at the time he saw the doctor, so I had to listen to the audio recording again to double check what the participant meant.

> *MRO: Sometimes it's important. They monitor us. Ha. But the doctor also depends on his/her mood. Sometimes if the doctor is okay, then okay. But if the doctor is moody then we can't say anything. Just agree with the doctor.*

Certain words and phrases in Malay when translated to English can give different meanings. Hence, to avoid this from happening, the word is left in its original language in a double quotation mark and the definition which is closely related to the word was put in bracket next to it. For example, the word *"jamu"* which is a traditional Indonesian medicine was not translated because it was easier to understand the text in its original word.

> *CYT: Like they will just bring some weird herbal drink or "jamu" (traditional Indonesian medicine) and then said oh this for diabetes treatment, my friend take already right, no need to eat diabetes medications.*

While the sentence *"Tidak mati punya"* if translated directly from Malay language to English means you won't die, but if you read the whole texts of the participant's respond, it has a different meaning.

> *KLE: It's something like, oh, my mom has diabetes too. She's doing okay. "Tidak mati punya" (It will not harm you).*

2.4.10 Health Literacy Questionnaire (HLQ)

The HLQ was used in this study to assess patients' levels of health literacy. It was chosen to be used in this study because the other health literacy measurement tools available only focus on certain literacy skills such as comprehension, reading and numeracy skills, and lacks insights and guidance into the actions needed to improve health literacy. The 9 scales of HLQ also covers the health literacy areas which are relevant to the health literacy components which are important for diabetes patients in Malaysia.

The HLQ comprises of 44 items spread across the 9 scales. Each of the 9 scales contains between 4 to 6 items or questions that are scored as a graded response (see Appendix 21). For each time, the participants were asked to respond as follows:

- For scales 1 to 5: Strongly disagree = 1, Disagree = 2, Agree = 3, Strongly agree = 4.
- For scales 6 to 9: Cannot do or always difficult = 1, Usually difficult = 2, Sometimes difficult = 3, Usually easy = 4, Always easy = 5.

To determine the overall scale scores, item scores were added, and the sum divided by the number of items in that specific scale. With the scale score, the level of health literacy for each scale of a participant can be determined. Participants with a lower level of health literacy for a particular scale were defined as those having a:

- Mean scale score of less than 3 for scales 1 to 5, OR
- Mean scale score of less than 4 for scales 6 to 9.

While participants with a higher level of health literacy for a particular scale were defined as those having a:

- Mean scale score of 3 or more for scales 1 to 5, OR
- Mean scale score of 4 or more for scales 6 to 9.

The HLQ scale scores were analysed using IBM SPSS Version 28. The results obtained from the HLQ can be presented by using descriptive statistics which I will elaborate in Chapter 3. The HLQ scores obtained in this study can be used to support the interpretation of patients' health literacy level derived from the qualitative interviews that may influence their behaviours to practice self-care and this is further discussed in Chapter 6.

Permission to use the HLQ in this study was obtained from the Licensing Officer of the Swinburne University of Technology and the fully executed questionnaire license agreement was received on 17 June 2020 (see Appendix 22). The questionnaire was available on paper and online form. The online form was shared to patients using the link created on Microsoft Forms. During the patient recruitment process, patients were invited to fill in the questionnaire and they were explained about the HLQ beforehand. The patients who were recruited online were given the link to fill the questionnaire before interviews were conducted. Whereas for the patients who were recruited from the public health clinics, they were given a choice to fill the questionnaire in person using the paper form or to fill it online. The HLQ was available in both English and Malay languages. 28 patients filled in the HLQ but only 22 patients were interviewed.

2.5 Qualitative data analysis

All transcribed and translated data were imported to NVivo® software for data analysis. The coding and analysis of data were managed by using the NVivo® software. The data, as mentioned earlier, was analysed using the principles of reflexive thematic analysis guided by six phases of thematic analysis outlined by Braun & Clarke (2006) as shown in Table 2.1. The process of reflexive TA is not strictly linear, but it is rather a progressive and recursive process moving back and forth throughout the phases (Braun & Clarke, 2022).

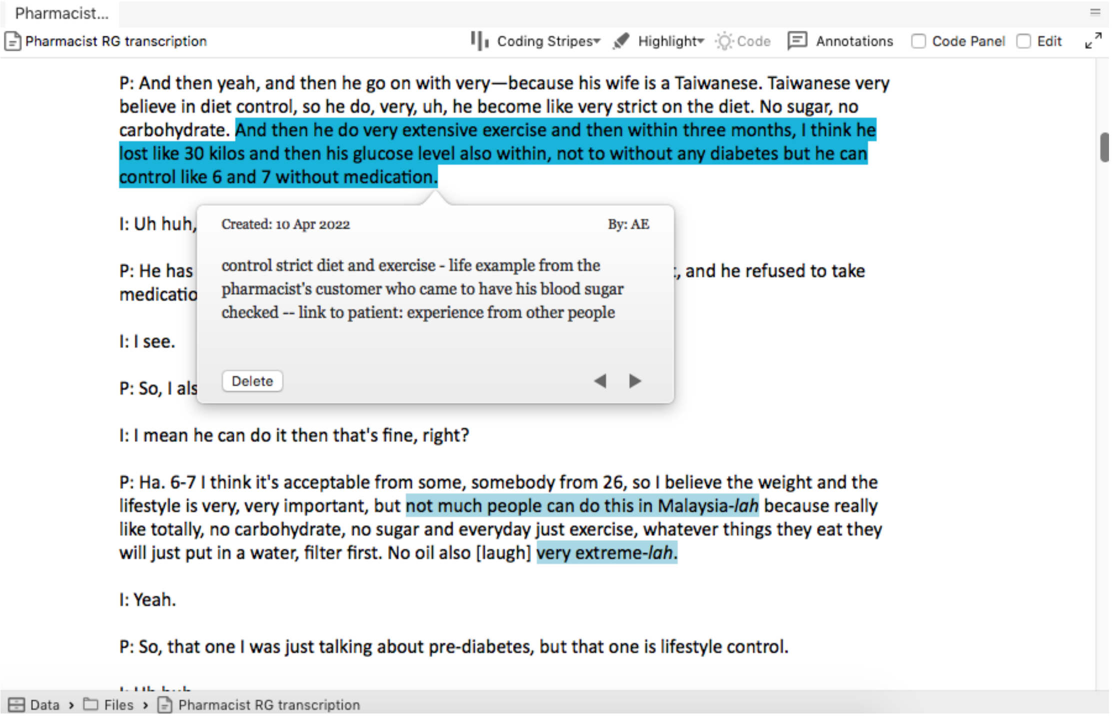
Table 2.1: The six phases of thematic analysis (Braun & Clarke 2006)

Phase	**Process**
Familiarising the dataset	Transcribe data collected, re-read the data, note down initial ideas and thoughts
Coding	Note down initial ideas from data and code data into small chucks of meaning
Generating initial themes	Collate initial codes into potential themes, gather all data relevant to each potential theme
Developing and reviewing themes	Check if themes work in relation to the coded extract and the entire data set, generate thematic ‘map’ of the analysis
Refining, defining, and naming themes	Ongoing analysis to further refine the themes and identify the essence of what each theme is about
Writing up	Write the report

2.5.1 Qualitative data analysis software (QCAS)

QCAS such as NVivo® does not have the function to analyse data as it is a tool that can assist researchers to analyse qualitative data by storing and managing the data in a more organised way. The labelling of the data or coding, which involves the process of exploring patterns of meaning in the dataset, developing codes, and applying code label to specific segments of the data item, in this study were assisted using QCAS, NVivo 12 (Braun & Clarke, 2022). Coding can also be done manually, for example, using different colour or highlighter pens or sticky notes. In this study, both NVivo® software and highlighter pens were used for the first few interview data. Once I have familiarised myself with the software, the remaining data were mainly analysed using NVivo 12.

Other than using the software for the process of coding, it can also be used to keep notes about the data item and linking related content within the data files. For example, I used the "memo" function to write down my reflective thoughts about the data item and any interesting meaning or patterns of meaning found in the data (see Figure 2.2). I also used "annotations" function which is a text note that can be linked to selected content within the data file to mark a content for follow up as shown in Figure 2.1.



P: And then yeah, and then he go on with very—because his wife is a Taiwanese. Taiwanese very believe in diet control, so he do, very, uh, he become like very strict on the diet. No sugar, no carbohydrate. And then he do very extensive exercise and then within three months, I think he lost like 30 kilos and then his glucose level also within, not to without any diabetes but he can control like 6 and 7 without medication.

I: Uh huh,

P: He has … , and he refused to take medicatio

I: I see.

P: So, I als

Created: 10 Apr 2022 By: AE

control strict diet and exercise - life example from the pharmacist's customer who came to have his blood sugar checked -- link to patient: experience from other people

I: I mean he can do it then that's fine, right?

P: Ha. 6-7 I think it's acceptable from some, somebody from 26, so I believe the weight and the lifestyle is very, very important, but not much people can do this in Malaysia-*lah* because really like totally, no carbohydrate, no sugar and everyday just exercise, whatever things they eat they will just put in a water, filter first. No oil also [laugh] very extreme-*lah*.

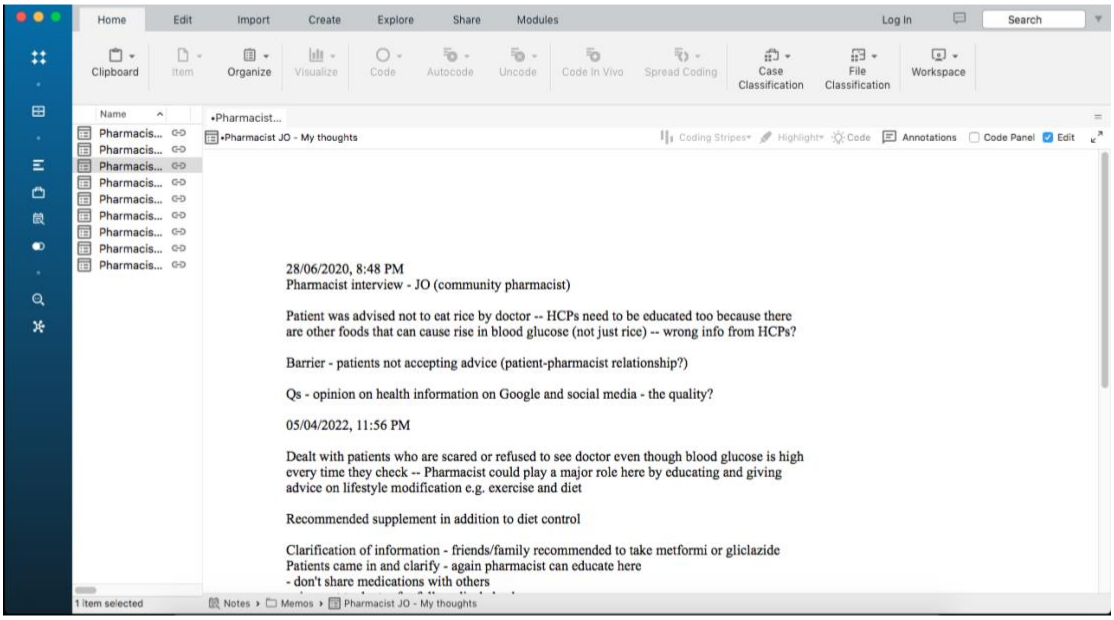
I: Yeah.

P: So, that one I was just talking about pre-diabetes, but that one is lifestyle control.

Figure 2.1: The use of "Annotations" function on NVivo 12

2.5.2 Familiarisation

In the following sections, I will discuss the six phases of TA, beginning with familiarisation. Familiarisation initially involves the deep and intimate knowledge of the dataset which is referred to immersion (Braun & Clarke, 2022). Immersing oneself with the data creates deep familiarity with the content of the data collected. This can be achieved by reading and re-reading the transcript texts, repeatedly viewing of visual data, or listening to audio recordings (Braun & Clarke, 2022). In this study, all transcribed interviews and focus group were checked thoroughly with the audio recordings at least twice i.e., during and after the transcription process as well as during the translating process. The transcribed and translated texts were read again to establish critical engagement with the data. This then brings us to the second part of the process of familiarisation which involves being critically engaged with the data obtained by being active as a reader and listener. At this phase, you start to ask questions and write down notes in order to make sense of the data. After each interview, I wrote down notes about the interview and any potential patterns on the data I found interesting on a notebook as well as on the "memo" function on NVivo 12 (see Figure 2.2).



28/06/2020, 8:48 PM
Pharmacist interview - JO (community pharmacist)

Patient was advised not to eat rice by doctor -- HCPs need to be educated too because there are other foods that can cause rise in blood glucose (not just rice) -- wrong info from HCPs?

Barrier - patients not accepting advice (patient-pharmacist relationship?)

Qs - opinion on health information on Google and social media - the quality?

05/04/2022, 11:56 PM

Dealt with patients who are scared or refused to see doctor even though blood glucose is high every time they check -- Pharmacist could play a major role here by educating and giving advice on lifestyle modification e.g. exercise and diet

Recommended supplement in addition to diet control

Clarification of information - friends/family recommended to take metformi or gliclazide
Patients came in and clarify - again pharmacist can educate here
- don't share medications with others

Figure 2.2: Notes written about the data on NVivo 12

2.5.3 Doing coding

In reflexive TA, coding involves a process of reading each data item closely and tagging all segments of the text that you find potentially meaningful to the research question with a code and a code label. A code is an output of the coding process where analytically interesting idea, concept or meaning is tagged on a particular segment of the data with a code label, and this helped in capturing a singular or particular meaning of idea in the data as shown in Table 2.2 (Braun & Clarke, 2022). For example, you could be tagging codes only on a few words in a data item, to a whole paragraph, or on a longer segment of text (see Table 2.2).

Table 2.2: The coding segments of interview transcripts

Interview transcript – Coding segments	**Code**
JK: First I don't usually go for—if my aunty is not available on phone, I will just go on Google first. But Google I will also look you know normally when you search Google, they have those first few that is quite valid from certain you know O R G or diabetes dot com or something like that. So, I really look at those myths. I look at those—I think those are facts. Yeah. I look at that first. And then I validate with my doctor.	Source of information
RG: But a lot of times more towards calm them down and motivate them, it's not the end of the world, they will feel like it's the end of the world and then their lifelong they have to take medication.	Reassurance
IS: Usually it's OK. If the reading is normal, then it's normal. If it's OK, then it's OK. But if it's a little high like it's not that OK then the staff at the pharmacy will say that if you want to confirm it, you can do the proper sugar reading. The one on the finger is only for you don't need to fast and all, you know. Our blood at that time, you know.	Aware of blood sugar reading

However, because coding is a systematic and an evolving process, codes may shift and change throughout the coding process for insight and rigour. Initial codes might be lack of nuanced or depth, rather than fixing the codes, richer analytical insights help to ensure we capture a more nuanced coding to identify patterns and shared meanings in the data. For example, as shown in Table 2.3, the initial code "lack of information" refers to participants' experiences getting information from healthcare providers or finding information online. As I refined the coding process, I was able to capture a more nuanced meaning from the dataset and changed the code to "difficulty finding reliable information".

Table 2.3: Example of the evolving process of coding

Interview transcript	**Initial code**	**Code**
SA: Because for some people who are new, who doesn't have any experience, you don't know how to handle it. Like me during 2018, I don't know how to handle it. Doctor just said I give you insulin to inject, OK inject. That's all [laugh]. Like dietitian, like that only.	Lack of information	Difficulty finding reliable information

2.5.4 Developing themes

When all the data have been initially coded and collated, we can now move to the next phase which is generating initial themes. A theme in reflexive TA captures the patterning of shared meaning across the dataset organised around a central concept (Braun & Clarke, 2022). As I have a long list of different codes identified across the data set, I need to re-focus the analysis at a broader level of themes which involves arranging the different codes into candidate themes and collating all the potentially connected codes within the identified themes. There are different ways you can do to help in visually sorting out the codes into themes for example, using tables or mind maps or write each code on a separate piece of paper and organise them into theme-piles (Braun & Clarke, 2006). I used mind maps to visually sort out the codes to see if they could be combined to form an overarching theme. I used the "concept map" function on NVivo12 to create the mind map. The initial thematic maps for patients and pharmacists are shown below in Figure 2.3 and Figure 2.4 respectively.

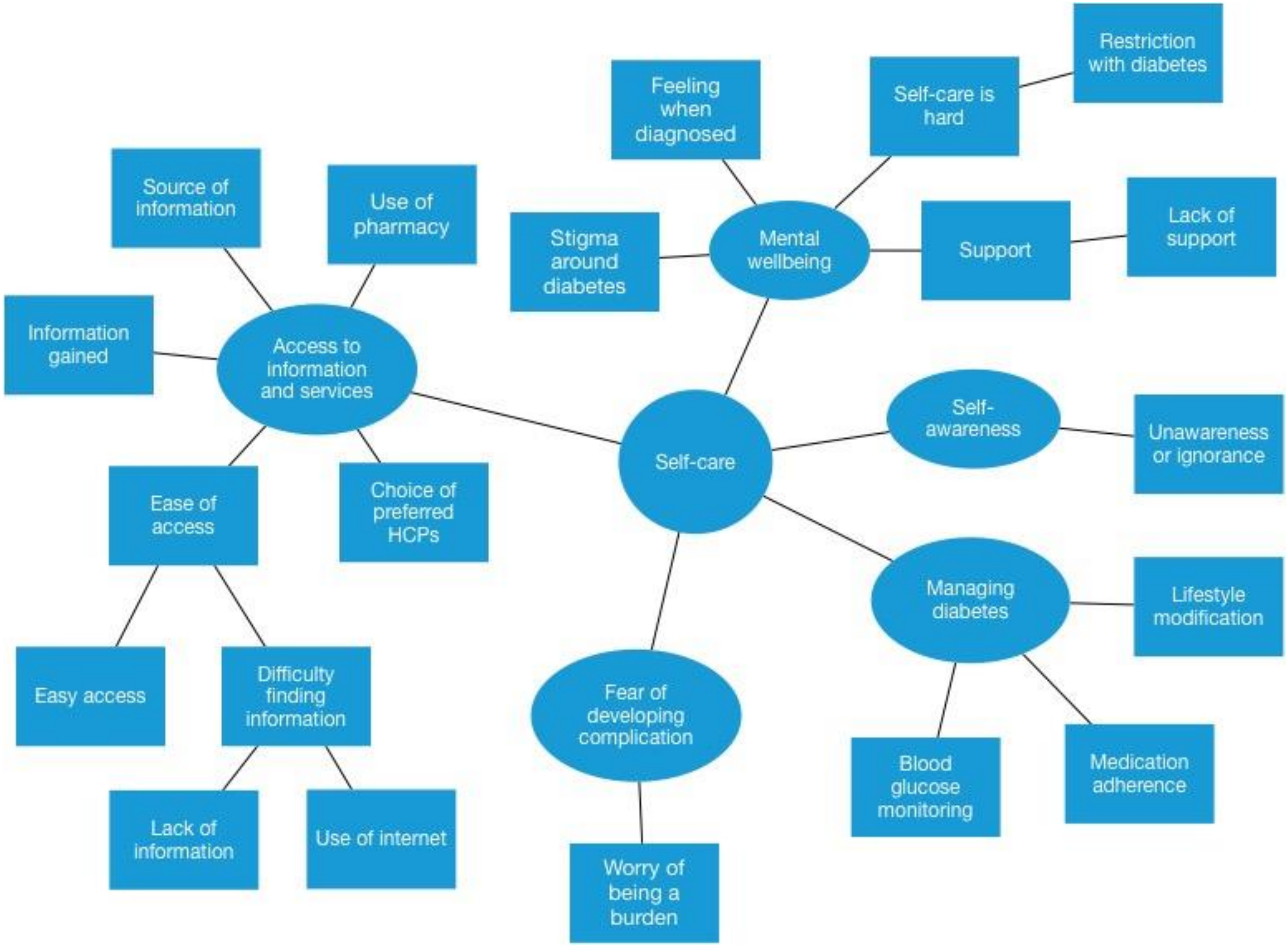


Figure 2.3: Patient's initial thematic map, showing five main themes with their subthemes

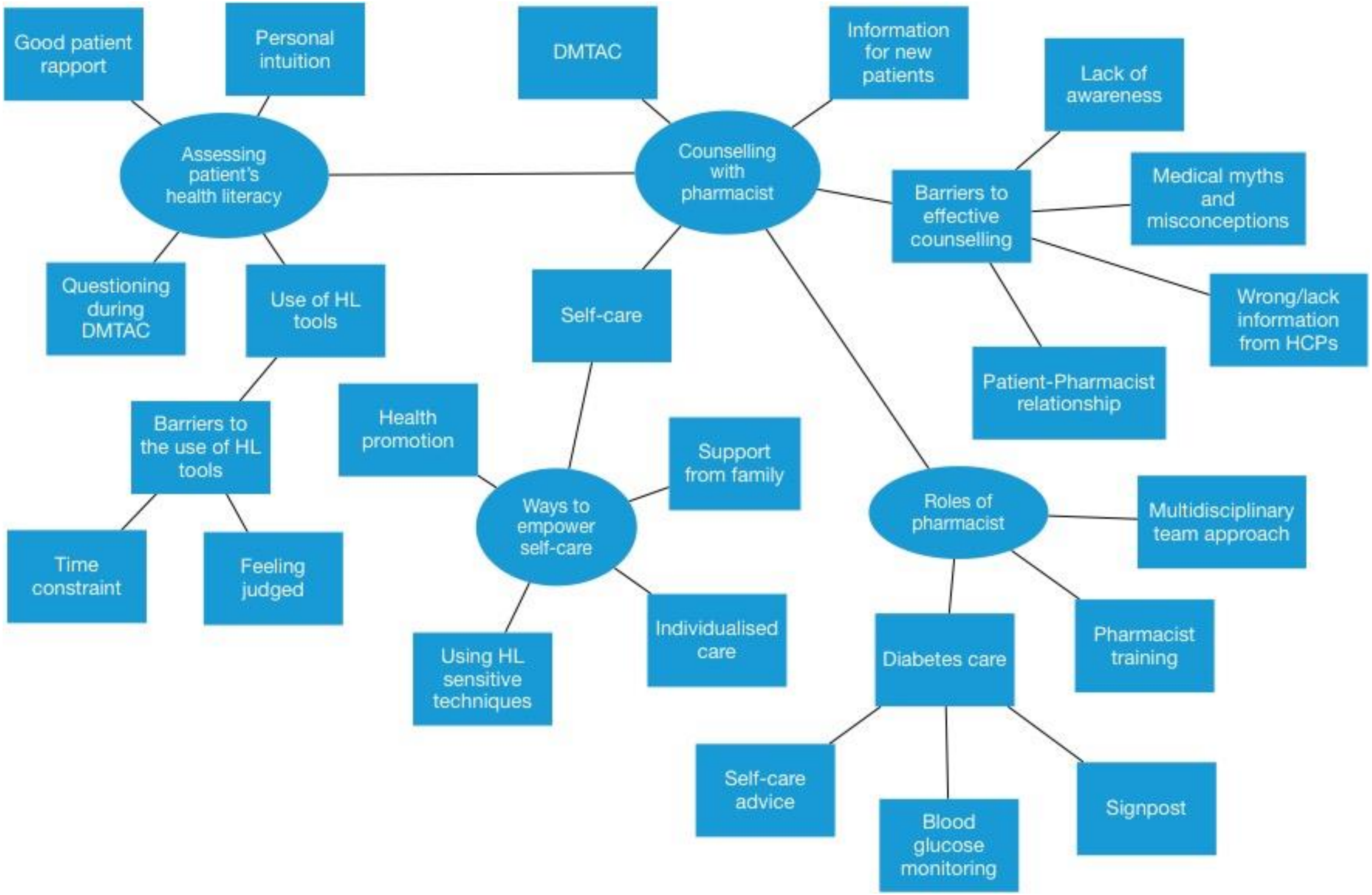


Figure 2.4: Pharmacist's initial thematic map, showing four themes with their subthemes

Once I have devised a set of candidate themes, the next process was to review those themes by checking if the themes make sense in relation to the coded extracts and the entire dataset. During this phase you may notice that some themes are not really themes, or you might need to combine two themes into each other, or you might need to break down some themes into separate themes (Braun & Clarke, 2006). For example, as shown in Figure 2.5, the theme "fear of developing complication" was put under the theme "self-awareness" as its subtheme and the theme "managing diabetes" was removed as the data around "managing diabetes" were too diverse. I also changed the theme "mental wellbeing" to "mental health". Figure 2.6 shows the developed thematic map for pharmacist where I removed the theme "counselling with pharmacist" and changed it to a theme called "challenges to effective counselling". I have also added the overarching theme "empowerment to self-care" as an organising structure to the other themes and subthemes.

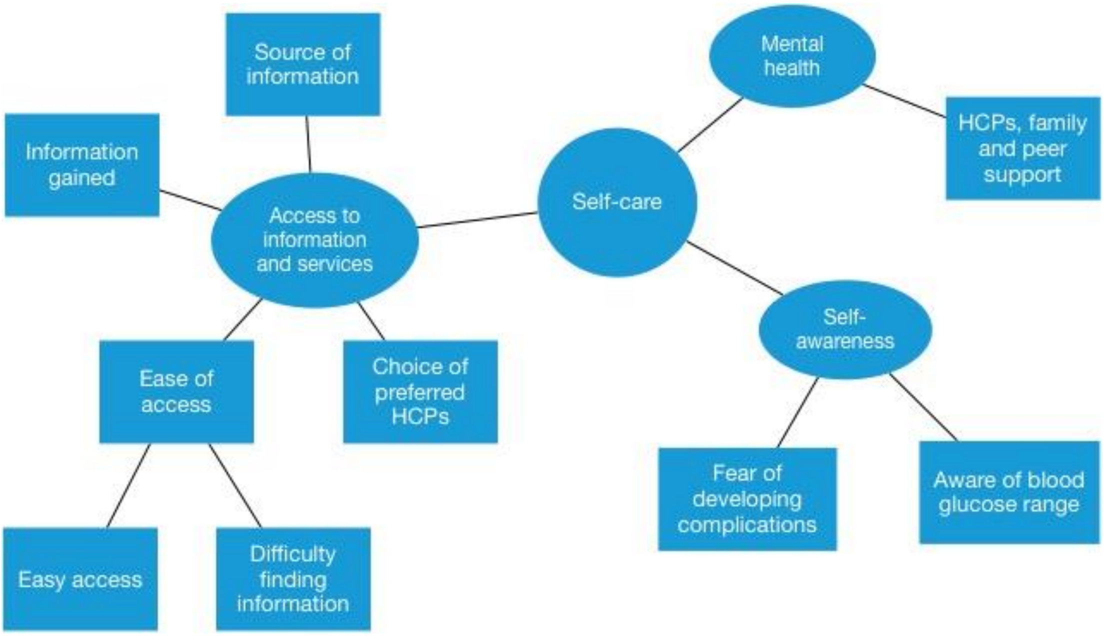


Figure 2.5: Patient's developed thematic map, showing three themes and their subthemes

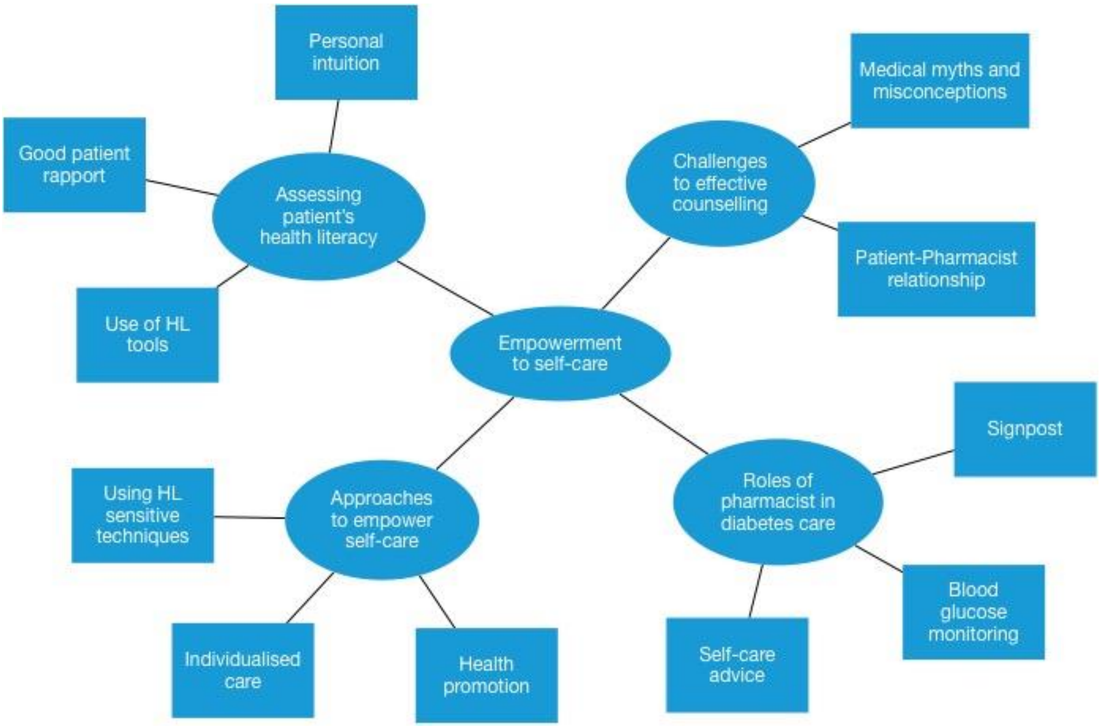


Figure 2.6: Pharmacist's developed thematic map, showing four themes and their subthemes

When you have a satisfactory developed thematic map of your data, you can then move to the next phase where the refinement of the thematic map can be conducted. In this phase, you define and refine the themes by identifying a strong core concept or essence of what each theme is about and write a detailed analysis or "story" of each theme and how they fit into the broader overall "story" (Braun & Clarke, 2006, 2022). In this phase, I have identified the core concept that answer the research questions of this study in terms of what empowers patient to practise self-care to prevent or delay diabetes progression as well as what can pharmacists do to empower self-care in diabetes patients and therefore, three major key themes and four major key themes were identified for patients and pharmacists respectively (see Chapter 3).

2.5.5 Writing up

Once we have a full set of work-out themes, the final analysis and write up of the report takes place (Braun & Clarke, 2006). In reflexive TA, writing is a key component of the analytic process as the analysis takes shape in the writing we do around the data (Braun & Clarke, 2022).

As we move to write a more formal report, the aim of this phase is to report the complicated story of the data analysis in a concise, coherent, and logical way within and across the themes (Braun & Clarke, 2006). This can be done by providing enough evidence of the themes within the data through data extracts which needs to be embedded within the analytic narrative to illustrate the story we are telling about our data (Braun & Clarke, 2006).

The findings of this study commence with the discussion of each theme identified from patients' interviews in three separate sections of Chapter 4 followed by the discussion of the four themes identified from pharmacists' interviews and focus group in Chapter 5. A final and overall discussion on both findings from patients and pharmacists as well as the HLQ results is discussed in Chapter 6.

CHAPTER 3 RESULTS OVERVIEW AND OUTLINE

3.1 Introduction

In this chapter, I will discuss the data collected from the patients' and pharmacists' interviews and focus group. The first section is about the details of the participants recruited for this study, followed by a section on the results obtained from the HLQ. In section 3.4, the main findings of this study and the flow of the next few chapters are explained.

3.2 Participants' details

The data was collected during the second year of the PhD, from June 2020 until March 2022. Patients were recruited from online platforms and two public health clinics as explained in Chapter 2. Total of 28 patients were recruited and 22 of them were interviewed either via Microsoft Teams or telephone call. Five patients were not interviewed as they did not respond to the text messages and telephone calls to schedule the date and time of the interview session. Additionally, one patient could not be interviewed as he had just received his blood test result, indicating a pre-diabetes diagnosis on the recruitment day. Therefore, he was not able to provide a comprehensive and in-depth account of his experience.

The age of patients ranged from 21 to 62 years, with a mean age of 41.3 years (SD = 10.33), and 14 of the patients were female (see Table 3.1). Because of the online recruitment process, I was able to recruit patients from various states in Malaysia including from East Malaysia. 18 of patients were diagnosed with type 2 diabetes and more than half of the patients were diagnosed less than 3 years.

Table 3.1: Demographic characteristics of the 22 patients recruited and interviewed

Variables	**Characteristics**	**No (%)**
Gender	Male	8 (36.4)
	Female	14 (63.6)
Age range	20 – 29	2 (9.1)
	30 – 39	8 (36.4)
	40 – 49	6 (27.3)
	50 – 59	5 (22.7)
	60 – 69	1 (9.1)

Race	Malay	17 (77.3)
	Chinese	3 (13.6)
	Indian	0 (0)
	Bumiputera Sarawak	2 (9.1)
State	West Malaysia	20 (90.9)
	East Malaysia	2 (9.1)
Type of diagnosis	Type 2 diabetes	18 (81.8)
	Pre-diabetes	4 (18.2)
Years diagnosed	Less than a year	6 (27.3)
	Less than 3 years	9 (40.9)
	Less than 5 years	7 (31.8)

For the pharmacist's pool, 14 pharmacists (4 males and 10 females) were recruited. All the pharmacists came from different pharmacy sectors such as hospitals (n = 4), public health clinics (n = 4) and community pharmacies (n = 6) and they had a practicing experience ranged from one year to 15 years (see Table 3.2). Further details of all the patients and pharmacists recruited are summarised in Appendix 23 and Appendix 24 respectively.

Table 3.2: Demographic characteristics of the 14 pharmacists recruited

Variables	**Characteristics**	**No (%)**
Gender	Male	4 (28.6)
	Female	10 (71.4)
Type of pharmacy	Hospital	4 (28.6)
	Public health clinic	4 (28.6)
	Community pharmacy	6 (42.8)
Health sector	Public	6 (42.8)
	Private	8 (57.2)

In this study, 36 participants were interviewed (see Figure 3.1). From the 36 participants, 7 patients and 10 pharmacists were individually interviewed online using Microsoft Teams and Zoom, 3 pharmacists attended a focus group discussion virtually via Microsoft Teams while the rest of the participants were interviewed individually via telephone calls.

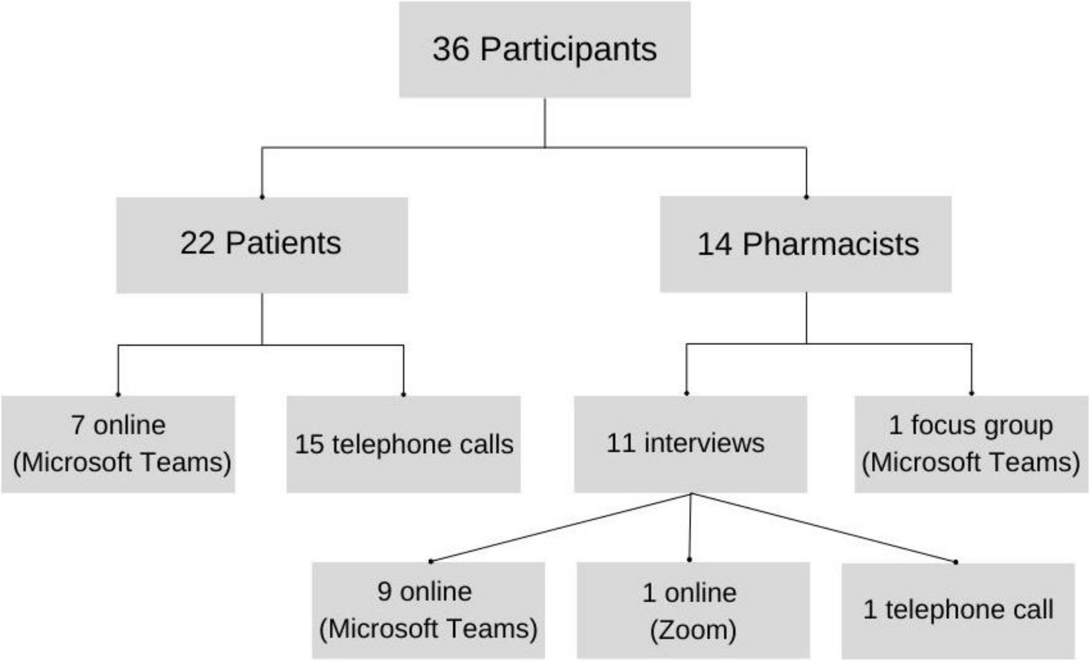


Figure 3.1: Participants interviewed and their modes of interview

3.3 HLQ results

As explained in section 2.4.10, patient participants were invited to fill in the HLQ before interviews were conducted. The HLQ were available both in Bahasa Malaysia and English language, and it can be filled online or using the paper form. 28 participants filled in the questionnaire where 17 patients filled in the paper form while the rest filled the questionnaire online. The demographic data for overall sample is shown in Table 3.3.

Table 3.3: Demographic data for 28 participated participants

Variables	**Characteristics**	**No (%) (n = 28)**
Gender	Male	9 (32.1)
	Female	19 (67.9)
Age	Age < 45 years	15 (53.6)
	Age > 45 years	10 (35.7)
Type of diabetes	Type 2 diabetes	22 (78.6)
	Pre-diabetes	6 (21.4)
Years diagnosed	Less than a year	8 (28.6)
	Less than 3 years	11 (39.3)
	Less than 5 years	9 (32.1)
Ethnicity	Malay	22 (78.6)
	Chinese	3 (10.7)
	Indian	1 (3.6)
	Bumiputera Sarawak	2 (7.1)

The mean age of participants was 37.9 years, with 53.6% of the participants aged under 45 years as shown in Table 3.3. Females comprised 67.9% of the sample, with 78.6% of individuals were diagnosed with type 2 diabetes. Among them, 39.3% were diagnosed within the last 3 years, and 78.6% of the sample were Malay.

The mean scores for each HLQ scale are shown in Table 3.4. For the first 5 scales, answered using response options ranging from strongly disagree to strongly agree (range 1 to 4), the highest overall score was seen for the scale "Social support for health" with a mean score of 3.04 (SD 0.46). The lowest score was for "Feeling understood and supported by healthcare professionals" with a mean score of 2.85 (SD 0.48). For the last 4 scales, answered using response options ranging from cannot do to always easy (range 1 to 5), the highest overall score was "Understand health information well enough to know what to do" with a mean score 3.74 (SD 0.630) while the lowest score was for the scale "Navigating the healthcare system" with a mean score of 3.38 (SD 0.65). To clarify, even though scale 9 ("Understand health information well enough to know what to do") represented the highest score for the last 4 scales, the mean score obtained does not reach the critical point of 4 or more to be considered as having high health literacy. Therefore, the majority of patients in this study exhibit low health literacy across all the scales of second part of the HLQ.

The third column of Table 3.4 shows the number of participants with a lower level of health literacy within the individual scale. The highest number of participants with lower level of health literacy among the 9 scales was scale 7, "Navigating the healthcare system" where 22 participants (78.6%) scored a mean score of less than 4, while the least number of participants with lower level of health literacy i.e., only 8 participants (28.6%) reported to have low health literacy within scale 5, "Appraisal of health information". Due to the small sample size and the focus of this study, the association between HLQ scores and demographic characteristics were not investigated.

Table 3.4: Health Literacy Questionnaire scores for 28 participated participants

	Mean (SD)	**Number of participants with a lower level of health literacy within individual scale**
HLQ scale		
	Range 1 (lowest) – 4 (highest)	
1. Feeling understood and supported by healthcare professionals	2.85 (0.48)	11 (39.2%)
2. Having sufficient information to manage my health	2.90 (0.48)	13 (46.4%)
3. Actively managing my health	3.01 (0.31)	11 (39.2%)
4. Social support for health	3.04 (0.46)	12 (42.9%)
5. Appraisal of health information	2.99 (0.41)	8 (28.6%)
	Range 1 (lowest) – 5 (highest)	
6. Ability to actively engage with healthcare professionals	3.69 (0.65)	17 (60.7%)
7. Navigating the healthcare system	3.38 (0.80)	22 (78.6%)
8. Ability to find good health information	3.57 (0.71)	19 (67.9%)
9. Understand health information enough to know what to do	3.74 (0.63)	16 (57.1%)

Abbreviation = *SD* Standard deviation

3.4 The main findings

Figure 3.2 and Figure 3.3 show the final thematic map for patients' and pharmacists' analysis respectively. In this study, the exploration of patients' knowledge on diabetes and its management helped to identify the three main themes as patient empowerment to practise self-care. They are (1) Mental health, (2) Accessibility to reliable resources and (3) Self-awareness. For the pharmacists' group, the interactions of pharmacists with the newly diagnosed diabetes patients were explored to recognise their contribution in empowering self-care behaviours. Four themes were identified, and the themes are (1) Roles of pharmacist in diabetes care, (2) Multidisciplinary team approach, (3) Approaches to empower self-care and (4) Continuing pharmacist's education. The themes identified in both patients and pharmacists can be interlinked to further empower self-care behaviours as shown in Figure 3.4.

Each theme identified in both patients' and pharmacists' interviews and focus group is discussed individually in different sections of Chapters 4 and 5 respectively. In Chapter 6, I summarise and conclude the findings derived from both patients and pharmacists, as well as the HLQ.

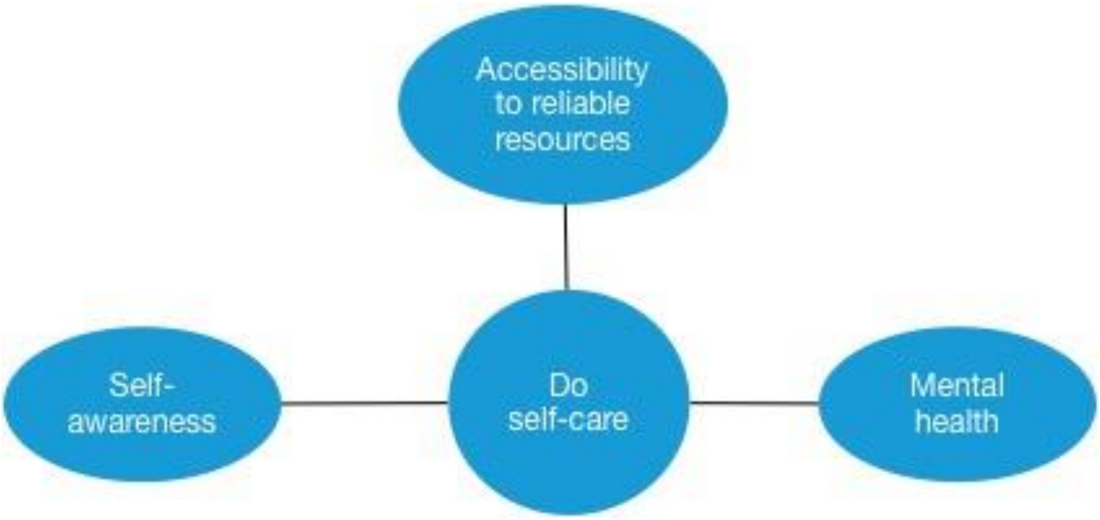


Figure 3.2: Patient's final thematic map, showing three main themes

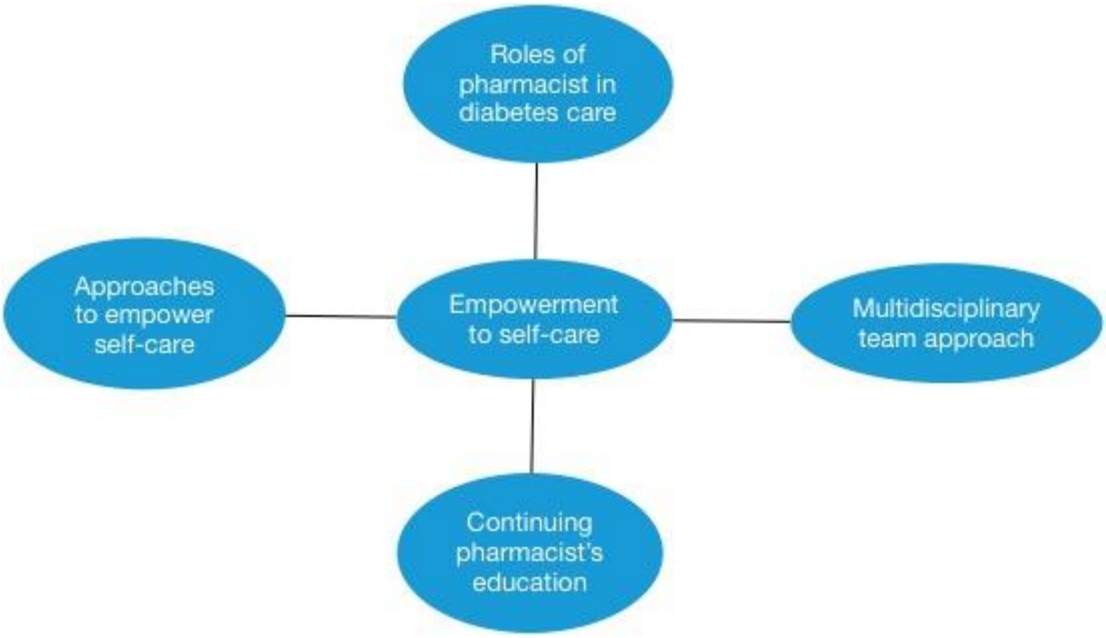


Figure 3.3: Pharmacist's final thematic map, showing four main themes

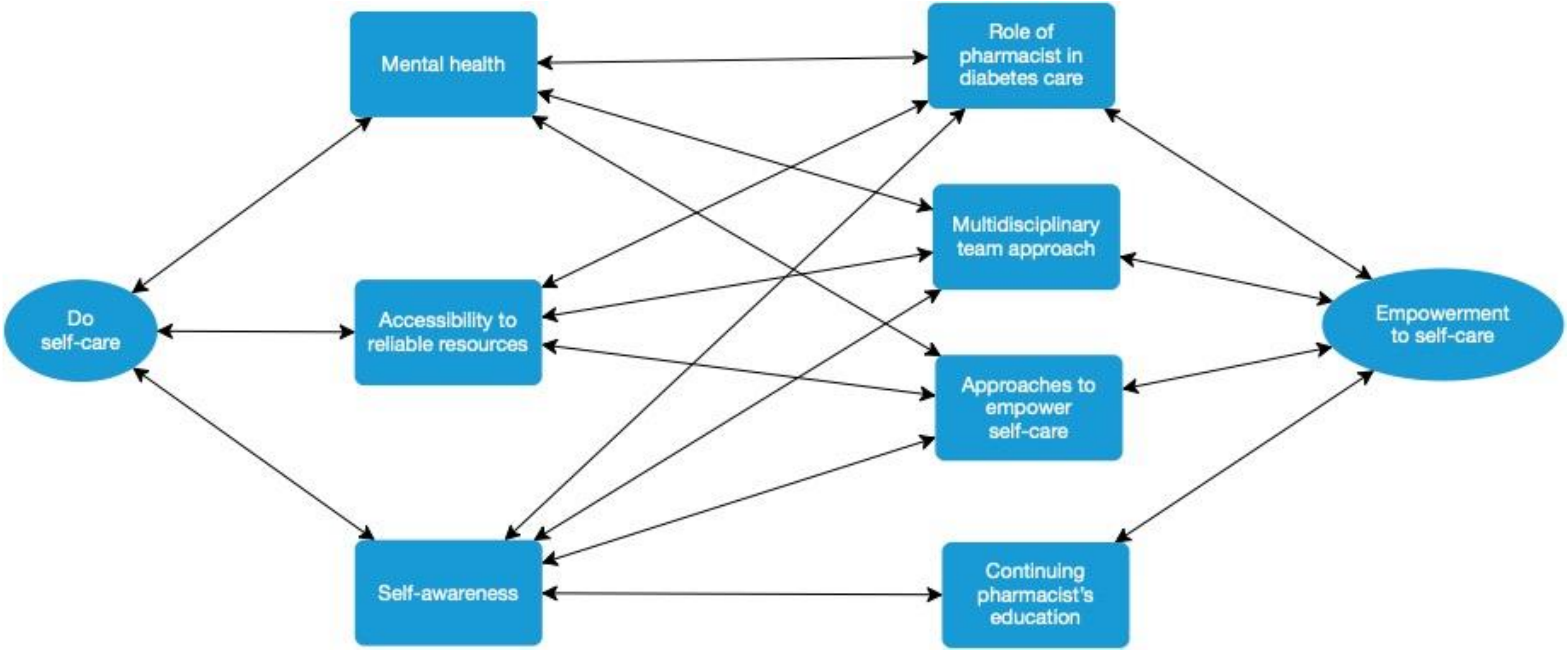


Figure 3.4: The link between the themes identified from patients and pharmacists

CHAPTER 4 PATIENTS' THEMES

THEME 1: MENTAL HEALTH

4.1.1 Introduction

Being diagnosed with diseases such as diabetes is not an easy thing to accept. With the complications associated with diabetes, it is not uncommon for people who are newly diagnosed with T2DM and pre-diabetes to be worried, scared and in denial at the time of diagnosis. In this section, I discuss the aspects of mental health such as diabetes distress (section 4.1.2) and diabetes stigma (section 4.1.3) that may affect diabetes self-care management of patients and the support they need to understand and manage the condition (section 4.1.4).

4.1.2 Feeling when first diagnosed

At the beginning of the patient interviews, patients were asked about their initial experiences of the condition, for example, how their diabetes was detected, their feeling when they first discovered it and their knowledge prior to the diagnosis. Since the patients were newly diagnosed it is interesting to find out about their feelings to understand their initial approach to diabetes management. Most patients expressed shock and were worried or scared while others felt the sense of disappointment and regret.

> *NHA: From my experience, when I was diagnosed with diabetes… I felt really down and scared.*
>
> ***56 years old, female, T2DM (2 years)***

> *JK: I was really shocked because I'm like I'm so young and I'm getting diabetes.*
>
> ***21 years old, female, T2DM (1 year)***

> *KCK: Aa so I feel a bit regret-lah so decide to change. Regret and change my life-lah.*
>
> ***45 years old, male, T2DM (4 years)***

It is important to tackle patient's emotional state during initial diagnosis as it can develop into psychosocial problems such as diabetes distress or even depression if left unnoticed. Diabetes distress, regardless of its type, refers to the negative emotional or affective experience which result from the challenge of living with the demands of diabetes (Skinner et al., 2020). This is due to a wide range of emotions such as feeling overwhelmed by the demands of self-care management required like adherence to diet, exercise and medications (Perrin et al., 2017). It is common for diabetes patients to develop diabetes distress and it has been increasingly recognised as one of the barriers to self-care management. In a study involving 2508 T2DM patients recruited from 12 public health clinics in Malaysia, it was found that 11.5%, 30.5% and 12.5% of the patients have depression, anxiety, and stress symptoms respectively (Kaur et al., 2013). From the same study, it was also found that diabetes patients of less than two years duration were 1.6 times more likely to have depressive symptoms compared to patients with longer duration of diabetes (Kaur et al., 2013). For example, a patient who was diagnosed with T2DM for 2 years mentioned about the difficulty to self-manage initially which then led her to feel defeated or overwhelmed.

> *NHA: Difficult at first. Mm. You really need to be determined. Need to be determined even though sometimes you feel that you can't be bothered with it…*
>
> ***56 years old, female, T2DM (2 years)***

Based on the MOH's diabetes guideline, it is recommended to assess patient's mental status during the time of diagnosis, at the diagnosis of complications, when there is a loss of glycaemic control or lack of treatment adherence and at the time treatment is intensified, as an integral part of diabetes management (Ministry of Health Malaysia, 2020a). The patient below, who has been diagnosed with T2DM for 5 years, talked about her experience on her HbA1c reading where there was a loss of glycaemic control and this needs to be assessed so that the patient's coping skills can be evaluated.

> *NL: Actually, I'm frustrated right now because when I checked my HbA1c, it's high. It was 9. It was 6 few months ago. The doctor was also frustrated. He said I need to be consistent especially on my diet. The doctor said that*

> *to me. He said that because I managed to do it before, if I haven’t managed to do it, that’s different, you know.*
>
> ***36 years old, female, T2DM (5 years)***

Both depression and diabetes distress have been shown to affect diabetes management through poor medication adherence and reduced self-care (Gonzalez et al., 2007). Nevertheless, some thought the perceived threat of an illness can also increase the motivation to act and hence, the distress from worrying about diabetes especially on future complications could be thought to increase self-care (Skinner et al., 2020).

> *AA: I want to motivate myself because I’ve seen people around me who had their leg amputated, some passed away because of diabetes you know.*
>
> ***36 years old, male, T2DM (2 years)***

4.1.3 Diabetes stigma

Diabetes-related stigma experience by diabetes patients, regardless of its types, can have significant impact on psychological well-being, self-care, and diabetes outcomes (Schabert et al., 2013). Diabetes-related stigma generally affects people who have diabetes and are overweight due to the role of individual behaviour in the development of the condition (Schabert et al., 2013). This could probably be due to the increasing publications of studies that demonstrated T2DM is preventable and being overweight or obese could increase the risk of developing T2DM (Centers for Disease Control and Prevention, 2022; Schabert et al., 2013). In addition, the need to inject insulin, monitor blood glucose level, restrict diet, and episodes of hypoglycaemia can also contribute to the experience of diabetes stigma (Liu et al., 2017). The stigmatisation can be experienced internally or externally. Stigma which involves the experience of being stigmatised through blame and judgement by others is termed 'interpersonal stigma' or external stigma, while the feelings or beliefs a person with diabetes has about themselves which include the feelings of self-blame, shame or guilt is termed 'intrapersonal stigma' or internal stigma (Centers for Disease Control and Prevention, 2022; Schabert et al., 2013). A study conducted in the USA found that individuals with T2DM have higher rates of weight stigma compared to the general population and they also experienced high rates of diabetes-related stigma (Himmelstein & Puhl, 2021). From the interviews I had with patients, some mentioned about their stigmatisation experiences. For example, participant ZE talked about the feeling of being judged, and participant MN was blamed for having diabetes by friends and family when he told them that he has been diagnosed with T2DM. While participant S was blaming herself when she found out she has diabetes.

> *ZE: People say people with diabetes, they say we can't go far.*
>
> ***35 years old, female, T2DM (2 years)***

> *MN: When they found out that I'm diabetic, they started to say things like that's why you shouldn't eat all that before this. It's more like blaming me.*
>
> ***43 years old, male, T2DM (< 1 year)***

> *S: The experience… Experience finding it [sigh] out that time, I really don't know how to say it. I was frustrated, frustrated because I was big at that time. Every day I eat rice, never missed. I eat a lot.*
>
> ***43 years old, female, T2DM (4 years)***

Fear of negative appraisal or judgement could lead to other problems such as feeling embarrassed when attending social events or going out with friends or family as they need to refuse unhealthy food options, and this can act as a deterrent for making healthy choices in the future and also lead to attempt of concealment of their condition (Schabert et al., 2013).

> *MN: Because I have to control what I eat. Like for me, I meet a lot of people. I'm a businessman. Sometimes, I have to see the supplier and sometimes we meet at restaurants. They will invite me for lunch. But when they see how I eat, they laughed. Why are you eating more fish than rice? It's like that. And then the others, you know Malay people. You're Malay, right? They like to say if you're going to die, you're going to die anyway. Ha, something like that.*
>
> ***43 years old, male, T2DM (< 1 year)***

> *JK: So, I felt like that I can still keep from my friends for sometimes until it's needed then I'll tell them. Because I don't want to, I don't want them to worry and be you know, every time they go to a restaurant that don't have*

> *rice, they go to restaurant that don't have sweet drink and those. I felt like it is sort of an inconvenience (for them).*
>
> ***21 years old, female, T2DM (1 year)***

The fear of stigmatisation can also contribute to the reluctance of sharing about their conditions openly with relatives, friends as well as healthcare providers, for example, about their self-care management and blood glucose levels because of the fear of receiving negative feedback or being judged by others (Schabert et al., 2013). For example, participant SL only talked about his diabetes to his wife but not with the other members of his family, while participant NJ felt that she cannot discuss about her diagnosis with her family and friends as she felt that they do not have much knowledge about the condition.

> *SL: Actually, I don't really talk about my diabetes with my family. They know I have diabetes but, I don't talk about my diabetes with them.*
>
> ***36 years old, male, T2DM (2 years)***

> *NJ: Not really because they (family and friends) don't really understand what diabetes is.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

> *JK: You know some doctors will say if you don't do this, then you'll get high blood pressure-lah. They say things like this that sometimes demotivating. And especially for people who you know are emotionally sensitive like me, when you say this kind of thing people may get down, you know?*
>
> ***21 years old, female, T2DM (1 year)***

> *NA: But this time around when I saw the doctor, he kept on nagging and scolded me and then after that he just said, "ha, take your medications".*

52 years old, female, T2DM (2 years)

4.1.4 Support

Both diabetes distress and diabetes stigma can affect negatively on self-care and the self-esteem of a person with diabetes which could then lead to more serious health complications affecting the mental health, for example, depression and anxiety. Adequate support is required to help them in managing their diabetes and in empowering self-care behaviours. It helps them to cope with the fear as well as the stigma especially when they have to give up on certain things in their life and constantly monitor their condition.

> *MRO: So, it’s like I have no life. Might as well don’t eat at all.*
>
> ***42 years old, male, T2DM (3 years)***

4.1.4.1 Healthcare providers' support

Managing diabetes involves a multidisciplinary healthcare team approach. Good interactions between patients and healthcare providers, for example, doctors, dietitians, diabetes nurses and pharmacists, is crucial in managing diabetes because they are seen as the providers of information, guidance and also support.

> *KA: I think we need, because we need guidance from the doctor or nurse or anyone who is qualified. If we don't, we don't get guidance from them, if we just rely on information on Facebook or online, sometimes we're also not sure if the information is correct or not.*
>
> ***34 years old, male, T2DM (< 1 year)***

To enhance patients' coping skills and resilience, collaborative care such as listening and learning from each other, sharing ideas, agreeing in measurable goals and support with goals achievement is needed (Skinner et al., 2020). This creates a positive relationship with healthcare providers and as a result increases patient adherence and also empowers self-care. One study found that the positive interaction between patients and healthcare providers facilitates them gaining new knowledge and developing health literacy capacity in terms of accessing and appraising health information (McKenna et al., 2020).

> *JK: So, he gave this goal and I'm slowly working towards it which is very motivating and also you know where you are heading towards. So, it's not like you must lose weight but you don't know to what extend you need to lose, you know? It's not like the doctor didn't give a clear number. If the doctor give you a clear number, or what should I work on and he gave me a range on how my blood sugar should be normal, within that range, that's*

> *really helpful for me to know that aa I know that my body is working fine. So, the doctor is helpful when I first started with diabetes.*
>
> ***21 years old, female, T2DM (1 year)***

> *AH: Every week I have a Zoom call with her so, I'm supposed to track my daily activities like what I eat, what's my daily weight and all that. So, every week I have a call with her. There, she goes through and then she will adjust based on what's the performance for that week.*
>
> ***51 years old, male, pre-diabetes (< 1 year)***

However, some patients mentioned about the lack of support they received from healthcare providers. Poor communication during counselling sessions and providing information or instructions without meeting individuals' needs may contribute to further distress and thus, reduce self-care. Participant NA talked about how she will not ask questions from the doctor when asked where she looks for information about diabetes and participant MRO gave fairly similar answer to the question while participant NSS did not know that she could ask questions from the doctor. The communication between patients and healthcare providers can be further exacerbated due to the limitations patient has in controlling their diabetes and this paternalistic approach may act as a barrier to self-care and remove the power and responsibility from the patient (Skinner et al., 2020).

> *NA: Umm… Definitely not the doctor. We don't have to ask the doctor because the doctor will nag at you. The doctor will say… "Madam, you must…" Yes. The doctor will say this, this, this. I don't have to ask. I have had look for it (information). I want to try… But I only watched on how to reduce my fat, how to do this and this. Aa and then I'm like I'll do it, I will do it. But I haven't actually done it.*
>
> ***52 years old, female, T2DM (2 years)***

> *MRO: The doctors most of the time they just want to scold you. Control your sugar, control your food and all.*
>
> ***42 years old, male, T2DM (3 years)***

> *NSS: But I'm afraid to ask. What will the doctor think if I asked? They will think that patients are cleverer than them now, you know. But if I'm allowed to ask then that's okay. Next time I will just ask.*
>
> ***62 years old, female, pre-diabetes (< 1 year)***

The use of right language, which is neutral and based on facts and actions, free from stigma and centred on the individual's goals and needs, during counselling is important so that patients do not feel that they are being downgraded or blamed for not controlling their diabetes (Ryan, 2017). The active participation of patients on their own care and supported by healthcare providers will results in greater success of effective diabetes care (Shrivastava et al., 2013). Also, the need to assess patients' causes of inconsistencies in their management is the primary goal so that we can tackle patients' problems with the appropriate guidance and support they required.

4.1.4.2 Family support

Many patients with diabetes face multiple barriers to effective diabetes self-care, and one of these is because of the lack of support from their families and friends (Heisler, 2007). Apart from getting support from healthcare providers, support from family members is also crucial because major part of the diabetes management is done at home with the help of family members (Mohebi et al., 2013). Support from family ensures there is continuation of self-care behaviours and successful control of diabetes at home.

> *ZE: I get support from my family, like my husband and all. My mother, my siblings. They tell me, they always remind me not to eat too much, reduce my rice. Eat more vegetables and fruits. With their support, I'm trying to lose some weight. Because my doctor also told me that I must lose weight.*
>
> ***35 years old, female, T2DM (2 years)***

In Malaysian culture, especially the Malays, having a close relationship with family members is a family obligation as well as religious and moral duty (Harun, 2017). Hence, the involvement of family members, for example, spouses, parents, and children, is expected in supporting members of the family with medical illnesses.

> *KA: The feeling of like getting guidance, advice from your family members, for example, my wife, is also quite important too. Ya-lah, if your wife doesn't, for example, doesn't give… doesn't give any support, you feel that you can't control on your own.*
>
> ***34 years old, male, T2DM (< 1 year)***

Some of the patients experienced positive reinforcing behaviours, for example, they are encouraged by family members to practise self-care, or accompanied them in doing self-care such as doing exercises, cooking healthy meals together or searching for information on diabetes. For example, participants AH, S and NHA who are all married, talked about the support they received from their spouses and children. This helps to empower patients to follow their treatment regimen and practise self-care.

> *AH: Uh, so because my wife helps (in preparing the meals) so you have the motivation, right? So, I think if I did it on my own then it would be harder because then you need a lot of self-discipline and determination, right? But when you do it with your spouse or your partner then I think there's you having the support, you know.*
>
> ***51 years old, male, pre-diabetes (< 1 year)***

> *S: If I'm at home with my children, my nieces and nephews, we will play badminton, skipping and all, always with the kids.*
>
> ***43 years old, female, T2DM (4 years)***

> *NHA: My husband also looked on Google on what I need to eat, what things I can't eat and all.*
>
> ***56 years old, female, T2DM (2 years)***

However, some patients complained about being nagged by spouses for nonadherence. The nagging may lead to the feeling of despair or unsupported and consequently decrease in self-care. Therefore, members of family play a major role in creating a more positive environment for the patients, for example, trying not to eat food which is not part of the patients' diet to encourage them to self-care behaviours.

> *NA: But now my husband keeps nagging on me (for not looking after my diet). So, now I'm eating less rice.*
>
> ***52 years old, female, T2DM (2 years)***

> *AA: Aa she (wife) nags a little [laugh]. Nags a little and support. She wants to see me get better.*
>
> ***36 years old, male, T2DM (2 years)***

> *NK: Because when they cook delicious meals, my appetite increases.*
>
> ***43 years old, female, T2DM (5 years)***

Studies have also shown that spouses are the most important supportive sources and one study which looked into the influences of spousal support and control on diabetes management through physical activity among older adults with T2DM found that spousal support were positively associated with physical activity whereas spousal control was either unrelated or linked to less physical activity (Khan et al., 2013; Mohebi et al., 2013). The findings from the study suggested that spousal support and control may facilitate daily diabetes management through physical activities (Khan et al., 2013). With this, the need to get the involvement and support of close family members during counselling sessions may be beneficial to the patients so that information about the condition and management can be shared to the members of the family in order to help patients improve their self-care behaviours and consequently lead a better quality of life (Mohebi et al., 2013).

> *NHA: They taught my husband. Because my husband will help me to check (my sugar level). I'm a little bit scared to prick my own fingers, you know. I don't dare, I have never done it myself. I'm scared, you know. My husband helps me. He will ask me before he goes to work. He will ask whether I want to check today if he thinks I haven't checked for a week or so. If I say yes,*

he will help me. If I don’t want to check then he will say if you don’t want then that’s okay.

56 years old, female, T2DM (2 years)

4.1.4.3 Peer support

Peer support is the support received from a person who has experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population (Heisler, 2007). Peer support provides the emotional, appraisal and information assistance a person needs to deal with chronic illnesses and cope with the stress (Brownson & Heisler, 2009). It can be conducted face-to-face, virtually or via telephone in a group or through one-to-one interactions (Holman et al., 2021). Having peer support among the patients with the same health problems may benefits both parties who are receiving and providing the support (Heisler, 2007).

One patient felt that having a group self-management programme could help her in managing her diabetes especially being a newly diagnosed patient, there are so much information that have to be taken in and learnt to control the condition. Having a peer support group will enable new diabetes patients to learn new tasks for example, insulin management, from the sharing of the experiences of others who have gone through the same medical tasks (Heisler, 2007).

> *SA: I feel that maybe they can invite people with experience. They can share their experience on how they get diabetes and how they manage it, especially people who have a good record, people who are well managed. Because sometimes people who are newly diagnosed, they don't know (what to do).*
>
> ***31 years old, female, T2DM (2 years)***

> *S: It's important (to have support group). Because if they do any activities, we can all share together our experiences. We can share in terms of diet and exercise.*

43 years old, female, T2DM (4 years)

Currently, there are no peer support programmes are being offered to patients in the public hospitals or health clinics. Some of the patients that I interviewed joined diabetes support group on social media such as on Facebook for moral support and to gain more information while others talked to friends and joined social events to try cope with diabetes.

> *MN: It's more for moral support. Something like that. So whatever they share on Facebook group I feel like giving me the moral support. Even though I never met them face to face. But I can see their progress. So, what they're doing I can see there's progression. So, it gives me the push to do it, that's all.*
>
> **_43 years old, male, T2DM (< 1 year)_**

> *SL: I joined this group on Facebook. I looked for international diabetes group. I joined the group, it's international, all westerners. They give a lot of guidance.*
>
> **_36 years old, male, T2DM (2 years)_**

> *JK: We openly talk about this and then she gave me support, I gave her support. So, we are very good friends. So, I don't mind discussing with her.*
>
> **_21 years old, female, T2DM (1 year)_**

> *NHA: I will join any events at the mosque. I don't like being alone because I'll start to think about silly things like I don't want to do it so, I have to fight the thought and think I can do it. I can control it.*
>
> **_56 years old, female, T2DM (2 years)_**

One of the patients suggested to create a one stop centre for diabetes patients where they can hang out to support each other and share information about diabetes management among themselves.

> *MN: I think we need to have a centre for communication, but we transformed the centre to a restaurant. Restaurant for diabetics. At least people can get information and eat healthy meals at the same time. People with diabetes can sit together and eat. But the problem is now when you dine out, it's like what I said earlier, when you eat little rice and more "lauk" (dishes), people will tease you, you know. So, if there's restaurant especially for diabetics, at least we have a place to discuss and talk about our problems and exchange ideas. At least you have a one stop centre. And at the same time, you'll get to eat healthy food. Ha. At least we can share the feelings of having diabetes with others who have diabetes too.*
>
> ***43 years old, male, T2DM (< 1 year)***

Therefore, having access to sufficient peer support, for example, talking to friends or joining diabetes support group virtually or attending social events, on a regular basis is crucial in order to improve patients' coping skills. This not only help patients to stay empower to practise self-care, but it also helps in their mental wellbeing as they feel supported in controlling their blood glucose level and coping with the stressor of diabetes.

4.1.5 Summary

It is important to recognise that the distress and stigma diabetes patients experience is a function of the social interactions they have with family and friends, healthcare providers as well as the social media (Skinner et al., 2020). As mentioned by some of the patients in this study, they are easily affected by the lack of support as well as the distress of diabetes and stigma they experience because of the blame and guilt they felt during diagnosis. This can consequently affect their mental wellbeing. Theme 1 showed that support received from family, healthcare providers and peers are important to empower patients to continue to practise self-care. Hence, it is important that diabetes patients have sufficient access to social support to increase their coping skills in order to have the sense of normalcy, and this will be discussed further in section 6.2 and section 6.3.

THEME 2: ACCESSIBILITY TO RELIABLE RESOURCES

4.2.1 Introduction

Access to the right and reliable diabetes care and resources is paramount to empower diabetes patients manage their condition and avoid complications. Lacking knowledge could lead to poor management of disease in terms of dosing, identifying side effects of medicines taken and interpreting blood glucose levels. With poor understanding, disease progression and complications that arise can affect patient’s quality of life which results from poor medicine adherence and no empowerment for self-care. Low health literacy could also affect the ability of individuals to access health information and services. In this section, I discuss about the experiences of patients in accessing reliable resources, the importance of it and the issues that they faced.

4.2.2 Diabetes knowledge

As stated in the beginning of section 4.1.2, patients were asked about their initial experiences of the condition and one of the questions is about their diabetes knowledge prior to the diagnosis. From the interviews, most patients did not have in depth knowledge about diabetes prior to their diagnosis and mostly mentioned that they only know diabetes is caused by eating too much sugar. Some of the patients were aware of the complications and the risk factors of developing T2DM due to family history, but they did not take the necessary measures to prevent it.

> *NS: Umm not really. I only know that you can't eat sweet things. Just that.*
>
> ***31 years old, female, T2DM (2 years)***

> *NSS: Diabetes is "kencing manis" (sugar in urine). Sugar in the blood, right? There's sugar in the blood, right? Ha. That's all.*
>
> ***62 years old, female, pre-diabetes (< 1 year)***

> *SL: Because all I know about diabetes, once a person gets it, the leg will get amputated or something like that, I don't know. That's all I know. Other than that, I don't know anything. Because in my mind, that's the only thing that I think. I'm going to lose one of my legs. I thought, die-lah. Confirm, my leg will get amputated. I'm finished.*
>
> ***36 years old, male, T2DM (2 years)***

> *S: Mm. I only know a bit because my late mother has it. She passed away because she had stroke and all. But still, I didn't bother to know more. For example, I didn't control what I eat. Now that I know I have diabetes, I control my diet.*
>
> ***43 years old, female, T2DM (4 years)***

This is expected because as newly diagnosed with T2DM and pre-diabetes, they might not have much knowledge of diabetes. A study done in Malaysia to compare the knowledge of healthy individuals with diabetes patients found that patients with diabetes were significantly more knowledgeable than healthy individuals and thus, there is a need to educate the general population about diabetes (Yun et al., 2007). The study also indicated that diabetes patients have more knowledge about the condition because they were educated by healthcare providers and attended numerous appointments. However, in this study, some patients indicated that they were not given enough information and education to manage their diabetes and pre-diabetes during their diagnosis.

> *KCK: Basically they tell you very general knowledge. Yeah. They sort of talk to you what to eat, what not to eat. So that's it-lah. So maybe more information on the food part-lah. Because diabetic is food control. Yeah. So they are not given-lah. But they tell you what are the symptoms, what to be careful. These are all general information-lah.*
>
> ***45 years old, male, T2DM (4 years)***

> *MRO: Control my sugar, control my diet. Very general, nothing scientific. If they want to tell scientifically, they have to refer, refer us to the specialist but it's quite difficult with the public health clinic.*
>
> ***42 years old, male, T2DM (3 years)***

> *NJ: She (the doctor) didn't emphasise on it. That's why I was quite shocked. So, I was like is it okay? And then she straight away talked about my thyroid and other issues, that's all. I was confused and I asked is it okay? My reading?*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

4.2.3 Access to reliable health information

Access to reliable health information and health services is crucial in diabetes management due to the complexity of its management experienced by patients. Patients perceived diabetes management as complex because they felt that it is hard to practise self-care in terms of making sure they eat the right food, do exercise, adhere to medications and the need to keep checking their blood glucose level.

> *AR: I was counselled on diet and food. I sat there and listened for two hours. Then I asked the doctor, do you have diabetes? The doctor said no. So, I said once you get it, then you'll understand.*
>
> ***51 years old, male, T2DM (5 years)***

> *KCK: To implement it, it's quite difficult because you understand but… to implement the food part is quite difficult because you don't know what, what contains carbohydrate and sugar and everything.*
>
> ***45 years old, male, T2DM (4 years)***

> *NHZ: It's because I'm busy, I have no time (to do exercise). Mm, I don't have time to do it.*
>
> ***38 years old, female, T2DM (1 year)***

4.2.3.1 Source of diabetes information

Educating patients on how and where to find the right health information at the early stages of their diagnosis is required especially for patients with low level of health literacy so that the patients know how to obtain reliable and correct information. The information shared with patients must be patient-centred and cater to their level of understanding and circumstances. All the patients interviewed in this study regarded the healthcare providers who they met during their hospital or clinic visits such as the doctor, dietitian, diabetic nurse, and pharmacist as one of the sources to obtain reliable health information.

> *SA: The other day after my check up at the hospital, I went to see the dietitian. The dietitian suggested what food is good, what time I must eat and how to take my medication. Especially during fasting, for diabetic people is different, right?*
>
> ***31 years old, female, T2DM (2 years)***

> *AA: At the beginning, the pharmacist herself taught me on how to use the insulin.*
>
> ***36 years old, male, T2DM (2 years)***

> *JK: My aunty (diabetic nurse) actually suggested to do that half an hour tabata (workout). That's very, very you know sweat one, it's like sweating kind of activity. And then she told me that you try to keep it to, you know, if you're very busy, one week at least do three days.*
>
> ***21 years old, female, T2DM (1 year)***

Other than the healthcare providers, some patients obtained information about diabetes from family members and friends, who are also diabetics, or work as healthcare provider, from the internet and social media and also from written materials such as books and pamphlets. Patients who have friends or family members with diabetes usually shared information related to food, while patients who have family members working as a healthcare provider asked about medication and self-care. Nevertheless, participant IS was not that happy to accept advice from family and friends because they mostly advised her to take alternative products to help to reduce her glucose level.

> *NHA: From my brother-in-law who has diabetes. Sometimes when we visit him, he will tell me what to eat and what to avoid.*
>
> ***56 years old, female, T2DM (2 years)***

> *AH: I have a colleague who is diabetic and he's from Holland. So, he was sharing to me he has to monitor his sugar level you know on a daily basis. So, like my brother he too monitors every morning. So, he was sharing, I think he was using the one where they implant the reader in his arms. And it will send out the reading to him. Every time before meal he will monitor his sugar level you know. So, he was explaining what he does to maintain the sugar level. But he didn't mention about having to inject insulin every day, nothing.*
>
> ***51 years old, male, pre-diabetes (< 1 year)***

> *SA: Actually because my sister is a pharmacist so, if I don't know I will ask her.*
>
> ***31 years old, female, T2DM (2 years)***

> *IS: Yes, a lot from family and friends. But sometimes I don't really take their advice. For example like… They will ask you to take this product, this*

> *product for high sugar. Ha, for example, take product that is said to be a substitute to sugar and all that stuffs. So, I don't really take those advice.*
>
> ***46 years old, female, pre-diabetes (1 year)***

Diabetes patients are sometimes provided with written information on diabetes and its management by healthcare providers to take home. Several patients mentioned that they were given a pamphlet to take home for further reading when they visited the public healthcare facilities. There are several pamphlets produced by the MOH which are available for patients. Some of the pamphlet contained guidance on nutritional care, exercise regime and treatment care. In addition to pamphlet as a mean to disseminate written information, participant MN obtained further information about controlling his diabetes from books, and he told me about a book he was currently reading when I interviewed him. Participant AH said that he found it helpful if healthcare providers could direct patients to find reliable information and the doctor that he saw suggested books to purchase to assist him in losing weight.

> *IS: But when I went to the public health clinic, I think I was given a booklet, if I'm not mistaken. Aa there was a leaflet, and everything was in there. Like in terms of diet, I remember it's quarter, quarter, half like that.*
>
> ***46 years old, female, pre-diabetes (1 year)***

> *NS: Ha yes, yes. (I got the pamphlet) from the dietitian. Umm… Like how many portions can we take. Food.*
>
> ***31 years old, female, T2DM (2 years)***

> *MN: Ah the latest is that I bought one book. So far, this book has helped me a lot in terms of my psychological and spiritual. The title is about diabetes, and it uses easy to understand terms. So, the writer is a doctor.*

> *A doctor who studies diabetes. So, I'm reading this book at the moment. The information that I learnt from this book, one of the options to control your diabetes is eating every two hours. One of the things I learnt from the book.*
>
> ***43 years old, male, T2DM (< 1 year)***

> *AH: I think it would be helpful like this one doctor who is helping me with the weight loss, so she did recommend books to read.*
>
> ***51 years old, male, pre-diabetes (< 1 year)***

Another source of information that more than half of the patients in this study used to obtain information was the internet because it was easily accessible. A study conducted to assess patients' use of the internet for diabetes information indicated that the internet was mostly used because it is convenient and it is fast in answering general diabetes health questions before their next appointment (Wilson, 2013).

> *IS: It's everywhere (information on the internet) because some are from local sites, even in the Ministry of Health's website, there are a lot of information in there if you look for it and there's even a topic on pre-diabetes. They even have PDF file, and you can download and all. On diet and all, it's there. It's up to us whether we want to go and look for it or not. That's only from the local sites, international ones are also a lot.*
>
> ***46 years old, female, pre-diabetes (1 year)***

> *AA: Usually from Google. It's easier. If I don't get to go to the clinic you know, usually I will find the information on Google.*
>
> ***36 years old, male, T2DM (2 years)***

In this study, patients used the internet or social media, like Facebook and YouTube, to find information which mostly focused on food and diet, while others searched information on the effects of nonadherence to medications, diabetes complications as well as people's experiences in dealing with diabetes.

> *NJ: For me, I focus more on what foods that are low glycaemic index, that don't have high carbohydrate and foods that are healthy. I avoid any food with sugar.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

> *NHA: I sometimes read information about diabetes (on the internet). What are the effects and then about the diet, what food I need to avoid or reduce.*
>
> ***56 years old, female, T2DM (2 years)***

> *NL: I also search on the effects, for example, medicines. I look for information on what happens if I don't take it, is there any alternative. What kind of beverages that can reduce blood sugar level.*
>
> ***36 years old, female, T2DM (5 years)***

> *NS: But if I do look for something (on the internet), it's more to the ones that people commented. Like their experiences.*
>
> ***31 years old, female, T2DM (2 years)***

Though there are a lot of diabetes information available on the internet, some of the patients were not keen of using it to look for information. They felt some of the information were limited, misleading and some were "clickbait" that led them to sites that are selling alternative products claimed to help in reducing blood glucose levels.

AH: Yeah, because sometimes like I think that the difficulty is that because a lot of the information on the internet are all mostly western right? So, it's very hard to, you know, look at food which is local based.

51 years old, male, pre-diabetes (< 1 year)

NS: Umm rarely (used the internet). Because internet sometimes you can't rely on it. Because I used, I used Google and then when I saw the doctor and asked the doctor, the doctor said it's wrong. Like that.

31 years old, female, T2DM (2 years)

KA: Information from the internet, they're 50-50. Some are true, and sometimes some can be nonsense.

Interviewer: What do you mean by nonsense?

KA: For example, like they sell product that can reduce sugar level. But some products can be true, some are not. And then the price is quite expensive. So, it's quite hard to believe. I'm worried they're counterfeit products.

34 years old, male, T2DM (< 1 year)

AR: Aa when I searched on the internet, things like pill products will come out. But all sorts of products so you feel unsure about it.

51 years old, male, T2DM (5 years)

AH: Ah yeah, they're selling their product you know. So usually is you can see it's like a clickbait you know.

51 years old, male, pre-diabetes (< 1 year)

Because of this, patients would ensure that they visited sites which are reputable, and they would clarify information they found on the internet with the doctors when they see them during their check-ups to make sure that the information they gained and the sites that they visited were reliable. Clarification of information with qualified and knowledgeable healthcare providers is crucial because numerous studies done to assess the accuracy of diabetes information available on the internet such as on YouTube and TikTok contained videos with misleading information and these videos had more hits than those reporting useful information (Burki, 2022).

> *AH: So, to me is you need to go to sources that you know more reputable. If not otherwise some of the information will be contradictory right. And a lot especially like on social media, there's a lot of people who are non-professionals, but they are sharing their opinions and all that. But the way they presented it looks very professional, right? So, it's easy to get confused which is why I only go to WebMD and Mayo Clinic because I trust these two to be reputable.*
>
> ***51 years old, male, pre-diabetes (< 1 year)***

> *JK: If my aunty (who is a diabetic nurse) is not available on the phone, I will just go on Google first. But Google I will also look you know normally when you searched Google, they have those first few (sites) that's quite valid from certain you know O.R.G. or diabetes dot com or something like that. So, I really look at those myths. I think that those are facts. Yeah. I look at that first and then I validate with my doctor.*
>
> ***21 years old, female, T2DM (1 year)***

> *NHZ: Umm… The information (on the internet), it depends… We can't just look on one source only, we must look on different sources and compare,*

> *you know. Because sometimes the information is quite confusing. Sometimes from this source will say this and another one will say something else. So, we must check properly. It can be quite confusing sometimes. Sometimes I'll ask the doctor anything I feel I'm not too sure. I'll ask the doctor.*
>
> ***38 years old, female, T2DM (1 year)***

Though most patients have no problem accessing diabetes information, some experienced barriers in finding reliable information due to lack of information received during counselling sessions as mentioned in section 4.2.2, difficulty understanding the information obtained and also because of digital illiteracy.

> *S: The doctor didn't suggest anything, the doctor only suggested to reduce my rice.*
>
> ***43 years old, female, T2DM (4 years)***

> *NS: There's some—because mostly it's in English. Some I understand, some I don't. I just guess.*
>
> ***31 years old, female, T2DM (2 years)***

It is interesting to see that most patients who were recruited online had no difficulties in looking for information online while some of the patients who were recruited from the public health clinics indicated that they do not use the internet because they do not know how to use it. Those who did not know how to use the internet to look for information were all in their 50s. To improve digital literacy among the over 50s, poor and the digitally illiterate, Datta et al. (2019) suggested that the human-computer interaction needs to be made easier so that the applications can matched to the skills of the users, for example, by using visual icons and widgets as well as voice or audio instructions (Datta et al., 2019). By improving the human-computer interactions, older people can use the internet easily to find health information.

> *CPC: No, no. I don't know how to use it (the internet) [laugh]. How?*
>
> ***53 years old, female, T2DM (< 1 year)***

> *NSS: I don't know how to use Facebook and all these [laugh]. I don't know how to use it, you know.*
>
> ***62 years old, female, pre-diabetes (< 1 year)***

> *NA: …because not everyone, especially us, the elderly, we're not good at it (look for information). We need guidance… Guidance and we need to be reminded always.*
>
> ***52 years old, female, T2DM (2 years)***

4.2.3.2 Applying health information received

In the interviews, patients were also asked whether they understood the information received and what did they do with the information they obtained from the different sources. Most of the patients stated that they understood what have been told to them because most of the time healthcare providers used the language that they can understand and used aids such as pictures and diagrams when explaining about diet or how to use insulin.

> *NHA: I understand because if… I think I understand. Because sometimes when I overeat especially when you see people during gatherings, or when I go back to my hometown, sometimes I overeat. When I overeat, I remember the things that I read, and I felt guilty.*
>
> ***56 years old, female, T2DM (2 years)***

> *NL: They (the healthcare providers) explained in Malay.*
>
> ***36 years old, female, T2DM (5 years)***

> *SA: Umm from the dietitian, yes, I understood. Because the dietitian explained using pictures. So, the dietitian showed the pictures, and then she explains one by one using the pictures.*
>
> ***31 years old, female, T2DM (2 years)***

With sufficient access to correct information and the support they need, diabetes patients may be empowered to practise self-care. Although not all, those who did not apply the information they obtained stated that they were not adhering to their medications due to misinformation or just forgetting to take their medications, while others said that they were too busy to exercise or simply cannot be bothered to practise self-care.

> *MRO: I don’t take the green box tablet because it effects the kidneys.*
>
> ***42 years old, male, T2DM (3 years)***

> *NA: It’s like this, the one in the morning, when I wake up I’ll take it. The one before meal, that one I’ll always take. But the after meal one, sometimes I forget because I’ll start do my work and I forgot about it. When I rest only, I remember… and then I forget again. Ha. Keep forgetting. I mean it’s not like… I still take but not compliant. It’s like some days, I forget.*
>
> ***52 years old, female, T2DM (2 years)***

> *AA: It (self-care) is actually quite easy, but I can’t be bothered. Actually, well you know sometimes we’re busy, sometimes when you see nice food you become like you know. There are times I just can’t be bothered. It’s easy but I’m just too lazy.*
>
> ***36 years old, male, T2DM (2 years)***

> *NHZ: It’s because I’m busy, I have no time (to exercise).*
>
> ***38 years old, female, T2DM (1 year)***

Several patients said that they did practise the health advice they received from their doctors in their daily lives, for example, participant AH, IS and JK talked about doing intermittent fasting, exercising, and losing weight, which were suggested by their doctors respectively, to manage their diabetes.

> *AH: Yeah, so like now I’m heavy on intermittent fasting. I’m totally off sugar. Carbs are a bit hard because carbs are almost everywhere, right? But I seem to go for more whole carbs rather than processed carbs. And*

then like… I'm also off dairy products, they might actually have lactose sugar and it may not be suitable, right?

51 years old, male, pre-diabetes (< 1 year)

IS: I make an effort to walk every day but not 10000 steps. 3 to 4 kilometres a day for now. I have stopped walking for quite some time because I had sore feet but if I don't walk, I cycle at home. I make an effort to sweat.

46 years old, female, pre-diabetes (1 year)

JK: Because you know the doctor said if you lose weight, you don't have to go stabbing your stomach. So, I said I don't want to go for that. So, I exercise, I reduce carbs, I drink a lot of water which is very different from my lifestyle before I was diagnosed. And then I quickly lost 7 kilograms throughout half a year.

21 years old, female, 1 year

4.2.4 Access to health services

Navigating the healthcare system requires a high degree of health literacy because the healthcare system in many countries have expanded to different areas of specialisations and thus, become more complex for patients to manoeuvre through the system (Griese et al., 2020). With adequate or high health literacy level, patients are able to find the right services and support they need as well as decide which healthcare providers they need to see (Osborne et al., 2013).

4.2.4.1 Preferred healthcare providers

Getting to see the same healthcare providers especially doctors, during patient's regular appointments empower patients to be more disciplined to follow self-care measures because of the personal continuity of care (Ahmad Azhari et al., 2021). A study done to see the patients' views on seeing the same doctor found that more than half of the patients interviewed are willing to wait to see their usual doctor due to their good or close relationship with their usual doctor, while the rest cited that it is because of the doctor's knowledge of their condition (Freeman & Richards, 1993).

> *AH: Yeah, like the clinic that I go to, so far I've been fortunate to have the same doctor. So, like I think it's fixed you know, so, my preference is to have the same doctor because she has all your background and record.*
>
> ***51 years old, male, pre-diabetes (< 1 year)***

> *NL: Actually, it's important to get to see the same person. Because the doctor knows, right? From the first check. So, when we come again, he/she already knows about our progression, what to check, you know. So, he/she knows.*
>
> ***36 years old, female, T2DM (5 years)***

> *NA: I think… I became like this (nonadherence) because I don't get to see the same doctor. If let's say I get to see the same doctor, I'll be more discipline. Because the doctor understands me, right? The doctor knows this and this about me.*
>
> ***52 years old, female, T2DM (2 years)***

Nonetheless, not all patients who attended the public health facilities in this study had the opportunity to see the same doctor or dietitian during their follow up when asked.

> *NK: No, the doctor changes every time.*
>
> ***43 years old, female, T2DM (5 years)***

> *NL: I used to, I used to get to see the same doctor. But since they changed their system, I don't get to see the same doctor.*
>
> ***36 years old, female, T2DM (5 years)***

> *NSS: It's the same clinic but the doctor changes. Sometimes, it's a different doctor.*
>
> ***62 years old, female, pre-diabetes (< 1 year)***

Due to this, the information that they obtained sometimes were different from their previous check-up which caused confusion in their diabetes management and no continuation of care. Other than that, even though the clinics keep their medical records, some patients expressed that it is quite tiresome to explain their condition each time they attended their appointments. Participant IS also said that because her regular dietitian was transferred to another public health clinic, she did not bother to continue going for her regular follow up with the new dietitian.

> *NHZ: For example, doctor A said, "okay, we'll try do this and this". But when I come for the next appointment, it's a different doctor so, what doctor A said he wanted to do didn't happen. Because it's a different doctor, you know.*
>
> ***38 years old, female, T2DM (1 year)***

> *NA: …I mean when you see the same doctor, for example this doctor said to me, "okay madam, if your blood sugar is still high, I'll have to give you insulin". When I came back the week after, I've also given up and I don't care anymore because I can't reduce my blood sugar, but the other doctor said, "it's okay, just continue as long as you take your medications". So, it's like that.*
>
> ***52 years old, female, T2DM (2 years)***

> *NJ: I prefer to see the same doctor. Firstly, because I don't need to tell the same story about an issue to different doctors. Secondly, the first doctor that I saw is more understanding compared to the different doctors that I met just for a short moment and then a different story will pop out.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

> *IS: But after that I stopped going because the dietitian moved. After she moved, I stopped going because I have to see another dietitian. I have to report to a different person so I'm like I can't be bothered. I felt like I know what I needed to do so I just did it myself.*
>
> ***46 years old, female, pre-diabetes (1 year)***

Having say that, several patients did not mind if they did not get to see the same doctor during their check-ups because they felt that the information shared to them were all the same, regardless of who the doctor was, and as long as they are still practising self-care and the doctors are providing sufficient support and guidance they need.

> *KA: I think every time I go for my check-up, I don't see there's a problem seeing different doctors. Because I think the information that they give must be the same information. But… Counselling, they must do counselling. I*

mean not counselling, but advice. They must give advice, but it doesn't matter if it's not from the same doctor. I don't see there's a problem if it's from the different doctors.

34 years old, male, T2DM (< 1 year)

CPC: It doesn't really matter because I'm still eating healthy balanced diet. Then when they checked my record, they said everything is normal.

53 years old, female, T2DM (< 1 year)

NK: I don't mind. As long as they give me encouragement and advice.

43 years old, female, T2DM (5 years)

4.2.4.2 Signposting

As mentioned in section 4.1.4.1, the management of diabetes involves multidisciplinary team approach. The involvement of different healthcare providers with different skills and specialities allows patients to obtain in depth knowledge and understanding about T2DM and accept responsibility for their self-care management (Ministry of Health Malaysia, 2020a). Various healthcare providers which include doctors and specialists, diabetes nurses, dietitians, assistant medical officers, ophthalmologists, and pharmacists are regarded as diabetes educators that provide education and training to patients during diabetes self-management education (Ministry of Health Malaysia, 2020a). When necessary, patients are signposted to appropriate healthcare providers to receive the education and training needed.

> *IS: At that time, it was upon recommendation after I did my medical check-up at the public health clinic. It's not really the clinic. The clinic and some women organisation who organised it. So, after my medical check-up, the doctor referred me to the dietitian. I went to see the dietitian. So, the dietitian explained to me everything about diet to avoid getting diabetes and all.*
>
> ***46 years old, female, pre-diabetes (1 year)***

> *JK: So, the doctor is also very nice-lah. She referred me to the hospital for eye check-up to check whether my eyes have any problems.*
>
> ***21 years old, female, T2DM (1 year)***

> *S: After I was discharged, doctor told me to have my appointment at the public health clinic. And then, the doctor sent me to the nutrition department.*

43 years old, female, T2DM (4 years)

Diabetes medication adherence therapy clinic (DMTAC) is an ambulatory care service which is available in public healthcare facilities to help diabetes patients achieve better medication adherence level and glycaemic control (Pharmaceutical Services Division, 2014). The clinic is run by pharmacists in collaboration with the doctors, and patients are enrolled to the clinic if their diabetes is uncontrolled, do not adhere to their medications, who HbA1c is more than 8.0% and those who has multiple co-morbidities/medications and complications (Pharmaceutical Services Division, 2014). In this programme, patients will have follow-up appointments with pharmacist for a minimum of 8 weeks. Participant NL talked about her experience being enrolled into DMTAC after her blood sugar level increased.

> *NL: Like yesterday, I told you my blood sugar has gone up, right? The doctor straight away asked me to go for counselling. After I collected my medications, the pharmacist took my medication into the counselling room. So, she asked me what's wrong with me, what did I eat, do I exercise. So, she advised me. I know her very well. Then she said, the other day I saw you, you have lost weight, but now you look bigger [laugh]. Like that. So, they will call for counselling over there.*

36 years old, female, T2DM (5 years)

Upon further questioning, participant NL mentioned that the pharmacist also explained to her again on how to use her insulin correctly.

> *NL: Insulin, insulin. She will talk about insulin as well. Even though I already know about it. How to use it, don't inject wrongly. She will explain everything. She will teach you how to use it. I already know that, but I just listen.*

36 years old, female, T2DM (5 years)

In 2015, the impact of pharmacist managed DMTAC in 14 public health clinics was assessed and it was found that the programme significantly improved patients' HbA1c, medication understanding and medication adherence post-intervention by pharmacists (Lee et al., 2015). Thus, introducing a similar concept clinic such as DMTAC but specially for newly diagnosed T2DM and pre-diabetes patients can improve the accessibility of these new patients to health information and support they need, and consequently, empowers patients to take control of their diabetes self-management and practise self-care in order to prevent disease progression. This can also further strengthen the role of pharmacists in educating patients as well as in reducing the health burden to the economy and healthcare system caused by NCDs such as T2DM.

4.2.5 Role of pharmacists

From the DMTAC programme, it is evident that pharmacists play a major role in educating and supporting diabetes patients. With the skills and knowledge pharmacist acquired, they could also be one of the reliable resources for diabetes patients to gain information. The roles of pharmacists can be further expanded in diabetes self-care especially those who are working in community pharmacies due to their accessibility to the public. Countries like Australia, Canada, England, the Netherlands, and the United States are implementing strategies and policies to expand the role of community pharmacists from just "retailers" to health care providers in order to contribute to the safe, effective, and efficient use of medications especially when caring for people with chronic conditions (Mossialos et al., 2015). The community-based setting is seen as a more relaxed and easier to access setting for people who are taking responsibility for their own health and treatment to get informed advice (Anderson, 2000).

Patients in this study were asked about their perspectives on the role of pharmacists and it was not surprising to hear that nearly all the patients said the role of pharmacists is to just give out and provide information about medications. This is because pharmacists are usually the last healthcare provider that they see to collect their medications during their routine check-ups.

> *IS: Aa pharmacist eh? Provide medicines, give simple advice.*
>
> ***46 years old, female, pre-diabetes (1 year)***

> *MRO: Pharmacist, they're supposed to explain about medications. But mostly don't. Mostly just want to make sales and sell products only.*
>
> ***42 years old, male, T2DM (3 years)***

NHA: What I know is that pharmacist gives out medication, I think. I'm not too sure.

56 years old, female, T2DM (2 years)

NHZ: Umm… Pharmacist. Pharmacist explains to us on how to use our medicines.

38 years old, female, T2DM (1 year)

4.2.5.1 Use of community pharmacy

Pharmacists are highly skilled and highly accessible, but they are mainly underutilised by the public. Chua et. al (2013) studied the utilisation of community pharmacists by the general public in Malaysia and found that there is an underutilisation of community pharmacy in filling prescription medicines, and the main reason people visit the community pharmacies is to purchase certain medications or supplements and getting advice on minor health problems (Chua et al., 2013). In this study, patients were asked about their use of community pharmacy and various answers were given by patients which echoed the study done in 2013. Some used community pharmacy to buy supplements, to get advice and medicines for minor ailments such as fever or cough and cold, while others used community pharmacy to buy their equipment for their blood glucose machines or insulin pen such as test strips or needles respectively. A few of the patients said that they went to community pharmacy to purchase blood glucose machine and to get their blood glucose checked by the pharmacist because they did not have the machine at home.

> *CPC: Depends on the sickness. If I feel not too well like fever, I'll go (to the pharmacy), and they give me Panadol something like that.*
>
> ***53 years old, female, T2DM (< 1 year)***

> *NJ: I usually only go to buy supplement related to vitamin for example, vitamin C.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

> *AA: Ah I buy the needles at retail pharmacy. I just bring the sample and show to them.*
>
> ***36 years old, male, T2DM (2 years)***

> *NSS: Before this I don't have those machines, you know. So, I go to the pharmacy to get it checked.*
>
> ***62 years old, female, pre-diabetes (< 1 year)***

During the interviews, I also asked patients if they asked pharmacists for advice on their diabetes or self-care during their visits to the community pharmacy, and mostly said they did not.

> *AA: Not really. Usually, I just go and buy (needles) and leave.*
>
> ***36 years old, male, T2DM (2 years)***

> *AH: Yeah, I mean I go to retail pharmacy to purchase medicine but not for advice on what medicine to take and stuff. Ah, the normal things like antihistamine or you know for myself, yeah, it's just antihistamines. Yeah, I don't ask for advice from pharmacist.*
>
> ***51 years old, male, pre-diabetes (< 1 year)***

> *NL: Aa no. I don't go there (for health information). I only go to pharmacy if I need to buy test strips.*
>
> ***36 years old, female, T2DM (5 years)***

Further questioning on why they did not ask pharmacist for advice on diabetes and self-care because pharmacists who are working in community pharmacies are as knowledgeable and skilful as the healthcare providers they see in hospitals or public health clinics, several patients mentioned it was because they think that community pharmacists are more about selling products and making profit for their business, and they do not know much about diabetes.

AA: Because they don't really understand sometimes when I explained you know. They usually just want to do sales and we are well informed of that.

36 years old, male, T2DM (2 years)

MN: The other day I went and asked if there are any other options than taking supplements. They gave me this tablet and the price is only around RM5 or RM6 per strip. But instead, they're trying to sell me a supplement milk which is around RM150 to RM200. So, for me it's more to business.

43 years old, male, T2DM (< 1 year)

MRO: Because pharmacist mostly they are for selling products. Simple. They don't want to share knowledge. They're just like "okay, this medicine is for blood pressure this this this, okay this you take once a day", that's all. And then you pay. NO INFORMATION. Ha, just… More to selling products. Simple.

42 years old, male, T2DM (3 years)

SL: Umm for, for advice? At the pharmacy, I don't think so. Because at the pharmacy, some they don't, they don't know much about diabetes. They only know about medication.

36 years old, male, T2DM (2 years)

Though it was not surprising that the public are not fully aware of the role of pharmacists beyond the scope of just giving out of medications or just as "retailers", it is quite saddening to see that they are underused and undervalued. Hence, strategies and efforts to address issues to the use of community pharmacies and to promote the role of community pharmacists in Malaysia to the general public need to be evaluated and implemented. This is crucial in order to broaden the accessibility of diabetes patients as well as the general public to healthcare services and reduce the burden of secondary care.

4.2.6 Summary

It is apparent that patients with greater understanding and knowledge about their diabetes management demonstrated better self-care management and glycaemic control. As we can see from theme 2, most patients have limited knowledge and understanding about diabetes and its management prior to their diagnosis. In order to achieve good understanding, access to diabetes information and care must be made easier for patients. However, some of the patients in this study have difficulties accessing reliable diabetes information due to reasons mentioned in section 4.2.3.1, section 4.2.4.1 and section 4.2.5.1. Two studies which looked at the relationship between low health literacy and access to care and health information stated that individuals with low health literacy are more likely to delay getting care, have difficulty finding healthcare providers and less likely to get sufficient health information from multiple sources (Levy & Janke, 2016; Suka et al., 2015). Hence, there is a need to tackle the issues around accessibility especially for patients with low health literacy. Several patients also stated that healthcare providers also need to provide sufficient information and guide them on where and how to access correct information and the services they need in order to empower self-care behaviours. The importance of accessibility to reliable diabetes information and services will be further discussed in section 6.4.

THEME 3: SELF-AWARENESS

4.3.1 Introduction

According to the National Health and Morbidity Survey 2019, the prevalence of high blood glucose among those not known was 8.9% (Institute for Public Health (IPH), 2020). Untreated undiagnosed diabetes can lead to the development of serious diabetes complications. In this section, I will discuss about the impact of self-awareness in empowering patients to practise self-care and the effect of lack of awareness to diabetes management and why is it important to increase awareness among diabetes patients about T2DM.

4.3.2 Reasons for diabetes detection

One of the first few questions asked during the patient interviews was about how they found out that they had diabetes. A number of interesting stories were told by patients about their experiences of finding out. Some patients did not realise that they had diabetes until they developed serious symptoms and had to attend the emergency department at the hospital.

> *SL: I went out to eat with my wife. Then when I got home suddenly I felt dizzy, I felt like I wanted to faint. Then my face turned pale, everything went pale. My hands were pale, like there's no blood. So, I sat down to rest. I felt much better, but I still felt weak. So, I immediately went to the hospital, to the emergency department. When I got there, the doctor took my blood. Then, I waited. I don't know how long I waited. Then the doctor called me, I saw the doctor and he told me that my blood sugar was very high. He said it's gone up to 12.*
>
> ***36 years old, male, T2DM (2 years)***

> *SA: Actually, at that time it started with gastric. And then doctor detected sugar was high. Then immediately I was admitted to ICU because my sugar was too high, up to 21.*
>
> ***31 years old, female, T2DM (2 years)***

> *S: I first found out when I had a carbuncle. That's how I found out… The boil was at my stomach. It was small initially and then it got bigger and bigger. I only went to the clinic when it's gone really big because I thought it's just a normal boil. After a week, it's still not getting better. The doctor gave me antibiotic but still the same. I went to the clinic again, the doctor asked to go to the hospital. I went to the hospital, they took my blood, and*

it was high (my sugar). I was straight away warded because the boil has gone bad.

43 years old, female, T2DM (4 years)

Several patients said that they found out after having a blood glucose check because of the symptoms that they experienced while a few mentioned they went to the healthcare facilities for other health problems and found out that their blood glucose level was high.

MRO: I found out because I need to urinate frequently. Ha, frequent urination and then aa sleep a lot.

42 years old, male, T2DM (3 years)

NJ: I found out I have pre-diabetes because I have been experiencing symptoms like always feel thirsty and tired. I asked my mom about it, and she said if I want to know whether I have it or not, go check my sugar at the clinic. And then when I got my result then I found out I have pre-diabetes.

24 years old, female, pre-diabetes (< 1 year)

JK: Okay basically I do not have any symptoms. But I went on a blood check-up when I found out that (I have diabetes)—I went to treat my chronic urticaria.

21 years old, female, T2DM (1 year)

NHZ: Umm because I usually go to the hospital for my follow up appointment. Because I have migraine. And then one day the doctor said she wanted to check everything. They wanted to check everything and then after that the doctor said I have this diabetes.

38 years old, female, T2DM (1 year)

Several patients found out when attending their regular check-up appointments and postnatal check-ups at the public health clinic. While one patient mentioned that he found out as he needed to do a full blood test before undergoing a surgery and one patient said he went to check at the pharmacy because his wife told him she saw ants in the toilet.

> *CPC: The other day the doctor asked me to drink that glucose solution. And then after I took it then she told me I have diabetes.*
>
> **_53 years old, female, T2DM (< 1 year)_**

> *ZE: I found out like this miss, I went to the public health clinic for my progesterone implant. So, this doctor, before inserting the Nex implant, he asked me to take the diabetes test. Because when I was pregnant, I had diabetes.*
>
> **_35 years old, female, T2DM (2 years)_**

> *KA: And then recently, I needed to go for a surgery, so I was admitted. That's when the doctor found out my blood sugar was high. They monitored and monitored and then they declared me as having diabetes. Type 2.*
>
> **_34 years old, male, T2DM (< 1 year)_**

> *KCK: My wife told me because she saw ants in the toilet. Aa. So… We went to a pharmacy to check.*
>
> **_45 years old, male, T2DM (4 years)_**

Hence, most patients in this study were unaware that they have diabetes until they went to have a full blood test or blood glucose check due to different reasons mentioned above. Patients who recognised the symptoms of diabetes stated that they went to check because they have family members who have diabetes and also looked for information on the internet after experiencing the symptoms.

4.3.3 Effects of others’ experiences

During the interviews, patients were asked what motivated them to manage their diabetes. Several patients indicated that seeing the effects of uncontrolled diabetes on other people close to them, for example, amputation and death, made them aware of the consequences of high blood glucose and thus, they are then motivated to manage their diabetes.

> *AA: I want to motivate myself because I’ve seen people around me who had their leg amputated, some passed away because of diabetes you know.*
>
> ***36 years old, male, T2DM (2 years)***

> *MRO: Because a lot of my friends have already passed away. I watched one by one get diabetes and then they die. I have friends who had their leg amputated and then die.*
>
> ***42 years old, male, T2DM (3 years)***

> *CPC: I’m scared because one of my relatives, she’s quite young you know. But she has this same case last time you know. Type 2 diabetes mellitus right. But she didn’t listen, and she didn’t eat healthy balanced diet and then she didn’t control you know. After that she started to have pain at her leg for a long time… and it got worse and then the leg got amputated.*
>
> ***53 years old, female, T2DM (< 1 year)***

While participant NJ stated that the stories people shared on Facebook about their experiences dealing with diabetes gave her the awareness to look after her health so that her pre-diabetes does not develop into type 2 diabetes.

> *NJ: Mm like from the Facebook group, a lot of them talked about the experience with diabetes, for example, about amputation. It gives me a lot of awareness to look after my health and helps me to be aware of things that I need to avoid as well as to reduce my sugar intake.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

Participant NJ would jot down some of the information that she gained from the sharing and practise them as her daily self-care to control her blood glucose level.

> *NJ: Aa sometimes I jot it down. And some of them, I practise in my daily life. For example, I don't drink sugary drinks, I don't take sugar if possible. I eat less starchy and fried food.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

Another reason that increased the awareness of some of the patients in this study to practise self-care was that they did not want to be the burden to their family members if their diabetes got worse due to complications. This is again due to their experiences seeing other people who had to cope with diabetes complications which has significantly affected the person and also the people around them. As stated previously in section 4.1.4.2, the management of diabetes is mainly done at home with the help of family members, and this could directly or indirectly affect the quality of life of the caregivers (Anaforoğlu et al., 2012). A Turkish study which looked at depression, anxiety, and quality of life among family caregivers of patients with T2DM and control group found that even though there was no difference between the groups in terms of anxiety, family caregivers of T2DM patients appeared to be more prone to depression and tended to have a poorer quality of life compared to the control group (Anaforoğlu et al., 2012). Hence, the development and management of diabetes complications not only have negative impact to the patients, but it can also affect their caregivers.

> *NA: Mm… If we think… about the long-term effects, we want to be healthy. Haa! When we think about it. We have to go for dialysis when you think about all these. What if one day we lay down sick, who is going to look after us?*
>
> ***52 years old, female, T2DM (2 years)***

> *NHA: You really need to be determined. Need to be determined even though sometimes you feel that you can't be bothered with it but when… when you think about the effects of not controlling it like who's going to look after you? I don't want to trouble my kids, my husband. It's like that. So, when you think about all that, you'll be determined again to control your diabetes. I don't want to be like that. You have to think that way.*
>
> ***56 years old, female, T2DM (2 years)***

> *NJ: Umm for me, I have to be strong to take care of my health because I'm thinking about the long-term effects for example, when I get married, I don't want to bring this pre-diabetes problem to my children. And then if I fall sick who's going to look after my parents? I have to take care of myself to look after others too.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

> *S: Because I have experience from taking care of my mother, so I thought to myself if I get stroke, who's going to look after me? Just like that. So, every week I'll go exercise, aerobic and all. I go for aerobic classes three times a week.*
>
> ***43 years old, female, T2DM (4 years)***

Some of the male patients said that because they are the main breadwinner hence, they felt there is a need to stay healthy to look after their family.

MN: The motivation is easy because I'm the breadwinner. I have kids, wife that I have to take care of. That's the reason I have to force myself to keep going.

43 years old, male, T2DM (< 1 year)

SL: The factors because umm… I have family, I have children. So, I'm doing this for my children and wife because if I don't manage my diabetes, it can cause so many problems. When I have too many problems, it'd be troublesome for my family, right? So, I look after my health, for my family.

36 years old, male, T2DM (2 years)

4.3.4 Fear of developing diabetes complications

A study which looked at the associations between barriers to self-care and diabetes complications found that individuals with reduced self-efficacy, for example, lack of readiness to exercise, are more likely to report any complications (Sina et al., 2018). Almost all the patients recognised that uncontrolled diabetes could lead to the development of complications, and they were fearful of it especially amputations.

> *NSS: The factor is I don't want I don't want to get diabetes. I heard so many things you know. It's scary. So many things like some people when the condition is bad, have to get amputation and all you know.*
>
> ***62 years old, female, pre-diabetes (< 1 year)***

> *NK: You know I'm scared if it's not controlled and it get worse, I might get my leg amputated or something like that. It's scary.*
>
> ***43 years old, female, T2DM (5 years)***

> *KA: I'm only 34. When you have diabetes, one of the effects is your leg can get amputated, heart problem and all. It's scary, right? When you're scared, like for me now if I'm scared, I have to control (my sugar). If before I just take it for granted, can't be bothered. I still eat (sweet stuffs). Sometimes I control, sometimes I don't. And then when I'm scared and when I realised the level of seriousness, I must control.*
>
> ***34 years old, male, T2DM (< 1 year)***

> *JK: When I first diagnosed, I was like cried for a few days because I thought that oh, I need to be amputated and when I'm old, I need to you know those complications. I will die because I cannot see.*

21 years old, female, T2DM (1 year)

> *AR: So, when I was diagnosed with diabetes, I see where the effect on me. Okay, like me the effect is from my knee to my feet. I can't have wounds from my knees to my toes. Even if I get bitten by mosquitoes. You know when you get bitten it'd get itchy, right? So, I'd scratched it and sometimes it caused abrasions you know. The abrasion will turn to wound that's very hard to heal. But if it's above my knee it'd get healed faster.*

51 years old, male, T2DM (5 years)

According to the National Diabetes Registry Report 2020, the proportion of patients with amputations remains at 0.68% and 0.73% for 2019 and 2020 respectively (Ministry of Health Malaysia, 2021). Lower limb amputations affect approximately half of diabetes patients, and it can significantly affect their daily activities and increased their risk of psychological distress such as anxiety and depression (Coffey et al., 2009; Razak et al., 2016). Due to this, it is not surprising that almost all the patients in this study mentioned leg amputation as one of the diabetes complications that they feared the most because amputations are quite commonly linked to diabetes.

Apart from amputations, a few of the patients mentioned about other complications associated with diabetes such as heart problems, kidney problems and erectile dysfunction, if diabetes is not well controlled. Uncontrolled T2DM is associated with increased risk of developing heart problems, kidney diseases and erectile dysfunction compared to people without diabetes (Ministry of Health Malaysia, 2020a).

> *IS: Ah and another thing is because of kidneys you know. I'm worried if it affects the kidneys and all.*

46 years old, female, pre-diabetes (1 year)

> *MN: So, one of the symptoms (effects) really makes me feel down. One of it is, I'm sorry but umm… Impotence. I'm talking professional here, don't think otherwise. Ha… That's why I feel moody. And then I feel tired all the time. That's the problem.*

43 years old, male, T2DM (< 1 year)

> *ZE: They said if I don't look after my health, I'll get sick, and it'll be troublesome like heart problems and all. When I think back, they are right.*

35 years old, female, T2DM (2 years)

The patients recruited in this study were diagnosed with T2DM and pre-diabetes within 5 years period and more than half of them were aged 45 years and less. Based on the study conducted by Hillier & Pedula (2003) on the complications in young adults (aged 18 to 45 years old) with early onset of type 2 diabetes, they found that younger adults diagnosed with T2DM have a higher risk of developing cardiovascular disease compared to older patients (Hillier & Pedula, 2003). Therefore, with their awareness about diabetes complications, it is important to educate and empower these younger patients in practising self-care so that the development of diabetes complications can be delayed or even prevented.

4.3.5 Self-awareness

Self-awareness is defined as the personal and practical application of an individual's health knowledge to their own health situation (International Self-care Foundation, 2022). Having self-awareness of one's health situation and need allows individual to identify and act on areas needing improvement and empowers oneself to practise self-care. Lack of awareness of patient's own diabetes self-care management could lead to the development of various diabetes complications as mentioned in previous section.

Lack of awareness is associated with poorer control of HbA1c level. A study on Singaporean Malay patients on the awareness of diabetes and diabetic retinopathy found that high proportions of these group of patients were unaware of their diabetes or diabetic retinopathy status, and the lack of awareness was associated with poor control of HbA1c as well as blood pressure levels (Huang et al., 2009). Another study found that lack of awareness of target blood glucose and blood pressure among most of the participants was found to be one of the barriers to self-management of diabetes (Onwudiwe et al., 2011). During the interviews, patients were asked whether they think it is easy or hard to practise self-care and why did they think that way. Some of patients mentioned it is not that hard to do self-care but because of lack of awareness, they could not be bothered to do it. A number of patients in this study showed that they were lacking self-awareness during their early diagnosis in terms of self-managing their diabetes. This could be due to lack of knowledge and understanding of the condition and its management.

> *AA: It's actually quite easy but I can't be bothered.*
>
> ***36 years old, male, T2DM (2 years)***

> *MRO: Actually it depends on our mood. Ha. If you want to do it, then do. If don't want to do it, "lantak" (don't bother with it). Ha it's like that.*
>
> ***42 years old, male, T2DM (3 years)***

> *SL: First I took it for granted. When I was first diagnosed, I didn't control. I didn't control anything. I eat like normal and all. I only follow a little bit. Follow a bit, and a bit.*
>
> ***36 years old, male, T2DM (2 years)***

> *NS: Just that when I found out, I didn't control. I didn't take medication.*
>
> ***31 years old, female, T2DM (2 years)***

> *KA: Before this I didn't know that if you eat rice, it can also increase your blood sugar. You eat bread, fruits can make your blood sugar go high. It's like the information, is like not enough. Plus, I also didn't care to know more. I just took it for granted. Means like before this, I wasn't serious.*
>
> ***34 years old, male, T2DM (< 1 year)***

One patient in particular, participant NS told her story about missing her follow up appointments after being diagnosed with diabetes due to lack of self-awareness.

> *NS: I don't know (why I didn't go for follow ups). I felt lazy. Just be it. Ha like that. Because my sister didn't go for her follow up after she gave birth. But aa… she, she didn't take medication so, just be careful only (with what you eat). Ha like that.*
>
> ***31 years old, female, T2DM (2 years)***

But after experiencing two urinary tract infections, she decided that she needed to take control of her diabetes after the doctor told her that it could affect her kidneys.

> *NS: When I first went to the clinic, the doctor said it's cystitis. The doctor asked me if I have diabetes and I said yes. So, the doctor gave me medication and then it's okay. Ah and then after a month or two, I got it again. I went to a different clinic. The doctor only gave me medication for cystitis but no antibiotic. I felt like why the doctor didn't give me antibiotic because the pain was the same. And then the doctor explained it's because my sugar is high so he's worried that it'll affect my kidneys. Ha like that. And then I said, oh God. I need to go for follow up again.*
>
> ***31 years old, female, T2DM (2 years)***

Because of the reasons mentioned in sections 4.3.3 and 4.3.4, several patients started to realise that they need to control their diabetes in order to avoid diabetes complications. Participant SL indicated that he started to look for information on the internet and made changes to his diet after noticing black spots on his legs. While participant NJ looked for more information about diabetes after the doctor did not explain to her about her pre-diabetes result and participant S said that she started to find for more information on social media on how to control her diabetes after she failed to do it on her own.

> *SL: And then I started to feel like my legs, I saw my legs there's like black spots. It made me worried. Then I did more research. Then I found out that actually when your legs started to get darker means that your cells are damaged. I mean nerve, nerve. Ha your nerve is damaged. That's because it's not controlled (the sugar), right? Because I didn't watch what I eat when I got diabetes. I watched sometimes but I still eat big amount. And then because of that, when I saw there's changes on my legs, I got worried. After that I started to do my research again and I started to look after what I eat until now.*

36 years old, male, T2DM (2 years)

> *NJ: …because the doctor didn't really emphasise on it. After that I started to do my own research on why I'm always thirsty and always tired, and I found out that if I don't manage it, I might get diabetes in 5 to 10 years.*

24 years old, female, pre-diabetes (< 1 year)

> *S: I control myself but it still the same (sugar level), it increased and increased very high. Like 11. Just recently I followed and saw on FB a lot of information. The doctor (from Facebook) said so many things when I saw on FB, this doctor will say this, that doctor will say that. So, I will try whichever is good.*

43 years old, female, T2DM (4 years)

Many diabetes patients have difficulty achieving their recommended glycaemic levels due to many reasons such as difficulty in controlling their diet, doing physical activities, managing stress levels, or taking medications (Whitehead et al., 2022). This could hinder patients to continue practising self-care, for example, participant MRO stopped taking his diabetes medications because he did not see the improvement on his blood glucose levels when asked why he could not be bothered to practise self-care.

> *MRO: It's not that (I'm lazy), I just need to put one and prick but when I see my reading and it's still the same, I become down. I tried before. I tried taking my tablet for a month you know… I took them for a month non-stop, and it's still the same. It didn't go down at all. Ha, that's why sometimes I felt down. Emotionally down.*

42 years old, male, T2DM (3 years)

To achieve and maintain good glycaemic control is crucial as it can minimise microvascular and macrovascular changes and thus, patients need to know what target they need to achieve. Therefore, setting a goal for diabetes patients may be an effective strategy to support people to achieve good glycaemic control (Whitehead et al., 2022).

> *JK: If the doctor gives you a clear number, or what should I work on and then he gave me a range on how my blood sugar should be normal, within that range that's really helpful for me to know, I know that my body is working fine. So, the doctor is helpful when I first started with diabetes. Yeah. Because it's very clear you know, it's just me aiming for A for our, our studies. So, it's like for diabetes we aim for like 4.5 every time when we first woke up, less than 6, less than 5, we give ourselves a goal like that to make sure we are on the right track on being normal and this blood sugar it would not be too high or too low that would affect my body or any other you know complicated organ.*
>
> ***21 years old, female, T2DM (1 year)***

A number of patients indicated that they are aware of the glycaemic level they need to achieve and maintain in order to reduce the progression of their diabetes. With the knowledge of the target range they need to achieve and what they need to do to achieve it, patients are empowered to practise self-care in order to maintain their HbA1c levels. For example, participant AR said that he is aware of the ideal HbA1c for diabetes patients, but he finds it difficult to achieve it because it is difficult to find the right diet to control his diabetes.

> *AR: So, for the finger pricking I can get whatever I want. But I can't get down my average blood sugar level. Do you know what I mean by average? The average level you take every three months, blood taken from my arms*

> *you know. I only get to reduce it a few times. From 14 to 12. There's once they took my blood twice in 6 months and I got 10.2. That's the only time. It should have come down to 7.8 or 6.8. For people with diabetes, the ideal average blood sugar level is 6.8. Ha. So, ideally should be 6.8. But I never achieved it. I asked the doctor about this a few times already but because maybe it's because of the food. The sugar we don't see in our food for example, like bread.*
>
> ***51 years old, male, T2DM (5 years)***

Participant NJ indicated that sometimes she checked her blood glucose levels after meals. She knew that if her glucose level is high, it may be due to consuming food with high glycaemic index. Participant NL said that she managed to achieve her target HbA1c level through exercise and diet but because of the MCO, her HbA1c has gone up again.

> *NJ: Sometimes after meal maybe around 8.2, sometimes it's more than 10. I was quite shocked but because I ate food with high carbohydrate content you know. But if I eat food which doesn't have high content of carbohydrate, it's around 6 or 7.*
>
> ***24 years old, female, pre-diabetes (< 1 year)***

> *NL: It was 6 in March. But after the MCO, I was stranded at my hometown so, I started to eat a lot again you know. Because you know you're just staying at home. My blood sugar started to go high. So, the dietitian asked me to look after my diet like I did before. So, I'm working towards it now.*
>
> ***36 years old, female, T2DM (5 years)***

With sufficient knowledge and understanding of diabetes, it can help people to develop a sense of self-awareness and empower them to practise self-care. Also, fear of developing complications and seeing the effects of uncontrolled diabetes to other people motivated patients to look after their health and manage their diabetes.

4.3.6 Summary

Theme 3 showed that self-awareness is crucial to increase patients' awareness to the importance of diabetes self-management. Talking to other diabetes patients and having experience looking after family members who have diabetes increased the awareness of the patients in this study to the consequences of uncontrolled diabetes such as amputations. However, some patients expressed lack of motivation or concern regarding self-care practices. This may be due to limited understanding of their condition and also lack of support. This emphasises the importance of providing continuous education, training and support in diabetes self-management to increase patients' skills, knowledge, and self-awareness on what improvements need to be taken to control their blood glucose level, which is further discussed in section 6.5. In the next chapter, I discuss the themes that were identified from pharmacists' interviews and focus group, and how pharmacists can support and help in empowering self-care behaviours among the newly diagnosed T2DM and pre-diabetes patients.

CHAPTER 5 PHARMACISTS’ THEMES

THEME 1: ROLE OF PHARMACIST IN DIABETES CARE

5.1.1 Introduction

In Chapter 4, I explained the three themes that empower patients to self-care. Pharmacists can play major role in supporting diabetes patients especially for the newly diagnosed and pre-diabetes patients because they are easily accessible, qualified, and well-trained. In this chapter, I discuss the four themes identified from the pharmacists’ group in empowering self-care behaviours and in this section, the role of pharmacists from different healthcare facilities in Malaysia and their experiences supporting and educating diabetes patients are discussed.

5.1.2 Patient counselling

It is evident from section 4.2.5.1 that patients in this study viewed pharmacists as only capable of giving out medication and advice on medication because pharmacists are perceived as the expert in medicines. When I interviewed pharmacists working at different healthcare facilities regardless of the sector, they have done extensive work in counselling and educating diabetes patients more than what is perceived by the patients in this study. In the next few sections, I discuss the experiences and the roles of pharmacists in diabetes care.

5.1.2.1 Counselling pre-diabetes patients

At the beginning of the interviews, pharmacists were asked of their experiences counselling newly diagnosed T2DM and pre-diabetes patients to explore their feelings and perspectives dealing with these patients. Many mentioned that they have had experiences counselling newly diagnosed T2DM patients but not many pre-diabetes patients. This is because most pre-diabetes patients were not prescribed medication upon their diagnosis hence, they mainly see the doctors or the dietitians for lifestyle modifications. For example, participants CYT, H and HN work in public health clinics, and they only see pre-diabetes patients when they are being prescribed with metformin if lifestyle modifications failed.

> *CYT: …usually for pre-diabetes just refer to the nutritionist and dietitian. No intervention. Yeah. Usually, those patients will never come to pharmacy. Because we are in different department right then they won't refer them to the pharmacy.*
>
> *H: For health clinic, not so much for pre-diabetes. Pharmacist doesn't really get involved. And then just doctor will diagnose and refer to dietitian for diet (advice).*
>
> *HN: If patient requires lifestyle changes, they don't need to collect medication so they will leave after seeing the doctor. So, when they come for the second time, if the doctor started them with metformin, I'll only encounter them when they're already started with medication.*

Pharmacists who are working in the hospital also mentioned the same thing where they do not see pre-diabetes patients that much because they usually see the doctors, diabetic nurses, or dietitians for counselling on lifestyle modifications.

> *MH: Normally they will be counselled by the doctors. Meaning that of course the doctor will emphasise on lifestyle changes, diet modifications so that they won't get into diabetes state. Not by the pharmacists because normally that type of questioning, it's enough with the doctors only.*

> *RI: Not really, that will be handled by the diabetic nurse as well.*

Community pharmacists may have a better opportunity of seeing different group of patients as they are accessible by everyone. Currently, most community pharmacies in Malaysia offer different pharmacy services such as blood pressure, blood glucose and cholesterol monitoring as well as medication counselling. The blood glucose tests offered include the random and fasting blood glucose tests and some pharmacies offer the HbA1c test. Due to this, people now have easy access to blood glucose screening and the detection of undiagnosed diabetes and pre-diabetes can be done at the primary care level.

> *LSP: Basically what we do in community a lot of people will come and have a blood test with us including the normal blood test and HbA1c test.*

> *MR: We have a blood test like the normal glucometer test reading, and we also have HbA1c in particular in certain outlets only. Whichever has that machine we'll do HbA1c as well.*

> *RG: Yeah, the normal fasting sugar. We only do those HbA1c if those lab people come and partner with us like once a month or every two months.*

As mentioned by some of the participants who are community pharmacists, they encountered a number of individuals who came to their community pharmacies to get their blood glucose checked. If they found the person has an increased risk of developing T2DM, for example, due to family history or their fasting blood glucose is high, they would then counsel these individuals accordingly. Some of the information included during the counselling after a blood glucose check include creating awareness of the condition such as the blood glucose range, the management of diabetes, for example, diet modification, exercise and medications, the complications of diabetes as well as recommending appropriate supplements such as bitter melon extract pills or milk powder, that can be taken in reducing blood glucose level.

> *MR: Uh and pre-diabetes also when they come to us with that because we do the screening, glucose test screening so we will—the moment that we diagnosed like okay these people are you know they have the potential to get type 2 diabetes so how we can actually help them is to create awareness. So, normally we will tell them what is good range, good glucose management and then how actually if let's say they are not in a proper diet control and how it's going to affect them and then in terms of medications that they need to take for long term and all. So, we will advise them accordingly. For pre-diabetes patients, we will start on like supplements initially only.*

> *LSP: We'll ask about family history. If they have family history, then maybe they're on the high-risk side. And actually, we will test on HbA1c, if the HbA1c is on the high side then we will start on supplements. If there's no harm-lah. Yes. And of course, we will actually try to understand how their diet is, how their lifestyle is. Yes. So, if we think that supplements will be a great thing for them then we will start on supplement first.*

5.1.2.2 Counselling newly diagnosed T2DM patients

Pharmacists who are working in hospitals and public health clinics will usually encounter diabetes patients when they come and collect their medications from the pharmacy department. For patients who are newly diagnosed, a more thorough and detailed counselling needs to be conducted initially so that patients have a good understanding of the condition and its management. As mentioned earlier, pharmacists were initially asked about their experiences counselling newly diagnosed T2DM patients and they were also asked what type of information were usually shared with the patients. Most participants stated that they would focus on the medications, for example, metformin, and sometimes they talked about diet and how to monitor their blood glucose level. This is in line with the guideline for diabetes management for newly diagnosed T2DM where the first line of treatment is to prescribe metformin when lifestyle modifications failed (Ministry of Health Malaysia, 2020a).

> *CYT: We'll counsel on the adherence of the medications and what's the medication for. For example, let's say metformin, so we need to explain to them for what, the indication then they'll ask about side effects and all. Then they will ask you whether can they stop the medication once they've recovered and all. They will ask all these questions. So, we will answer based on whatever their medication that they're being prescribed.*

> *MH: If it's a new patient, we will tell them from A to Z-lah. Meaning that from what is diabetes, what is their target sugar level, what is the 1Ac sugar level. And then their current sugar level. How often they need to check their sugar, how is their diet going to contribute to their sugar. The medication regimen, how does it going to work, expected side effects.*

Some newly diagnosed patients will be prescribed with insulin if their HbA1c level is too high. According to the management of T2DM guideline, insulin is given if patient's HbA1c level is more than 10.0% (Ministry of Health Malaysia, 2020a). If patient is prescribed with insulin, pharmacists would then counsel patients on how to use the pen and how to inject and store the insulin. For example, participant RI who is a hospital pharmacist in a private hospital stated that she would normally counsel patients on how to use insulin using a checklist to ensure all points are covered during the counselling session.

> *CYT: Insulin usually doctors will just prescribe with a starting dose then we'll teach patients how to use the pen and how to store it and how to inject.*

> *RI: There will be a checklist provided by my hospital so we will follow through from the storage, disposal, how to use and what to do next and how to set the unit and all, and also symptoms of hypoglycaemia. Usually, we will just follow through the checklist given and then we will provide with one pen and few needles for newly started patients only.*

The information shared with patients during counselling sessions will depend on their individual comprehension ability as advancing age is associated with declining health literacy (Chesser et al., 2016). For example, participant AK mentioned that if the patient he is counselling is an elderly patient, he would only share basic information. While participant MH said that if the patient has a good control of his/her diabetes, they will teach the patient on how to taper up or down their insulin dose.

> *AK: If let's say, the patient comes to my pharmacy and then he's 80 years old, for example, being suddenly being diagnosed with diabetes, usually I will tell them very basic information.*

> *MH: For certain patient, a very good patient, even the pharmacist and the doctor will teach them how to taper up and taper down their insulin.*

Other than teaching patients how to take their medications or how to use insulin, pharmacists would also need to support patients in terms of reassuring them to use their insulin regularly and tackling problems around barriers to nonadherence such as fear of needles or misinformation about diabetes medications.

> *HN: And then if the HbA1c is more than 10, normally doctor will start insulin as well. Either insulatard or mixtard. And then of course this young patient will be very concern with insulin, like "Kenapa doctor start?" ("Why do the doctor start me with insulin?"). I also experienced before where the patient didn't want to inject because the patient is worried of the needles even though we have convinced that the needle is very short range.*

> *KLE: I believe that in our counselling I'll, we always tell our patients the indication and the function of insulin and not just straight away to the technique, you know how to put the needle, how to "cucuk" (inject) and all those. Yeah, I always believe that we need to make our patients understand what is insulin, what is this treatment about. It's not always that you "oh you sudah sangat sakit, sangat teruk barulah dapat insulin ni" ("You only get insulin when your diabetes gets worse"). No. This is a very common misconception among our patients…*

> *RG: But a lot of the times umm towards calm them down and motivate them, it's not the end of the world, they will feel like it's end of the world and then their lifelong they have to take medication.*

As for those who are working as community pharmacists, they would normally provide self-care advice to the newly diagnosed patients on lifestyle modifications, for example, changing their diet and doing exercise and recommending supplements that could be added on in controlling patients' blood glucose levels. As mentioned by participant CT, through her experience she felt that newly diagnosed patients usually do not have enough and correct understanding on how to control their blood glucose level with diet and thus, she would emphasise more on this when talking to the patients.

> *CT: Basically for me, personally I'll emphasise on how to guide them to choose the right food to eat. Mainly is to help to have the right concept about adjusting their (inaudible-1:32) because a lot of them actually do not have the right concept about low GI, high GI diet. And this is a very critical part that has been missed out.*

> *MR: So, if you're newly diagnosed and they have already seen doctor and they're coming to us with their initial treatment medication, normally we will advise them how important for them to keep up a healthy lifestyle. They have to do some lifestyle modification on their diet and also exercise and about the medication compliance and also, we normally we will suggest some supplements like milk. Yeah, milk powder which contains some extract, herbs extract that can actually reduce their glucose control also.*

Additionally, pharmacists also noticed that some diabetes patients or people generally do not have sufficient knowledge on what food such as fruits that can cause the increase of blood sugar level. Also, because rice is the staple food of most Malaysians, many perceived that rice is the major cause of the rise in blood glucose level. Hence, many will avoid eating rice and replace with other sources of carbohydrates such as breads and noodles without knowing that they could also contribute to the increase of glucose in the blood.

> *JO: Actually, there are a lot of patients that umm, I don't know whether they tell the truth, but most of the time they say things like, "The doctor told them that they cannot eat rice. And they should eat bread". Bread instead of rice. They should eat chapati instead of rice. Or they can eat cream crackers instead of rice. But you know all the alternatives that these doctors supposedly suggested are actually refined carbohydrate as well.*

> *LSP: A lot of people thought fruits, yes, it's healthy. I didn't eat rice, I didn't eat noodles, but I just eat fruits, right? Like no, no issues when we hear like that. A lot of them like I just eat fruits what, I didn't eat rice. But actually, they're not aware that actually fruits are the factor that actually increased their blood sugar.*

> *CT: I've got new DM patient that do not know that umm to stabilise their sugar, means to actually adjust their dietary habits. But they thought is not to eat or eat less. So, for example, one of my patients, drink Milo. Instant Milo as their breakfast every day, because nobody ever mentioned to him what kind of food should be chosen to actually stabilise their blood sugar.*

Therefore, pharmacists would take the opportunity to interact and talk to patients about diet, exercise, and weight management.

> *RG: If they are obese or overweight with other risk factors then we will ask them to do exercise and reduce weight. And control their diet, diet control. Like reduce carbohydrate and sugar and try to, cannot totally abstain from carbohydrate because being in Malaysia is a bit harder…*

> *CT: So, I'll be more focusing on umm counselling about helping them and guiding them how to eat the right food to eat. More about dietary habits beside medication counselling.*

Apart from that, I felt that community pharmacists have a better patient-pharmacist relationship when I spoke to them. This is probably due to their openness to the public and the counselling might feel less formal compared to having it in hospitals or clinics. For example, participant RG would tell successful stories of other patients in managing their diabetes to encourage and support newly diagnosed patients to accept and manage their diabetes and meanwhile, participant LSP felt that people are starting to see pharmacist as a healthcare provider that are capable to provide the health information that they need.

> *RG: If you want them to (be) very strict like on the first day, they (only) get to know, first thing they cannot accept already. Second thing then also a big time for them to adjust. So just ask them to cut down and tell them what other things, what is carbohydrate and then how carbohydrate will eventually change to sugar. And then also motivate them with some of the story from other examples, from other customer…*

> *LSP: You can see how the customers walk into us and then believe us a healthcare professional and ask us. Actually, a lot of people, they came in with a blood test report and come in and ask us. And some very interesting one. They go to the clinic and then take their medication and ask us. In fact, they (already) asked the doctor, you already pay for the doctor and (still) come in the pharmacy and ask us, and they didn't have to pay us for counselling. But anyway, at least they believe us-lah. I mean this proves that they trust us. Yes. The best thing in community pharmacy is actually most of the time we treat customers or customers treat us like a friend.*

5.1.2.3 DMTAC

In section 4.2.4.2, I discussed about DMTAC where diabetes patients who have problems managing their HbA1c levels will be referred to this clinic to have a series of thorough counselling sessions with pharmacists. Pharmacists would talk to patient during the sessions to find out the issues that are affecting patient's diabetes management and they will educate or train patients appropriately. From the pharmacists' interview sessions, most of the pharmacists who are working in the public hospitals and health clinics were aware of the clinic and its functions.

> *AK: DMTAC is diabetes mellitus medication therapy adherence clinic. Usually, pharmacist will be attached to this clinic and will go by every single thing related to diabetes. Medication, insulin, diabetic footcare and what not.*

> *CYT: It's the problematic patients that won't adhere to the injections, won't adhere to their medications. So, you realised those patients usually the HbA1c is very not good. The level is not good-lah, the reading is not good. So, mostly the HbA1c can show whether that particular patient needs MTAC or not.*

> *TN: So, at that session we'll go more details on how they can monitor their DM, so we will give them pamphlet, diagram, and the aids to help them to understand more about their condition.*

Two of the pharmacists interviewed in this study were qualified DMTAC pharmacists. One of the questions I asked about DMTAC was that why is not being offered to all newly diagnosed patients regardless of their HbA1c level, as a way to assess if patients needed support and information about their diagnosis. This is because a number of studies done have showed that DMTACs have helped patients in terms of improving their glycaemic control and increase medication adherence (Iqbal et al., 2021; Lee et al., 2015; Lim & Lim, 2010) and hence it could be beneficial if it is also offered to newly diagnosed patients in order to delay or even prevent disease progression. Both of the pharmacists mentioned that patient's referral to DMTAC is based on the criteria set by the MOH as indicated in section 4.2.4.2 and if patient's diabetes status fall under the criteria, then only they would be referred to DMTAC. Hence, not all newly diagnosed T2DM patients will be qualified to be referred to DMTAC as indicated by participants KLE and CYT.

> *KLE: Well as I mentioned before this is actually set by the government I mean. By the Pharmacy Services Division in MOH. I don't know what their exact reason, but I believe personally that it's because that when patients with HbA1c are more than 8, we can expect more than one, more than one pharmacotherapy agents, yeah. And this kind of patients tend to have compliance issue, so this also I believe that these are the possible reasons that I could think of and so they would like us to do interventions for such group of patients.*

> *CYT: Umm no, because some patients let's say doctor said, "oh you have diabetes, and I will start on this medicine". Then if the patient is very good like "okay doctor, I will follow whatever you give me and all", then most probably doctor won't (refer to DMTAC). It's only those that, "doctor can you not start me (on) diabetes medications, I worry after I take diabetes medications I will die, I will have kidney failure". This and all that then those problematic patients usually doctor will start (on DMTAC).*

Despite that, both of the pharmacists emphasised that it will be useful if the service can be expanded to all newly diagnosed T2DM regardless of their HbA1c status so that they can be evaluated earlier in terms of diabetes knowledge and understanding.

> *KLE: I actually agree also where we can have a greater role for such categories of patients. And as you know pre-diabetes, those very newly diagnosed diabetes patients, well they may not have a lot of pharmacotherapy agents. Yep. They maybe have just metformin where we don't really have a lot of counselling, a lot of education to tell them in terms of pharmacotherapy and as I mentioned before, I think MNT (medical nutrition therapy) will be very important for this type of patients as well. So, I really hope that the government can actually consider to, to recruit those, this kind of patients into our programme as well and not those with just HbA1c larger than 8%.*

> *CYT: After years of working right, I still can conclude that a one-to-one session counselling is way more effective than a counter counselling for diabetes patients…*

5.1.2.4 Barriers to effective counselling

There are so much that pharmacists could do in educating diabetes patients, but they are also faced with several barriers in delivering the best and effective counselling. Some of the barriers that the pharmacists mentioned in this study include time constraints, misinformation, lack of patients' self-awareness and knowledge on diabetes itself and the public perception of the role of pharmacist.

5.1.2.4.1 Time constraint

The issues with time constraints during counselling session were experienced by most pharmacists across the board. With the piling of other tasks to do such as dispensing and sometimes the pharmacies are packed with patients, it is understandable that time spent with diabetes patients for counselling and education is sometimes compromised. Due to this, pharmacists are unable to provide sufficient information to diabetes patients in one session and sometimes require a few sessions to provide diabetes education and training. However, this could pose another problem especially in public hospitals and health clinics because patients might not get to see the same pharmacist the next time they come and collect their medications, and this may result in lack of continuation of care. Apart from that, the pandemic has also limited the time pharmacists could spent with patients to avoid the spread of the virus.

> *AK: They are doing dispensing, they are doing like ward pharmacy. So, sometimes they cannot follow up the same patient. So, they will go to another pharmacist, and it will be umm pass over using a case note-lah. Pharmacist's case note.*

> *NO: Because it takes time (to do counselling). Usually in community pharmacy, people usually are rushing. So, depends on umm usually we depend on patients, depend on the condition. If let's say a lot of time, there's no patient, no other patients, maybe we can counsel them more. But if let's say there's a lot of patients, we cannot counsel them longer time because other people will be waiting-lah in community pharmacy like that. Usually time constraints. That's the problem.*

RI: Like most of the time since we now try to limit the time to counsel patient, so we don't really get to have proper counselling with patients. So, even that we have a counselling room and it's with a limit of 20 minutes and also, it's a bit difficult to, to be with the patient for a long time and explain the thorough diabetic issue.

5.1.2.4.2 Misinformation

The recent outbreak of COVID-19 virus has caused another problem to emerge which is "infodemic". Even though misconception and misinformation around diabetes and its medications have been around before COVID-19 pandemic, the increased use of social media and internet during the pandemic has also increased the spread of false information about diabetes medications as mentioned in section 4.2.3.1. This misinformation has caused patients to stop taking their medications and lead to uncontrolled diabetes. Some of the misinformation or misconception pharmacists encountered when they talked to patients include the perception patients have on diabetes medication, for example, the side effects of the medications can kill them or cause kidney damage, and the halal status of insulin injections.

> *RG: Normally newly diagnosed patients or customer, they will be very worried. Do I have to take? I heard the medication has side effects to my kidney and then do I have to take this for lifelong. Then I would tell them, even if you don't take the medication, the diabetes also can cause your kidney got problem.*

> *CYT: Usually is because they think if always jab, they will die soon. Every day jab they will die soon, every day eat diabetes medicines they will die soon. Kidney failure or whatever…*

> *H: Patient for example, like the patient doesn't want insulin. Because the patient read from a WhatsApp group, he said that insulin comes from pig. So, he didn't inject since then.*

Both of this misinformation has resulted in patients to be nonadherence to their diabetes medication and due to the beliefs, pharmacists sometimes faced difficulties in counselling patients due to their refusals to take medications.

> *TN: But most of the patients, they came in they don't want to take in our information because they already believe what they believe. So, it's really hard.*

The widespread availability of diabetes information on social media and internet has also increase the problem around misinformation because some patients might not know how to appraise the information received is truthful and reliable. As stated by participant AK, anyone can post anything on the internet, and this may mislead and harm diabetes patients.

> *AK: Because the information inside social media, Facebook, Twitter and what not is too broad. And to validate that information is very hard. Because it can, can come from somebody who is not accredited, for example, they claimed they are doctors, they are in practice before but instead they are not even giving the right advice in terms of medicating the patients. And there are certain circumstances whereby patients being admitted just because of they are being badly influenced by the so-called doctors inside Facebook.*

The overclaims of supplements and products claimed to reduce blood sugar levels has also hindered pharmacists in educating patients appropriately. Patients felt that taking traditional medicines and alternative products are safer than modern medicines. The widespread advertisements and testimonials from people on the internet and the easy access to the sale of these products online has also contributed to the issues of nonadherence and uncontrolled glycaemic levels.

> *LSP: It's too overclaimed. Yes. So, that's what makes us very headache when customers come and then they just said, I take this product, I don't need to take medications anymore. They claimed that actually this product can stop you from taking medications something like that.*

> *KLE: Some of them actually, they believe in direct sales supplements. Yeah, and I personally have encountered a few of them actually developed complications or side effects resulted from this kind of supplements. You know like liver impairment, sometimes even worse hypoglycaemia.*

In the focus group, pharmacists also highlighted this concern, emphasising the challenges they face in educating patients due to overclaims by supplements and products touted to reduce blood sugar levels.

> *TN: But most patients, they came in they don't want to take in our information because they already believe what they believe. So, it's really hard.*

> *Interviewer: Is it to do with taking supplements or about diet?*

> *TN: Most of it because of the supplement, because of the advertisement or something around that, to replace the modern medication.*

> *CT: Totally agree. The biggest challenge that face in retail is umm a lot of them are either they are pre-diabetic, or they are newly diagnosed diabetic, they walk in and then they are looking for supplement or TCM aa hopefully to cure the diabetes or to reverse the condition. Because influence by some information through the internet or through the social media. So, a lot of*

> *them having a misconception that, thought that umm supplements can actually treat diabetes.*

The misinformation could be due to patients' lack of knowledge of diabetes, or they did not receive the appropriate education during diagnosis. Due to this, patient would tend to find information which is easily accessible, for example the internet or friends and family, instead of going into the pharmacy or to the doctors again.

5.1.2.4.3 Lack of self-awareness

Lack of self-awareness of patients on their own condition has also caused issues in counselling and managing patients' diabetes treatment. Several pharmacists mentioned that they have encountered a number of diabetes patients who are not taking their condition seriously which causes problems to deliver a more effective counselling. The lack of self-awareness of patients could be caused by lack of knowledge as discussed in section 4.3.5 but participants JO and AK said it could also be due to their own ignorance.

> *AK: We do have several cases in hospital whereby patient is so passively receiving treatment, and (those) taking medications without knowing why they are taking those kinds of medications. As a pharmacist, I do find that this kind of people usually have problem in the future in terms of medications, whether it will be drug litter problem, adverse drug reactions or even sometimes umm medication adherence will be an issue later on.*

> *JO: Malaysian patients they, they don't really umm think it's important to know the medicines they're taking. I mean I'm sure you know when they come to the pharmacy, they don't sometimes even know that the name of the medicine is metformin. They just simply tell you is, "The white tablet which is RM1.50". So you know umm if you, if you wanna do a medicine review with them, it's very hard. And like often times you have to make them bring in the, the strips of the medicine and then only you know for sure whether if it's really metformin they're taking.*

> *JO: Because I notice like if those who, those who come and get their test, glucose test at the pharmacy. Umm even, even if it's high—you, you tell them that it's high they won't, they won't ask you umm… You know like how*

can I make it lower. Or they will, they will try some sort of like tactic where aa they will starve themselves, and then only come and get their glucose test so that they can cheat themselves into thinking that their blood sugar is low. I noticed that when I, when I try to advice this kind of patients, it normally falls to deaf ears. Yeah. So, that's sad, the sad part about some patients unfortunately.

5.1.2.4.4 Public perception of the role of pharmacist

As indicated in section 4.2.5.1, some patients in this study were not fully aware of the roles of pharmacists beyond the scope of giving advice on the safe use of medications. Several pharmacists in this study mentioned that they felt that customers or patients see them as a "glorified sales promoter" and that they should not interfere with the doctor's instructions. Because of this perception, it was quite difficult for pharmacists to provide patients with non-drug services such as giving advice on self-care.

> *KLE: Personally, I think that the public think of us as a glorified sales promoter. Especially in the community pharmacy setting, yeah, this is very sad. I mean, in hospital, in the government setting, it's still okay. Although we always get, we always get complains from our patients that "kami macam buat berlagak je, kami bukan doktor tapi still nak bagi a lot of advice" (pretend to be like a doctor and give a lot of advice) or something like that.*

> *CYT: That's why they will say, why you, why you ask so much? You give what the doctor asks you to give. Some will say like that.*

> *NO: They don't have the awareness that actually pharmacist can consult them. Actually, pharmacist's role is more than just telling about medicines. So, for them, the one who want to counsel is usually when they talk to the doctor.*

Nonetheless, some pharmacists stated that they felt that public perception towards the role of pharmacists are improving especially during and after the COVID-19 pandemic because they were the only primary healthcare facilities that were open and accepting patients during the lockdown. Hence, more efforts should be made to promote the roles of pharmacists to the general public.

> *LSP: It's increasing, it's increasing. The role is increasing. Yeah. Especially after happened Covid case. Because all the people scared to go to the hospital, right? Clinic also don't want to accept them if they have flu or fever, scared also. So, they will come to us.*

> *MR: But after Covid, I would say that because generally right, the patients are saying to me the clinics are rejecting them. So, the only place, even, even hospital, government hospital and all the nurses and also the doctors in the private clinic, they are asking them to go to pharmacy to get the medicine.*

5.1.3 Blood glucose monitoring

Self-monitoring blood glucose (SMBG) is recommended to patients who are on insulin and oral glucose lowering drugs in order to monitor patients' blood glucose levels so that optimum treatment can be provided and also to monitor the signs of hypoglycaemia (Ministry of Health Malaysia, 2020a).

> *KLE: I will let, I will ask them to do SMBG. Yeah. And then based on the 3 days SMBG, I would see whether if I need to titrate their insulin doses or not.*

In section 5.1.2.1, I briefly talked about the services community pharmacies offer to the public in assessing blood glucose levels. Pharmacists from all sectors are able to educate patients on how to do SMBG and interpret their results. For example, participant AK who works in hospital pharmacy, he stated that in his hospital they have SMBG machine for pharmacists to teach patients on how to use it. He further explained that for facilities that do not have the machine, they would signpost patients to community pharmacy to buy the machine and get trained on how to use it by community pharmacist.

> *AK: But in those setting we don't have any demo set, usually we will advise them to buy from a pharmacy and then get umm being educated on how to use it there.*

Other than teaching patients how to use it, pharmacists would also check patients' technique every now and then and if there were problem, they would advise patient accordingly on how and when to check their blood sugar levels as well as how to keep their glycaemic control in range. In the public health clinic, patient education on the use of the SMBG machine is also extended to patients who cannot afford to buy the machine or to patients who have bought the machine but do not know how to use it.

> *AK: And those patients who is already understanding on how to use blood glucose monitoring, we will emphasise on the compliance, and we will re-check and re-check. Because there are patients who bought the things, but still cannot or being using it wrongly every day, after food those kinds of things. Usually we will educate them back-lah.*

> *CYT: They can, that's why they can always come to our clinic and just say oh, I bought this glucose meter but I'm not sure how to use it then we will teach them even though we don't have that brand.*

> *CYT: But most of the people they don't have much money to buy the thing (SMBG machine). That's why they joined the MTAC, so that we can do it for free for them.*

5.1.3.1 Diabetes programme in community pharmacy

I mentioned earlier that the blood glucose tests offered in community pharmacies include random and fasting blood glucose tests as well as HbA1c tests in selected pharmacies. Several community pharmacies have also offered different consultation services, facilitating access to routine blood glucose monitoring and individual guidance. This helps people to have easy access to blood glucose screening and the detection of undiagnosed diabetes and pre-diabetes can be easily done at the primary healthcare level.

> *MR: We always open for any patients. Those who don't have diabetes, but they want to make sure they have, they have regular monitoring so, they also will come, so we do for them also.*

For example, participant MR discussed about the diabetes programme at her pharmacy, conducted in collaboration with a pharmaceutical company. In this programme, patients' readings can be accessed through an application by a pharmacist or a nutritionist. Patient would then be counselled on diet plans according to their blood glucose readings.

> *MR: In this diabetes programme we have a self-test monitoring, ,and we also have the apps for them to sync their readings in the glucometer to their data, I mean like to their computer. So, the computer we also can access. So, the nutritionist or pharmacist, we can access into the data and then from there we will actually uh we will assist them on their proper meals especially.*

She further explained that customers or patients who joined this diabetes programme will get free online or face-to-face consultation with a nutritionist or a dietitian and if patient needed medication, they would be referred to a doctor appropriately.

> *MR: And they'll be getting unlimited advice or consultation. Free consultation from the nutritionist and dietitian.*

> *MR: We have online doctors, Doc2Us. So, Doc2Us is a platform where we interact with doctors. So, in a case like where we have to initiate the patient on metformin or we have to initiate them on uh or even Poison B (prescription only medicines), we will always consult with doctors to get proper prescriptions.*

Because the diabetes programme is not a standardised programme offered by all pharmacies, thus some pharmacies might have different services they offered. For example, in the pharmacy participant LSP worked for they would introduce intermittent fasting to pre-diabetes patients.

> *LSP: I only start in those patients that really got determination. That really can do it and maybe we can start on it-lah. So, we will start on some intermittent fasting and most of the cases I start off yeah, it really works. But of course, I more prefer start with pre-diabetes… Those that haven't started on medications.*

She further explained that her pharmacy offered a number of tests for the customers such as body fat analysis and they would provide support and advice to patients on how diabetes develops and how to control blood glucose levels.

> *LSP: That's what we do for our customers, and we have lots of tests for our customers like body fat analysis, everything. And actually, we talk about*

> *insulin resistance. We have a lot of people they don't know about (how) insulin resistance work, how they control our glucose. And how the weight affects the glucose level.*

While several other community pharmacists indicated that customers would normally come to the pharmacy just to check their blood glucose levels or to buy the SMBG machine, and some of the initiative community pharmacists offered to the public in terms of SMBG is to advice customers or patients to monitor their blood glucose levels for a few days and come back to the pharmacy for the pharmacist to review.

> *JO: Umm I would give them sort of like a record sheet. So they can record their blood sugar before and after meals, for like at least three days consecutively. And then to also record that, on that sheet of paper what they ate for each meal. And then I will ask them to bring it back so that I can see what could be causing them to have the high sugar, is it like a random thing or does it have to do with their food, or could it be that their, their insulin secretion is impaired. So like if their blood sugar was high even before eating, then I would normally advise them to see the doctor.*

> *NO: If they want confirmation, in two to three days they can come and check again. If it's high, it's best to get it check three times. If let's say the level is still high, then next time we'll ask them to fast to see how. If the level is still high, then we have to refer to the doctor. Or we can ask them to or when we first found out that the level is high, we ask them to reduce their sugar intake and all. Look after their diet and all. And then see next when they look after their diet, do their sugar level go down or not.*

5.1.4 Clarification of information

In section 4.2.3.1 and section 5.1.2.4.2, I discussed the issues around misinformation that cause various problems for the patients as well as for the pharmacists in conducting effective counselling. In the interviews I had with the pharmacists, many indicated that they have had experiences where patients or customers were asking various questions to clarify the information they obtained from the internet, friends and family and also other healthcare providers especially on diabetes medications.

> *KLE: I, actually, over the counter uh, almost daily. We will encounter. Yeah. I mean not just diabetes patients. Any patients in general, yeah. Very frequently they will bring certain products or maybe just show a product through their phone and then, "Ini boleh saya makan ke? Ini selamat ke?" ("Can I take this? Is it safe?") or something like that. Yeah. So actually, we are happy about this. At least the public is actually approaching us to ask about their supplements.*

> *LSP: Oh, every day. It is a very common thing. Actually last few days I received one customer who already stopped their metformin and gliclazide for about six months and come to me and the glucose level is super high. And I asked her whether she is on any medication and she said, yes. Doctor gave the medications but she said stopped for six months because scared of the side effects. But the good thing after she's convinced by me, she takes back the medications and asked for the follow up.*

> *CYT: Too many. Too many info and the patient will analyse it wrongly. So, let's say they will say, okay if I take metformin, you see metformin, you Google, so many side effects. So then, as a pharmacist you have to counter.*

Pharmacists play an important role in helping people especially diabetes patients in debunking the misinformation and misconception around diabetes treatment and also directing patients to the right direction when looking for diabetes information. In a qualitative study done in Indonesia on the role of pharmacist in debunking misinformation, it was found that most of the pharmacists would clarify any misinformation, educate patients with the correct information with evidence-based information and direct patients on where to find reliable information (Hermansyah et al., 2021).

> *LSP: I will deliver whatever message I have. One more thing is what we do is sharing the YouTube to them. YouTube. Whatever we find that is relevant, example, the intermittent fasting. How the intermittent fasting helps with your burning fat, how they actually revert the diabetes. Actually we send the YouTube to them. Instead of telling them you go and find, I don't know whether their info is correct or not accurate, but actually we are proactively sending the link to the customers. Yes. And actually, we are communicating with the customers all the time.*

> *CYT: Usually they will ask to go to Facebook, the diabetes organisation Malaysia and KKM (MOH). So, usually I will say, "Pak cik, mak cik, you ada Facebook kan?" ("Uncle aunty, you got Facebook right?"). And then yeah, and then just add in the diabetes Malaysia. If not, just follow KKM website. The Facebook. Basically, usually we will just ask Facebook. The official page. Because if you ask them to Google, then the weird thing will come out. And then they will say journals all I don't understand this and that.*

> *AK: But apart from the working hours, we do also encourage people who has idea and time to educate people in social media. Because I do so. I will*

educate the patients, not generally specific patients but in general population in terms of diet, in terms of self-care, you can include a lot of things, not only self-care and diabetics. But also in terms of adulterated products, in terms of what to do if let's say there's an emergency, things happening, stroke and what not. Educating, educating people is I think is one of the major things we can do-lah.

5.1.5 Summary

It is apparent from the interviews and focus group conducted in this study that pharmacists contributed extensively to diabetes management. Even though they are seen mainly focus on educating and training patients on how to take or use medication correctly, pharmacists are also capable of expanding their roles in empowering self-care behaviours. The roles of pharmacists in diabetes care can be further expanded and this is discussed in Chapter 6. In the next section, I will discuss the second theme identified on the role of multidisciplinary team approach in diabetes management and how pharmacists can play their part working in a team.

THEME 2: MULTIDISCIPLINARY TEAM APPROACH

5.2.1 Introduction

Diabetes management requires a comprehensive patient-centred care and to obtain this, it involves a multidisciplinary team (MDT) of different healthcare providers. Other metabolic disorders such as hypertension, hyperlipidaemia and obesity often co-exist with T2DM which further increases the risk of the development of diabetes-related complications (Tan et al., 2020). This can increase the complexity of diabetes management even more and thus, the skills and specialties of each of the healthcare providers acquired will contribute to more holistic patient care and consequently allows patients to obtain in-depth knowledge and understanding of their condition. In this section, I discuss the experiences of pharmacists working in a MDT, or working together with other healthcare providers in ensuring patients are receiving the best possible diabetes care to empower self-care behaviours.

5.2.2 Access to health services

Having high or adequate level of health literacy increases the individual's ability to access different health services and healthcare providers. People with low health literacy might have difficulty finding the right healthcare providers to see and this may delay them getting the care and the treatment needed (Levy & Janke, 2016). Various studies which seek the perspectives of various stakeholders to MDT approach to diabetes management found this model of care increases patients' accessibility to health services (Daley & Wallymahmed, 2014; Tan et al., 2020). MDT is a group of people from different healthcare disciplines who work together to organise and coordinate health and care services to meet the needs of individuals with complex care. In diabetes, various healthcare providers are involved in patients' management, for example, diabetes nurse educators, dietitians, doctors, nurses, pharmacists, and ophthalmologists (Ministry of Health Malaysia, 2020a).

In this study, pharmacists who are working in hospitals and public health clinics explained that in their setting, working with other healthcare providers such as the doctors, diabetic nurses, dietitians, and nutritionists is part of the MDT approach in managing diabetes patients. Each of the team members have their part to play in educating and training diabetes patients in terms of controlling their diet, doing exercise, checking their blood glucose levels and checking medication adherence. As mentioned by participant AK, regardless of whether the patient is newly diagnosed or not, if the patient has other co-morbidities or complications and requires seeing a specialist doctor such as an endocrinologist, they will usually have their regular appointments in the hospital. Whereas patients who are well controlled or have no co-morbidities can continue having their follow up at the public health clinics which are more easily accessible and convenient for the patients.

> *AK: If let's say the situation is patient in DMTAC, (it) can be in health clinics, can be in hospital. If let's say patient is having multiple co-morbidities in terms of having stroke, having what not and at least the same time having diabetes or even newly diagnosed, they will follow up in hospital mainly. If everything is stable enough, no need other specialist requirement to be into the picture of the treatment usually they will refer patients to the health clinics. Ha. That's the whole situation-lah. Usually not all patients-lah. If possible, we will let the patients be managed by those in the health clinics so that it is near to their house-lah.*

Participant CYT explained based on the MOH's T2DM clinical practice guideline, doctors will refer patients to different healthcare providers depending on the HbA1c status. Patients will usually be referred to dietitians for diet counselling initially.

> *CYT: So, of course with the agreement of the doctors so then doctor will refer them to the dietitian and nutritionist. Cause in MOH, we have dietitian, we have nutritionist.*

And if lifestyle modification failed, patients will be prescribed medications, and they will be referred to the pharmacists for medication counselling as discussed in section 5.1.2.

> *CYT: Yeah. Which they already tried on the diet and of course the nutritional plan and probably they failed or maybe they just cannot, cannot reduce their glucose levels or anything, the doctor will prescribe and start with medications. So, it depends on which doctor and of course whether the patient's HbA1c all is it really very bad or borderline.*

However, as mentioned by participant CYT not all government health facilities have access to different healthcare providers such as dietitians and nutritionists and hence, this limits the access of patients to diet education.

> *CYT: Depends on whether your clinics got enough staff, whether you have a big clinic or small clinic. And then not all clinics like I said got the supporting team like the nutritionist and dietitian which also play an important role in controlling their diet.*

Meanwhile, participant RI who works in a private hospital that specialises in heart problems, stated that while her hospital does have a diabetes clinic which comprises of diabetic nurses and other healthcare providers for patients with T2DM, pharmacists were excluded from the clinic and thus, patients were restricted in receiving education about their medicines. Upon further questioning, participant RI said that she felt that pharmacists were not included probably because there is a lack of understanding of pharmacist's roles beyond just helping patient to differentiate the different insulin available.

> *RI: Because the diabetes clinic actually comprises of the nurses and all except pharmacists.*
>
> *Interviewer: I see so if pharmacists you have to go through the pharmacy department?*
>
> *RI: Yes, correct. During the outpatient they will say like upon dispense they will show you which colour is the insulin. I think for them that's our role just showing, oh, this is the new insulin, this is a basal insulin or just the different colours. I think that's what they see our roles are.*

Having said that, participant RI further stated that after the pandemic, she felt that perceptions of other healthcare providers towards the role of pharmacists has improved. She noticed that they are getting more telephone calls from nurses for medication counselling advice and also requests from doctors to check patients' medication administration technique.

> *RI: Some nurses even in the hospital, some nurses even call us for simple medication counselling. I think they're starting to realise that we can do more of this counselling. We do understand about our medication.*

> *RI: Some doctors do leave a note for pharmacy saying like, "Dear pharmacy, please kindly check this patient's administration and all". Then from that, we will actually do extra.*

5.2.3 Working in a multidisciplinary team

Though there are challenges in implementing an MDT approach, there were great stories of pharmacists' experiences working in an MDT captured in this study. Participant KLE who is a DMTAC pharmacist working in a public hospital indicated that he would refer patients to the appropriate healthcare providers depending on individual patient's need.

> *KLE: If I think that the patient just requires general dietary advice, then I would, I will refer the patient to the dietitian myself. But if I think that the case is a little more complicated which require a doctor's intervention, then I will refer to the doctor first and see whether the doctor would like to refer to the dietitian or not. But basically, in my setting because my hospital is a very small hospital where everyone knows each other, so, whenever there's a problem arise, then all those with the doctor, the pharmacist, the dietitian, the nurses then we will just discuss things together, not necessarily through formal procedure.*

As for participant HN, she explained about group counselling programmes her clinic organised. The group counselling is open for all diabetes patients which is called DM-MAP. It is called DM-MAP because the doctor will discuss about diabetes in presentation slides, and they would use a map to explain about diabetes.

> *HN: They called it 'MAP' because in the presentation, the doctor will use like one map, the map is like a diagram which explains about how diabetes happened.*

She further explained that the group counselling is conducted with the involvement of different healthcare providers such as doctors, pharmacists and occupational therapists and each healthcare provider will explain about diabetes self-management, for example, foot care.

> *HN: There's one session called umm 'DM-MAP', where it's one group counselling session. This group counselling session which is provided involves everyone that will present to the patients. From doctors, the doctors will explain what DM is. From occupational therapists, they will explain about foot care and all. And then umm there's pharmacist as well that explains about medications.*

To ensure efficiency of MDT approach, good communication and positive interactions between different healthcare providers is important in order to increase patients' access to medical services and to ensure patients receive the right and appropriate treatment and care. As told by participants MH and CYT, pharmacists usually have a good interaction with doctors, and they frequently communicate and discuss with doctors either in writing or verbally on patients' progresses and they would support each other in counselling and educating patients.

> *MH: In MOH facility, we do communicate with the doctors. And then if we counsel the patient, we will enter it in the system and we also will leave, jot down in the BHT (bed head ticket). And for example, like this patient right after we counsel, we will write into the BHT. We also write the patient's like seem to be like reluctant to take the insulin. And then like this kind of patient of course the doctor will know-lah. Umm that "mak cik" (aunty) don't want to take insulin and then ya-lah. Sometimes pharmacist try to deliver the message, but it doesn't work. But then perhaps with different doctor that aunty will "dengar cakap" (listen) and sometimes like umm with the doctor they don't want to listen but with pharmacist they want to listen.*

> *CYT: Of course with the consent of the patient because some patients are really very scared of needles so, we will always discuss with doctor whether can or not start insulin first because we do have patients who really afraid of needles. So, they are really reluctant.*

Communication between the healthcare providers is also important to ensure this approach of care work well in terms of building trust among the team members as well as to reduce the repetition and overloading of information to the patients.

> *CYT: Usually all of us is like working in one team, even though DMTAC is pharmacist only, but we'll put all cases notes together, so the doctor is well informed, we are all well informed. The dietitian and the nutritionist also well informed. So, usually pharmacist will see the dietitian and the nutritionist key in because we need to know what they told the patients. Yeah. So, we don't repeat the same things to the patients.*

> *RI: Because that one (counselling on diet or nutrition) will be referred to the nutritionists or dietitians, but we do try our best to tell them (about) all these carbohydrates, but we rarely touch this issue because we try not to intervene from other healthcare professionals' roles.*

As we are moving to digitalisation of healthcare, the MDT approach is not only limited to hospital and clinic settings but has also expanded to some community pharmacies. As a result, this helps in increasing public accessibility to different health services and healthcare providers. As mentioned in section 5.1.3.1, participant MR's community pharmacy offers different range of health services such as diabetes programme, where her customers can have access to dietitians and nutritionists online or offline, as well as the doctors through an online consultation platform.

While for other community pharmacists, they did not have many interactions with other healthcare providers and hence, they would help diabetes patients in terms of signposting them to the right healthcare facilities or providers after reviewing patients' or customers' blood glucose levels.

> *JO: If their blood sugar was high even before eating, then I would normally sort of definitely advise them to see the doctor.*

> *LSP: For those whose HbA1c already super high of course we actually ask them to go back to the hospital and double check with the lab test-lah.*

> *NO: If the level is still high, then we have to refer to umm refer to the doctor.*

5.2.4 Summary

There is no doubt that the MDT approach can help improve patients' accessibility to navigate the healthcare system as well as to improve patients' glycaemic control by providing diabetes patients the support and information they need to manage their condition (see section 6.4). This consequently can improve patients' empowerment to practise self-care. However, from this study, it is found that they are some challenges in implementing it such as lack of workforce and lack of understanding of each other roles in the management of complex diseases such as T2DM. As we all know, pharmacists are the expert in medicines, and the roles of pharmacists should be included and be further expanded in MDT in order to assist in evaluating patients' specific educational needs and addressing patients' concerns in their treatment regimen (see sections 6.2 and 6.7.3).

THEME 3: APPROACHES TO EMPOWER SELF-CARE

5.3.1 Introduction

Poor understanding of T2DM and its management can lead to poor glycaemic control and increase the risk of developing diabetes-related complications. With the complex management of T2DM, patients who have low health literacy may find it difficult to cope and manage their condition. Therefore, it is crucial that they are well supported and educated based on the level of their understanding in order to empower self-care behaviours. In this section, I discuss the importance of health literacy in empowering self-care behaviours among newly diagnosed T2DM and pre-diabetes patients and the approaches pharmacists took to increase patients' understanding of their condition.

5.3.2 Assessing patients’ health literacy

Assessing patients’ ability to understand their diseases especially chronic diseases such as T2DM is important so that healthcare providers can understand and tackle the issues patients are facing in providing the most effective treatment regimen cater to individual patients (Mayer & Villaire, 2007). In this study, pharmacists were asked whether they assess diabetes patients’ health literacy levels before conducting counselling, and all pharmacists stated that they do not assess patients’ health literacy as it is not a standard practice and there were no standardised or structured tool or questionnaire available for them to use to assess it.

> *AK: There’s no specific tool. There are no accredited tools or whatever to assess the literacy. If let’s say there’s any umm I’m sure we are not using it.*
>
> *CT: Currently, there wasn’t any structured or systematic ways in, in written form say or how you should initiate your interview by assessing literacy of this patient and such.*
>
> *H: In the health clinic, it’s the same. There’s no particular SOP for us to assess.*

Upon finding out that there were no standardised health literacy tools that healthcare providers in Malaysia can use to assess patients’ levels of health literacy, I further asked the participants how they evaluate the patients’ health literacy and personalised their counselling for each patient. Some of the pharmacists indicated that they would use their own judgement or personal intuition when talking to the patients.

> *CT: We can only based on initial impression that we first met the patient and umm having a bit of a shallow conversation with them and through that it will, it will help us to know how to further go with that person throughout the conversation.*

> *TN: Because I'm working in third class hospital, I mean for most of my patients, they don't really read a lot. They, I mean from the background themselves, from the rapport, we know that, we already know that they have limited health literacy.*

> *RI: I use my own judgement… But other than that, I can't really assess how good are they, but sometimes we can really tell when patients aren't really following up.*

While some of the pharmacists would gather information through questioning when they talked to the patients, and from there they would evaluate patients' understanding and cater their counselling for individual patients.

> *NO: With the conversation. The first thing how we know is when we ask them. First, the first when we ask them (and) how they answer our questions. From that we know their health, health literacy.*

> *LSP: We just ask questions. Most of the time we just ask questions. Try to get whatever information that we think it's useful for our next step.*

> *CYT: Through the counselling sessions when you talk to the patients you will know whether they really don't know anything or whether they are more educated and still refusing. Because you will have two types of patients. One is health literacy is literally zero and another type is health literacy is*

> *all about google dot com and they will trust everything. Yeah. All the side effects they will make it very serious. Those are, those are educated. Those are educated patients, yeah.*

It is a normal human nature that when we see, for example, a well-dressed person from an urban area, we would automatically assume or have a perception that the person is well educated compared to a person who is from a rural area. However, education level alone is not shown to appropriately determine a person's level of health literacy (Wilcoxen & King, 2013). This could pose an issue to healthcare providers who use their own judgement when assessing patients' health literacy because without a proper and systematic assessment, this perception or intuition could lead to patients not receiving the appropriate education they require. Healthcare providers might overestimate patients' understanding due to unreadiness of patients to admit to having low or inadequate health literacy (Wilcoxen & King, 2013). As a result, I further asked the participants on their opinions on the use of health literacy assessment questionnaire in their healthcare facilities and mostly stated it is a good idea to have it in their practices as it can give them the overview of the patients' status before conducting counselling sessions.

> *CYT: We can try. We can try it. We never had it before so, but not sure what's the outcome.*

> *TN: For the hospital, I think it's a good idea. But then I don't know how to put it into practice specifically.*

> *CT: I think for me, yeah the most important thing in this discussion is to actually have an idea about how to initiate an assessment about health*

> *literacy among our population. Because our population is quite diverse. So, having this idea is not bad, is a good start.*

Even though having a standardised assessment tool is useful, some of the pharmacists raised the issues around implementing it in the real world. Some of the issues they mentioned include time constraints and the willingness of patients to be assessed. For example, during the focus group discussion, participants CT and TN not only raised but also concurred on the two issues. While almost all community pharmacists indicated that it would be difficult to implement it due to time constraints.

> *CT: Because the patient may, may start to think why is this pharmacist umm…*
>
> *TN: Judging?*
>
> *CT: Something like interviewing me like that.*
>
> *TN: Mm.*
>
> *CT: It's a bit yeah… It's like asking more than what is required. Some people may think that. And also time constraint-lah.*

Hence, some of the pharmacists proposed that the questionnaire should be a simplified version that can be administered quickly, a suggestion agreed upon by all the pharmacists in the focus group.

> *TN: Maybe one or two questions to just quickly know their literacy level probably would, would help but not too intense or specific session around that.*

> *H: Umm, good idea.*

> *CT: Yeah I think for retail, let's say, if let's say your store is located in a high street section, it'll be great if the assessment form can be, let's say less than five questions that the pharmacist can naturally incorporated into their conversation with the patient that'd be good.*

Meanwhile, participant NO suggested that the doctors will be the right healthcare providers to introduce patients to the questionnaire.

> *NO: Then if doctor conducts the questionnaire, maybe they can accept it. Because they're going there for counselling, sometimes there's counselling fee and all, right? Then if pharmacists conduct it maybe they can accept, maybe they can't.*

5.3.3 Literacy sensitive techniques

As you can see from the previous section, it is not easy to assess patients' health literacy, let alone to change patients' health literacy levels. Thus, what healthcare providers, for example, pharmacists can do is change how pharmacy staffs engage with patients as well as making the pharmacy environment a health literacy supportive environment. To empower self-care behaviours especially among diabetes patients, there is the need to increase patients' knowledge and understanding of their condition. Without proper knowledge, patients will not be empowered to take the necessary steps to manage their diabetes and improve their quality of life. There are different literacy sensitive techniques such as using simple and clear language, using the "teach-back" method, encouraging question-asking behaviours and supporting verbal communication with written information and pictures, that healthcare providers can use when counselling patients to improve patients' understanding (Collum et al., 2013). In this study, I asked the pharmacists what and how do they counsel newly diagnosed T2DM and pre-diabetes patients in order to help patients understand their condition and management better, and this is discussed in the next following sections.

5.3.3.1 Using simple language

As mentioned before, there are a number of techniques that are recommended for good health literacy practice to improve patients' understanding. From the interviews I had with pharmacists, many mentioned that they would avoid using medical jargons when explaining about diabetes and its management. They would explain in plain and non-medical language and use simple to understand words. If they see the patients have a deeper understanding of their condition, only then they would explain further.

> *CYT: We have quite a lot of patients that can't read because (inaudible- 24:50) public clinic yeah, so they can't read so when you explain to them, yeah, we really need to explain in laymen terms.*

> *LSP: Normally, in community most of the time we have to talk with laymen words-lah. Yeah. Most of the time it's just like we treat as a friend. So, we just talk like umm we didn't, we didn't use too much medical words.*

> *NO: I will explain to them as simple as possible that they can understand. And the most important thing is to make them understand because if we explain them a lot, they don't understand then there's no point we explain to them.*

> *HN: If we see the person is more interested and understand more, we can put more words, more technical words.*

A systematic review study which looked at health-literacy-sensitive diabetes management interventions for patients with low health literacy identified that using at least one of the spoken communication strategies such as teach-back method and clear communication, led to positive results on psychological outcomes, self-care, and health outcomes (Kim & Lee, 2016).

5.3.3.2 Teach-back method

In this study, pharmacists who are working in hospitals and public health clinics are equipped with insulin demonstration kit to teach patients on how to use the insulin. Hence, for patients who are prescribed insulin, whether they are newly diagnosed or not, will be taught on how to use the pen, how to store and to inject the insulin and how to dispose of used needles.

> *CYT: Insulin usually doctor will just prescribe with a starting dose then we will teach patients how to use the pen and how to store it and how to inject. We do have placebo in our pharmacy so, if they allow and they're okay, we will usually inject the placebo for them, let them try and then ask them to demo to us.*

> *KLE: We do have a dummy doll. Yeah. You know the small doll. Yeah. We use that to educate our patients how to use insulin.*

> *MH: For the insulin injection training they have some aid you know like some stuff-lah. Or some chart or even some like "sumo" kind of toy to help them where they can inject the insulin.*

Other than teaching patients on how to use insulin, pharmacists would also teach patients on how to use the SMBG machine.

> *NO: Ah, I teach. If people come and buy, of course definitely we have to teach them.*

> *RG: Some people they buy already then even like old people we demonstrate to them already then they still have difficulty in using the*

> *glucose machine then they will come back and ask us to demonstrate many times like that.*

Once they have explained to patients how to use the insulin or SMBG machine, they would usually check the patients' understanding. The teach-back method is a method used by healthcare providers to check the understanding of the patients by asking the patients to state what is being explained to them in their own words (Brega et al., 2015). Another term used is "show-me" method where patients are asked to demonstrate back on how to use their medication correctly, for example, insulin, to confirm that patients can specifically follow instructions (Brega et al., 2015). It is also crucial to understand that teach-back method is also a way for healthcare providers to test how well they have conveyed health or medical information to patients (NHS Education for Scotland, 2017). When teaching diabetes patients on how to take their medication and insulin, a lot of the pharmacists use the teach-back or show-me method to evaluate patients' understanding of medication taking. It is important to check patients' technique because this can help in reducing nonadherence and drug-related problems (Collum et al., 2013).

> *CYT: We will step by step guide them. So, that's why we will demo. We have a placebo, we will demo and show them how to do it and then they will demo how they do it in front of us. So, we can check whether you know their technique is correct or not.*

> *HN: Just what we have is maybe we will ask the patient to demo back to us how to inject insulin. That's one. Another one is in the diary, "My DM diary", there's a table to record their sugar reading for them to explain back to us what they understand. Umm I think that's the two things, for now.*

> *RI: So, when I counsel them on how to administer usually I will ask them to try as well in front of me, especially when putting the needle and removing the needle. So, I will ask patients to do it in front of me and see how they, they've done it and how would they titrate the unit.*

Studies reported that 40-80% of medical information given to patients during appointments with healthcare providers is forgotten immediately, and nearly half of the information retained is incorrect (Brega et al., 2015). Therefore, it is necessary to use spoken communication such as teach-back method routinely to increase patients' understanding of diabetes self-management (Kim & Lee, 2016).

5.3.3.3 Using written information, pictures and visuals

Spoken or written communication can be misheard or misread and as a result patients might misunderstand the health information received. Visual aids such as pictures and diagrams can enhance the understanding of written and spoken information and patients are more likely to read texts with visual then just texts only (Cork & White, 2022). Using written information together with visual aids may help healthcare providers in explaining complex texts about diabetes, for example, how diabetes develops or explaining self-care measures such as the healthy plate diet. As indicated by participant CT and MR, they felt that it is important to provide patients with written information to support verbal information.

> *CT: So, for me personally, I like to give out simple written information. It could be as simple as just a website, a video, or some resources that they can refer to themselves online. Can be written information like what is, what is the target, what is the goal, let's say dietary control or blood sugar level control that they should aim for just like written information that tailor made to that patient.*

> *MR: Yes, we do have a booklet showing mainly for the diet plan. And we have a booklet which means like it will give them a better understanding of what we are actually telling. Rather than we just talking without showing them any picture.*

When I was recruiting patients from the public health clinics, I noticed in public healthcare facilities that they have a flip chart on diabetes and its complications which is used as a teaching aid to explain to diabetes patients about diabetes and its management. Some of the pharmacists interviewed mentioned the flip chart and its usage when counselling diabetes patients. Other than the flip chart, there are also teaching aids that contain pictures that pharmacists use to help them counsel diabetes patients on the insulin injection sites.

> *MH: And then some pharmaceutical companies, even give us like a A4-shaped kind of paper and then with a lot of holes, that will help patients to decided where to inject the insulin on the abdomen site.*

Due to information overload, sometimes patient may not be able to retain or recall information that was given to them. A study which looked at the discrepancies between patient and professionals recall and perception of an outpatient consultation found that there were discrepancies between patient and professionals in the amount and the type of information recalled (Parkin & Skinner, 2003). To avoid this, written information such as pamphlet, may be provided to patients to take home to supplement the information that they have received during the consultation.

> *HN: I will give like one pamphlet, but it's like umm "My DM diary" for patients to bring back home. So, I'll tell them like, "further info you can refer back to the book", like that.*

> *H: Give leaflet. Because they won't remember what we say. We talk a lot also they won't remember. So, we give leaflets or diagrams, or we can show them videos too, if they want.*

> *RI: I saw that sometimes when they come to our pharmacy, they come with a leaflet from the diabetic clinic on how to, they will actually prepare a table, so this insulin which colour should it be, which unit should be used and then how to take it, before meal and all.*

Additionally, pharmacists in community pharmacies are also using various teaching aids to help them when consulting diabetes patients on diet and blood glucose range. Participant JO explained that she would draw to supplement her verbal communication to ensure patients or customers have a clear understanding on her explanation. For participants LSP and MR, they would use diagrams, charts, or booklet to explain about diet plan and blood glucose levels.

> *JO: I would, I would draw. Yeah. So like, like you know when you talk about diet then I would draw, I draw a circle to represent a plate. And then you know triangles to represent the portions.*

> *LSP: Yes, like type of food then actually we will show them this one is a low glycaemic, intermediate or high glycaemic with diagram, with the pictures. And of course we have table that shows them what range of HbA1c that you should be. If pre-diabetic, you have to be in what range, if you're diabetic, you have to be in what range.*

> *MR: So even for fasting time, we have a separate booklet showing them what proper meal that they should take for diabetes patients, yeah. Yes, what will be good for them and how many portions they should take and then how actually you know every portion can link like how much calorie they're contributing and then how it's actually going to affect their weight.*

5.3.3.4 Encouraging patient questions

To ensure we are providing a patient-centred care, healthcare providers need to provide the patients the opportunity and support to ask questions and raise their concerns comfortably. This is because, as mentioned in section 4.1.4.1, sometimes patients are afraid to ask questions to healthcare providers. The two most common barriers to asking a pharmacist question reported by patients were fear or intimidation and lack of awareness (Collum et al., 2013). Some of the ways that pharmacists can do to encourage patients or customers to ask questions are by using the "ask me three" method where they can ask three questions about their condition and situation or elicit patients' questions through patient-centred approach by using a more open-ended question (NHS Education for Scotland, 2017). Though not all the pharmacists I interviewed in this study use this technique to improve patients' understanding, some mentioned that they would prefer patients to ask them questions and be more active during their consultation.

> *JO: I just share what knowledge I have. Yeah. Umm and I normally prefer, prefer it if the patient is actually asking me the questions on how to get better.*

> *NO: Actually from their feedback then we know how to counsel them. Because if we don't know how they understand, we just explain to them like that, it's like no point actually. It's like we're talking to ourselves.*

> *CT: For me, I will be emphasising a lot of umm asking feedback from the patient, so that to also help me whether the patient understands what I'm trying to deliver. And umm so for me I think it's quite important for pharmacist to use open ended questions.*

5.3.4 Individualised counselling

In the previous sections, I discussed the literacy sensitive techniques that can be used to improve patients' understanding, knowledge and empowerment to self-care. There are other approaches that pharmacists can take to empower self-care during patient consultation. One of the ways is to individualise their counselling session that caters to the patients' health and psychological conditions as well as their environmental or external factors that could affect their self-management. For diabetes patients especially for newly diagnosed patients, it is crucial to find out more about their lifestyle and occupation so that a more detailed and thorough education can be given that suits patient's day to day activities.

> *LSP: And of course, we will actually try to understand how their diet is, how their lifestyle is.*
>
> *TN: So firstly, first for newly diagnosed patients, we'll have a thorough view about their lifestyle overall. Like how about diet, the working style and then if he or she got symptoms so far.*

Due to the complexity of diabetes management, it is important that a patient-centred care is offered to all T2DM and pre-diabetes patients in order to prevent and delay disease progression. An individualised care plan together with active collaboration and shared decision making needs to be encouraged for patients to receive the appropriate care and support needed. Most pharmacists in this study stated that individualised counselling is the most effective approach to offer to diabetes patients because the information shared are more realistic for them to follow and practise in their daily lives, and any other issues that are affecting patients emotionally or physically can be looked into.

CYT: After years of working right, I still I can conclude that a one-to-one session counselling is way more effective than a counter counselling for diabetes patients especially those who reject the medications. Yeah. And each individual is different, so you have to tackle their problem and why they have such problem.

CT: I believe all the pharmacists have the right thought that each patient counselling is always patients oriented. We can't standardise our counselling to all the same content for all patients. Each patient is different.

HN: When we give individualised information, patient will see the advice is more like realistic. So, patients feel that they are able to do it. So, they will do it. The patient won't feel like just listen to what they advise (but don't actually practice it).

KLE: Some of them (patients) will be in a serious denial mode, and they will be like, "Oh my God, I'm going to die". Something like that. And then, "No, I'm not. And I heard that if I start to be on any treatment, my life would be shortened". Something like that. Yeah. So, a very personal, very individualised counselling would have to be performed on such group of patients. And for another category where they are very keen to their treatment, yeah, I mean, there's a challenge in this group of patients as well because some of them will, they tend to be too aggressive you know and then they start to have like keto diet and they tend to rely on resources on the internet a lot. And some of them actually develop complication as a result of that. So, basically for both groups of patients we need to, we need to spend quite a lot of time, especially those newly diagnosed patients.

To improve patients' empowerment to self-care, some of the pharmacists in this study suggested that patients should be educated with information which are suited to themselves. For example, participant LSP mentioned that without individualised counselling, patients might not stick to their treatment plan, and participant HN said that sometimes patients are given too little information on exercise, and it would be good if the information could be based on patient's lifestyle. Meanwhile for participant KLE, he indicated that he would encourage his junior colleagues to do individualised counselling but if not possible, they could provide simple information for patients to follow.

> *LSP: It depends on your diet and your lifestyle. And I mean we set a routine that suits to you. Because, or else they won't stick on it.*

> *HN: In terms of self-care like exercise, maybe can give one exercise which is specific for everyone to follow depends on their lifestyle. Because maybe some people work at night, so have to advice depends on the patients' jobs and the also their ability. Maybe for some of the exercise is not suitable for them to do, for example, jogging. Patient can know what type of self-care, rather than just a general information like exercise for half an hour.*

> *KLE: I always advise my pharmacists to individualise their counselling, but I understand that not all pharmacists, especially those junior ones are good in individualising in this kind of MNT (medical nutrition therapy) concept. So in such cases, if they are not confident to individualise the education for the patients, then I will ask them to just give a very general advice like have brisk walking, moderate intensity exercise around 150 minutes a week and then to have more fibre in their diet to control carbohydrate. Little something like that.*

Patient-centred care also ensure patients are receiving the support they need emotionally and mentally. As discussed in sections 4.1.2 and 4.1.3, diabetes distress and diabetes-related stigma are experienced by most diabetes patients especially for those who are newly diagnosed as it can be difficult for them to accept their diagnosis. Therefore, one-to-one session with healthcare providers provides the place for diabetes patients to voice out their worries and feelings about diabetes. Participant RG who was diagnosed with gestational diabetes herself, stated that she can relate to what the patients are feeling and emphasised the importance of being supportive to the patients during counselling.

> *RG: But I can relate to their feelings more. More compassionate and more empathy. And instead of we just, because as a pharmacist like fresh graduate or what, I think you just tell them whatever you learned from the book. You do this. You do that, like this is the advice. And when we get to know their sugar level very high then we just tell this is no good or whatever. Maybe (need to provide) some more from the angle of the customer or the patient. Maybe you can tell them more information on what diet or what food they can go for.*

Individualised counselling also helps pharmacists to provide information based on patients' levels of understanding and also patients' requests to be explained further.

> *AK: Everything must be individualised. Because we can't really tell pathophysiology issues in terms of educating the patient in a patient who does not understand what is pathophysiology. Usually, we'll go by their level or understanding or if let's say I can use analogy that make them understand whatever they're having or what they should do, I will go that way-lah.*

> *CT: We did encounter patient that is highly educated, and they actually requested for more information. And with this, with this group of patients, definitely our counselling can be tailor made into more, more scientifically termed so that they are convinced about how they can manage their disease.*

> *LSP: Of course, some customers are those highly educated one, they can accept, and they actually prefer, we can actually talk to them in more professional way. It depends on different customers then we use different style to communicate with them.*

As discussed in section 4.1.4.2, family support is important in empowering self-care behaviours because a major part of the diabetes self-management is done at home with the help of family members. The involvement of family members during a patient's consultation is sometimes required to encourage shared decision-making and to ensure they received enough support and understood the information shared to facilitate self-management at home. Some of the pharmacists interviewed talked about the involvement of family members during patient counselling so that patients and their carers are receiving the appropriate support at home.

> *KLE: Sometimes I will have to get their family support. Yeah. For example, a 50-year-old mother is in, she's in denial mode, cannot really accept that she has diabetes. And then she sometimes she cries, okay then I would have to involve her son, her daughter, ask them to come, invite them to the counselling room. Umm have them to support their mother and something.*

MR: It should not be confined to only the patients. I think the whole family should be included in the counselling or consultation because it's, it's not easy for one single person to, you know, overcome the disease. It should be, it should come from the family support also. In terms of giving them emotional support because it is very depressing suddenly you know diagnosed with diabetes and then you have to cut lots of things and then you have to, you know really juggle your diet and all these things. But with the family support, I think it will be good for the patients.

RI: Usually when I do insulin counselling, it will be with their family members as well so they would know how to handle this.

5.3.5 Summary

The use of literacy sensitive techniques during diabetes patients' education and training and the impact of patient-centred care can help to improve the understanding of newly diagnosed T2DM and pre-diabetes patients on diabetes knowledge and self-care management. Both approaches have shown to have positive outcomes on psychosocial outcomes and glycaemic control (Kim & Lee, 2016; Olesen et al., 2020). Therefore, they should be applied in all patient counselling sessions and pharmacists should also be trained to deliver a more personalised counselling based on patient's health literacy. This is further discussed in sections 6.4 and 6.5. In the next section, I will discuss the importance of improving pharmacist's knowledge and skills in diabetes management and in delivering literacy sensitive services in pharmacy to empower self-care behaviours among the newly diagnosed T2DM and pre-diabetes patients.

THEME 4: CONTINUING PHARMACIST’S EDUCATION

5.4.1 Introduction

Pharmacists are expected to improve their skills and increase their knowledge through a lifelong learning model called continuing professional development (CPD). For example, in Malaysia and the UK, pharmacists are expected to attend or join various pharmacy activities and programmes such as workshops and seminars to ensure that pharmacists are taking responsibility of their own personal and professional development by keeping up to date with new knowledge in healthcare and pharmacy to broaden their knowledge, skills, and competency. In this section, I discuss the gap in knowledge and also the importance of continuing pharmacist’s education on health literacy, self-care, and diabetes management in particular, in order to strengthen pharmacists’ capability to empower self-care behaviours among newly diagnosed T2DM and pre-diabetes patients.

5.4.2 Pharmacists' understanding of self-care and health literacy

At the beginning of the pharmacists' interviews and focus group, I asked pharmacists to describe what self-care and health literacy are in their own words to see the depth of their knowledge about both terms. Most pharmacists were able to explain what is self-care and why it is important to diabetes patients, and as for health literacy, though most of the participants were not able to explain the definition of health literacy in full, they have a slight understanding of what it is. Some of the pharmacists explained both self-care and health literacy together in one sentence because both are correlated to each other that is, when patients have sufficient understanding of their diabetes, they were able to practice self-care.

> *JO: How umm aware the patient is about their health condition and how to take care of themselves.*
>
> *MH: Self-care management meaning that if they're well informed about their disease, meaning that they can take care of themselves.*
>
> *CT: For me, health literacy is mainly reliable health information, that is accessible to your own method like maybe online, maybe through books, e-books, mobile phone or something.*

There are various studies done to assess patients' health literacy, knowledge, and attitude towards diabetes management (Al-Qazaz et al., 2011, 2012; Siopis et al., 2021; Suka et al., 2015; Visscher et al., 2020), but not many studies done to evaluate pharmacists' knowledge and understanding in providing diabetes counselling. Surveys done in Ethiopia and Qatar found that there is a gap in pharmacists' knowledge on diabetes management such as foot care and diet modification and thus, specific diabetes training and continuing education needs to be provided both in academic and practice settings (El Hajj et al., 2018; Erku et al., 2017).

5.4.3 Pharmacists’ education

In continuation from the previous section, here I discuss the pharmacists’ experiences of learning diabetes self-care management and health literacy during their undergraduate studies. To find out more about the participants’ level of understanding in self-care and health literacy, I asked whether they have learnt these two topics during their undergraduate studies or whether they have attended any CPD programmes related to these topics. Because the pharmacists recruited in this study graduated with pharmacy degree from various countries such as Malaysia, the UK and Australia, hence, their learning experiences might differ from each other. Nevertheless, most of the pharmacists indicated that they did not have a specific topic on health literacy, but they did learn about how to counsel and communicate with patients. Meanwhile for diabetes self-care, they have learnt about it briefly in diabetes modules.

> *HN: Self-care and health literacy, not so much. But we have a subject called pharmacotherapeutics. In that subject, there’s pharmacotherapeutics for endocrine, for cardiovascular disease and all. So, in that subject we were taught in depth about pharmacological management and lifestyle modifications and management of diabetes.*

> *CT: There (participant’s university), they emphasised a lot of umm as a pharmacist, we play a part in developing a lot of self-care information for patients. So, they taught us a lot umm during my pharmacy degree programme.*

> *CYT: I don’t think there’s much, I remember we only have like one or two counselling modules.*

With the increasing awareness of the importance of health literacy and the high prevalence of low health literacy (Gursul, 2022; Institute for Public Health (IPH), 2020; Kutner et al., 2003), universities in the United States have started to introduce health literacy modules in their pharmacy degree programmes and continuing education programmes to assist pharmacy students and professionals with health literacy-sensitive communication (Chen et al., 2013; Wilcoxen & King, 2013). Some of the pharmacists in this study also felt that the introduction of these topics in undergraduate pharmacy programmes or in continuing education programmes is required to prepare pharmacy students and professionals to effectively communicate with patients with different levels of health literacy and empower diabetes patients to practise self-care. This is because even for some of the participants who have nearly 10 years or more of working experiences, they still have difficulty to communicate with patients effectively.

> *MR: Yeah, definitely, it is a very good thing to actually, because I believe before the patients have that, I mean have the knowledge about health literacy and self-care, we, the medical professionals should have that knowledge first of all.*

> *NO: I think that's great. Yes. Actually, that's great. Because up until now sometimes even we experience also sometimes we don't know what type of patients that we are dealing with. So, sometimes we don't know how to, how to explain, how to counsel different types of patients. All that from our judgement only. So, if there's a course or whatever CPD points for that, that's good-lah.*

5.4.4 Area of specialisation

As the role of pharmacists in patients' care are significantly expanding, more pharmacists are providing specialised services. I mentioned in section 5.1.2.3, there were two pharmacists in this study who are qualified and accredited pharmacists who specialises in diabetes management in DMTAC. One of the pharmacists, participant CYT, explained that to become a DMTAC pharmacist, she was required to attend classes and do coursework before she could pass the course.

> *CYT: So, you need to, you need to go for training and do the coursework and then attach with a person who is already got MTAC certificate then after that you are issued with a certificate. Provided of course (if) you passed the course.*

Participant KLE who is also a DMTAC pharmacist indicated that he was also trained in DMTAC and has an international Board Certified – Advanced Diabetes Management (the BC-ADM credential) which allowed him to manage and assist complex patient needs such as adjusting medications, treating and monitoring complications, advising on lifestyle modifications and addressing any psychosocial issues (ADCES, 2021).

> *KLE: So, I'm actually trained in diabetes MTAC and also have an international credential, BCADM yeah.*

With all these extra specialisation and qualifications, the role of pharmacists can be further developed more than just the traditional role of dispensing medications. This could also help in broadening the capacity of a pharmacist to work in a multidisciplinary team and consequently, increase patient's access to different health services.

> *KLE: Well, of course, in my clinical pharmacy team, each of us will specialise in certain disciplines. My case is diabetes, and for my colleague, we have pharmacist specialising in infectious disease, in cardiology, yeah. So, basically we learn from each other.*

Nevertheless, the advancement in practice and specialisation in pharmacy needs to be introduced and encouraged to all pharmacists regardless of its sector to increase pharmacists' accessibility to specialty programmes. This is because participant CYT and KLE are both working in the public sector, and I believe that pharmacists who are working in the community pharmacies should also be offered an opportunity to advance in their practice but due to costs of certification, this could hinder them to advance in their career (Jorgenson et al., 2017).

5.4.5 Future training

Several studies which looked at the impact of diabetes training programmes to pharmacy students and professionals found that there was an improvement in both students' and professionals' skills, knowledge and attitude in delivering quality diabetes education to patients (Axon et al., 2022; Ayadurai et al., 2019; Chen et al., 2004; Manigault et al., 2020). This shows that with training, pharmacists are able to provide a more patient-centred care and consequently, empower patients to practice self-care. For example, participant KLE stated that he would encourage his junior colleagues to give a personalised counselling, focusing on medical nutrition therapy (MNT) if possible.

> *KLE: I always advise my pharmacists to individualise their counselling, but I understand that not all pharmacists, especially those junior ones are good in individualising in this kind of MNT concept.*

According to the Malaysian diabetes practice guideline, MNT is provided to diabetes patients such as during diagnosis, to help in lowering patients' HbA1c levels, reducing their weight as well as other risk factors such as cardiovascular risk (Ministry of Health Malaysia, 2020a). MNT consisted of individualise counselling on proper diet mainly done by dietitian, but participant KLE felt that pharmacists should also conduct it because it is important as an adjunct to pharmacotherapy.

> *KLE: Well, as pharmacists, we'll usually counsel more towards the pharmacotherapy, but I've always believed that we need to counsel beyond that. Yet professionally we are, we are expected to be good in pharmacotherapy. But then umm for diabetes patients, as you know, medical nutrition therapy would be the most important factor, I would say even more important than pharmacotherapy.*

Hence, there is the need for pharmacists to be educated in MNT and be proactive so that they can advise and empower patients to not only adhere to medications but also on diet modifications, which many diabetes patients have also mentioned that it is one of the barriers for them to practice self-care.

> *JO: I think like to be very honest… probably a lot of healthcare professionals first need to be educated, yeah, about nutrition especially. Yeah. Not just the patients.*

> *KLE: I think we need to have more self-learning, yeah, in MNT. And not just purely focusing on pharmacotherapy. I believe this will help our diabetes patients a lot. A lot of time we are just restricting our roles.*

Two studies which introduce educational strategies such as health literacy assignments to pharmacy students found that students' understanding and attitudes towards communicating in health literacy-level appropriate manner and addressing health literacy of patients improved after the learning activities (Chen et al., 2013; Wilcoxen & King, 2013). As stated in section 5.4.3, there is a gap in health literacy knowledge among the pharmacists interviewed in this study. Therefore, there is also the need to incorporate health literacy themes in pharmacy curricula and continuing education programmes to improve the skills of pharmacists in this area.

5.4.6 Summary

In this theme, I discussed the importance of the skills and knowledge pharmacists need to acquire to ensure they are fully prepared to educate diabetes patients. Many pharmacists in this study indicated that to empower diabetes patients to practice self-care, the healthcare providers should also be trained and educated with the skills and knowledge to manage diabetes. They should be knowledgeable, aware and responsive to the needs of the patients especially to the newly diagnosed T2DM and pre-diabetes with inadequate health literacy, and this is further discussed in Chapter 6 (see section 6.5 and 6.8).

CHAPTER 6 SUMMARY DISCUSSION AND CONCLUSION

6.1 Introduction

In this chapter, I discuss and summarise the findings found from patients' interviews, pharmacists' interviews and focus group and how they may be associated with the results obtained from the HLQ. These are discussed in sections 6.2, 6.3 , 6.4 and 6.5.

The strengths and limitations of this study is discussed in section 6.6, followed by the practical implications and recommendations (section 6.7), future work (section 6.8) and the conclusion of this study in section 6.9.

6.2 The importance of social support

As discussed in patients' theme 1 (sections 4.1.2 and 4.1.3), diabetes distress and diabetes related stigma are common among diabetes patients, and newly diagnosed T2DM and pre-diabetes patients may develop both of these conditions due to various reasons (Kaur et al., 2013; Skinner et al., 2020). Receiving sufficient support from their relatives and healthcare providers helps diabetes patients cope with diabetes diagnosis and management. A study which systematically reviews the importance of social support in diabetes care found that the adherence to diabetes self-care had a relationship with social support (Mohebi et al., 2013). There is a need to include family members during patients' consultations with healthcare providers, especially at the beginning of patients' diagnosis, so that they can facilitate patients to manage their condition at home. Other than family support, peer support has shown to be beneficial to newly diagnosed diabetes patients in improving adherence behaviours, for example, a study that examined the effectiveness of peer-led intervention in recently diagnosed patients who received visits from experienced peers with diabetes who are adherent to their treatment showed that there were improvements in self-efficacy, coping and saturated fat intake (Van der Wulp et al., 2012). However, as I mentioned in section 4.1.4.3, there are currently no peer support programmes available in public healthcare facilities, hence a few patients joined diabetes support group on social media to interact with other group users for information and moral support. Nonetheless, not all patients have access to these support group, therefore, introduction of this programme should be considered and implemented in healthcare facilities.

As for the HLQ score, scale 4 was seen as the highest score of the first 5 scales among the patients in this study. Having a high score for this scale means that patients' social system provides them with all the support they want or need

(Osborne et al., 2013). Several patients mentioned that they obtained support and information from healthcare providers and also from their friends and family who were also diagnosed with diabetes or work as healthcare providers. They felt that they have the social system that they could rely on when dealing with complex illnesses such as T2DM.

Based on the Malaysian diabetes clinical practice guideline, psychosocial support needs to be offered during diabetes diagnosis. The multidisciplinary team approach may assist in identifying diabetes patients who may develop psychological problems such as depression, stress and anxiety during diagnosis and follow-up appointments, and patients can be referred to the appropriate healthcare providers for further support and treatment. The inclusion of all diabetes patients especially newly diagnosed T2DM and pre-diabetes patients, regardless of their HbA1c status, to DMTAC needs to be implemented for patients to receive patient-centred and individualised counselling from pharmacists. From there, pharmacists are also able to check for sign of psychosocial problems that could affect medication adherence and self-care, and signpost patients to the appropriate health services. Apart from that, issues that affecting patients such as nonadherence to medications and self-care, and lack of understanding and awareness to control their glycaemic levels can be intervened early and this consequently may delay or prevent the development of diabetes complications.

6.3 Lack of social support

However, there were patients in this study who mentioned that they lacked support from their relatives and also healthcare providers, especially in coping with their condition and also in getting resourceful information. This could be due to their reluctance of sharing about their condition openly fearing that they will be judged or be given negative appraisal. Furthermore, poor communication between healthcare providers and patients during counselling session was also found to be another reason why patients in this study felt that they were lacking support in managing their diabetes. A study on patient trust and diabetes self-care found that higher patient trust in doctors among diabetes patients is associated with reduced difficulty in completing self-care tasks (Bonds et al., 2004). This is probably because patients with higher trust are actively engaging with their healthcare providers in jointly making health care decisions and they may be more willing to overcome the challenges faced during the initial lifestyle changes related to diabetes management (Bonds et al., 2004). Even so, some patients in this study stated that they may be intimidated to ask questions to their healthcare providers such as doctors, due to some doctor's paternalistic behaviour. This can create a power dynamic that discourages open communication leaving patients with a sense of inadequate support from the healthcare providers. As a result, this supports the results obtained from the HLQ where the lowest score recorded in this study for the first 5 scales was scale 1. When someone scores a low health literacy in scale 1, it means that he or she is unable to engage with doctors or other healthcare providers, does not have regular healthcare providers and/or have difficulty trusting healthcare providers as a source of information or advice (Osborne et al., 2013).

Therefore, there is a pressing need to improve social support for diabetes patients, particularly those who are newly diagnosed, by encouraging open communication between patients and healthcare providers. Creating environment where patients feel comfortable to discuss their concern without the fear of judgement is also crucial. Furthermore, the accessibility to social support also needs to be improved, and pharmacist play a major role in facilitating these crucial aspects of diabetes management, especially among the newly diagnosed patients.

6.4 Access to diabetes information and services

Several patients in this study also indicated that it was difficult for them to obtain and also to understand information related to dietary changes. To facilitate diabetes patients in dietary change, there is a need to improve patients' health literacy and their access to professional support from dietitians (Siopis et al., 2021).Yet, not all diabetes patients have access to dietitians, and this is where pharmacists especially in the community pharmacies could play their role to support patients to cope with their lifestyle modifications such as diet change and weight loss. Moreover, due to lack of awareness of where and how to find reliable health information, patients might take the wrong recommendations received from relatives and the internet without verifying the information which can then lead to treatment failure. Several patients also mentioned that they were not keen of using the internet to look for information because they felt that the information was limited and misleading. As indicated by several pharmacists, they have encountered various misinformation from diabetes patients and have taken the necessary steps to advice patients accordingly. Pharmacists may take the opportunity during their interactions with diabetes patients to educate them on where and how to find reliable health information and to debunk misinformation. With the health knowledge pharmacists have, they are capable to refute false or misleading health information with evidence from appropriate and reliable sources (Hermansyah et al., 2021). In addition, the convenience of the public to access pharmacist especially in the community pharmacies makes it much easier for people to get the support they need and to obtain reliable diabetes information, for example, on diet and exercises. Pharmacists can use different health literacy sensitive approaches when talking to patients to improve patient's understanding on the right diabetes management and self-care. By using the different approaches such as using plain and simple language, visual aids, teach-back methods and encouraging patients to ask questions, pharmacists can provide a health literacy supportive environment and encourage patients to engage in a shared decision making on their health needs and therefore, empower self-care behaviours.

In Malaysia, diabetes self-management education and support programmes are offered by multidisciplinary healthcare team in public healthcare facilities as a part of a chronic care model to improve patients' glycaemic control, motivation and medication adherence (Ministry of Health Malaysia, 2020a). As per Malaysia's diabetes clinical practice guideline, formal diabetes education is recommended for all patients, covering the aspects such as diet, exercise, medication, SMBG, management of hypoglycaemia and coping skills (Ministry of Health Malaysia, 2020a). The guideline also advocates for self-management support through technology such as digital web-based apps, short messaging system or phone calls as well as having a peer support group to encourage patient participation. Despite these recommendations, some patients reported not receiving the necessary education and support. Additionally, certain pharmacists highlighted the challenges faced by some public healthcare facilities, noting that not all have the resources or manpower to provide extensive diabetes self-management education.

Furthermore, most patients who attended public healthcare facilities also mentioned that they did not get to see the same healthcare providers on their follow up appointments, and this consequently limits their access to choose their preferred healthcare providers. Lack of continuity of care with the same healthcare providers could also be another reason why most patients in this study scored low in scale 1. Relational continuity is an ongoing therapeutic relationship between a patient and one or more healthcare providers, and they are more appreciated by patients with chronic diseases such as T2DM due to the complexity of the disease (Alazri et al., 2006). Having a relational continuity with a healthcare provider may improve patients' quality of care as doctors are able to identify the appropriate therapies for individual patients and also facilitate in increasing patients' knowledge which can then improve their diabetes outcomes (Alazri et al., 2006). A small number of patients in this study who see their usual doctors mentioned that getting to see the same healthcare providers such as doctors and dietitians empower them to adopt self-care measures and adhere to their diabetes management. However, most did not have the opportunity to see or choose their preferred doctors due to lack of workforce or time constraints and this could result in loss of personal care due to lack of psychosocial support and continuity of care. Thus, multidisciplinary team approach is encouraged in diabetes management rather than personal approach to reduce the problem with lack of workforce and consequently, continuation of care is not compromised.

Navigating the healthcare system can be a challenging task for people with low health literacy (Griese et al., 2020). From the findings found in patients' interviews, some of the patients did not look for further information on diabetes and its management beyond what is given to them by their doctors. This could possibly be due to the lack of knowledge on where to access further information which are true and reliable either on the internet or from other healthcare providers such as pharmacists. This is consistent with the HLQ result where most patients scored low level of health literacy for scale 7 i.e. they have difficulty navigating the healthcare system. When someone scored low on this scale, it indicates they may struggle to advocate for themselves in navigating the healthcare system, have limited awareness of available resources, and may not fully know their entitlement (Osborne et al., 2013).

Furthermore, most of the patients that were interviewed expressed that they perceived pharmacist as only capable of giving advice on medication taking and supplements and that they are not capable of providing information on diabetes and self-care management. They also perceived pharmacists especially in the community pharmacies as "retailers" who are only focused on the business side and not on improving the health needs of a customer or a patient. Due to patients' misconceptions of the role of pharmacists, many did not use pharmacy as a source to obtain reliable diabetes information. Their perceptions were also found to be consistent with the result found from a study which looked at public perception of the role of pharmacist in 2018. The study reported that more than half of the respondents perceived pharmacist's role as only giving out medications and follow doctors' directions (Cheah, 2018). This misconception limits the access of diabetes patients to reliable resources that are easily accessible.

Nonetheless, a pilot study done in the northern state of Malaysia which explored the perceptions of general practitioners (GPs) towards the role of community pharmacists found that GPs are aware that community pharmacists are more patient oriented and recognised them as educators and advisers to patients especially on the safe use of medications and they would support the extension of the roles of community pharmacists in various patient care activities (Hassali et al., 2009). Currently, there are various health services being offered in community pharmacies for the general public as well as diabetes patients specifically such as blood glucose and HbA1c monitoring. People can get their blood glucose checked and monitored at the primary care level and the detection of pre-diabetes and high blood glucose can be detected early on which could then result in the reduction of undiagnosed diabetes and hospitalisation cost due to diabetes complications. Therefore, more efforts should be made to increase patients' access to different healthcare services and patients' awareness of the greater roles of pharmacists especially in the community pharmacies. This can be achieved through the utilisation of the public-private partnerships, promoting collaboration between the public hospitals, health clinics and community pharmacies. This partnership can address resources and manpower shortages and reduce waiting times in public healthcare facilities. Other than that, the implementation of MDT approach and the inclusion of pharmacists in the team can help to improve patients’ accessibility to various health services.

6.5 Self-awareness

With sufficient access to health services and health information, newly diagnosed diabetes and pre-diabetes patients can cope with the challenges and changes needed to be made to improve their diabetes outcomes and consequently empower self-care behaviours. This can be seen in patients' theme 3, where with self-awareness, patients were more aware of their treatment goals, for example, the target blood glucose range they need to achieve, and the consequences of uncontrolled diabetes. This encouraged some of the patients to start to do their own research on diabetes as well as practising self-care such as eating proper diet, doing exercises, taking their medicines as directed and checking their blood glucose level at home.

12 patients in this study scored high health literacy for scale 9 (see Table 3.4) which means that they were able to understand all written (including numerical information) in relation to their health and able to write appropriately on forms when required (Osborne et al., 2013). Therefore, continuous support and education from pharmacists and other healthcare providers needs to be provided to patients who are positive and committed to improve their diabetes outcomes for them to stay consistent, well and safe. Different strategies can be taken to ensure patient stay empowered such as offering patient-centred counselling, providing good health literacy environment during patient counselling and improving accessibility to patients' choice of healthcare providers. Having say that, to increase diabetes patients' self-awareness, healthcare providers such as pharmacists especially in community pharmacies should be trained and educated with the skills and knowledge to manage diabetes such as in DMTAC, medical nutrition therapy, weight loss management and exercise regime to enhance their role in providing diabetes self-management advice. Also, health literacy training needs to be introduced to pharmacy students and professionals to assist them to communicate

effectively using health literacy sensitive communication which is crucial to patient empowerment.

6.6 Strengths and limitations

To my knowledge this is the first study that explores the perceptions and views of newly diagnosed T2DM and pre-diabetes patients as well as pharmacists on health literacy and self-care in Malaysia. I also believe this is the first study to provide a better understanding of what empowers diabetes patients to adopt self-care measures in order to improve their diabetes outcomes. In addition, the study also focuses on pharmacists' perceptions which I believe was not focused on before this. By understanding what patients need especially for those who are newly diagnosed will help in improving the current diabetes management policies and interventions and also improve the practice of pharmacists, especially community pharmacists in facilitating other healthcare providers and policymakers in providing diabetes care in primary healthcare.

However, the patient sample recruited for this study does not align with the reported prevalence of diabetes among the ethnic groups. As reported in NHMS 2019, the Indian population had the highest prevalence of diabetes (18.5%), yet no Indian patients were included in the interviews conducted in this study (Institute for Public Health (IPH), 2020). Data from the National Diabetes Registry Report 2020 indicates that the ethnic distribution among the diabetes patients in Malaysia were Malay (59.35%), Chinese (19.42%), Indian (12.98%) and others (8.24%), and there were 60604 Indian patients with diabetes in Selangor and 14515 in Kuala Lumpur (Ministry of Health Malaysia, 2021). The distribution of T2DM patients registered in the health clinics used to recruit patients was not known, making it challenging to ascertain whether the absence of Indian populations in this study reflects their actual prevalence in both areas. Therefore, to address this, future research should aim to obtain more representative sample by ensuring targeted strategies such as exploring areas or healthcare facilities that can provide maximum variation in terms of demographic diversity among the individuals with T2DM.

Qualitative research is a useful approach to use when trying to understand people’s views and experiences. Due to the pandemic, the methods used to collect the data of this study were mainly done through online and telephone interviews. Online interviews used to be viewed as a “poor” substitute to face-to-face interviews due to number of reasons, but now they are increasingly viewed as a different type of method of interviewing and regarded as an extension of the traditional method rather than replacing it (Braun & Clarke, 2013a). I found that when conducting the interviews and focus group online, I was able to overcome barriers around geographical distance, and time and cost involved in travelling to meet participants. I was able to recruit participants from various states in Malaysia including from East Malaysia and thus, more people could be reached including those who may have disability problems and mobility issues. Conducting the interviews online or via telephone could also increase the participation of people who may have concerns about anonymity and people who would normally not participate if it were done face-to-face due to shyness or lack of confidence. Other that than, online interviews also offer the flexibility to both researchers and participants as they can be done at any time and at the comfort of participants own homes or at a location of their choice (Ahmad Azhari et al., 2022).

Nevertheless, using technology could posed a number of risks and consequences and there were challenges faced when conducting the interviews online in this study. Some of the challenges faced include technological issues such as participants’ level of technological competence and problem in accessing high-speed internet connection, getting the right timing to conduct the interviews, developing rapport and missing non-verbal cues and eye contact. One of the steps that I have taken to overcome these challenges include simplifying the interaction by giving participants the choice to choose the interview platform which they are familiar with, for example, using telephone interview. To ensure flexibility and convenience, most of the interviews were conducted in the evenings and at weekends at a mutually agreed date and time, and reminders were sent to participants via WhatsApp messenger one to two days before the interview day and a few hours before the session starts on the day of the interview. Open and honest conversation between researchers and participants is crucial in qualitative research for rapport building. Internet communication can be viewed as an impersonal and detached form of social communication and there are concerns on how rapport is developed due to lack of visual cues and eye contact. To overcome this in this study, I started off my interviews with easy and soft opening questions to warm up the interactions. I also found that exchanging WhatsApp messages with the participants prior to the interview helped in developing the connection with them beforehand. The participants in this study were also given the choice to use video or just voice and most of the participants preferred not to switch on their videos and therefore, these interviews closely resembled telephone interviews. Though it is quite difficult to express attentiveness online through non-verbal communications such as nodding or eye contact, unless the video is on, it could be expressed through verbal cues such as “mhm”, use a different tone of voice or repeat certain words or phrases for emphasis. This is to signal to the participants that we are listening to what they have to say. Rapport development is possible online, but it may take more time compared to in-person interviews and therefore, researchers need to have effective training in place to ensure they are sufficiently skilled and prepared to take time to engage in effective rapport development (Shapka et al., 2016).

Diabetes management involves a complex interaction of multidisciplinary team of different healthcare providers. However, in this study, only the views and experiences of pharmacists from different sectors were considered. In interviews with patients, many mentioned that they interacted a lot with doctors, nurses and dietitians, during consultation. Because they are newly diagnosed patients, some of them were not required medication for their treatment. Therefore, to capture the overall understanding of the importance of health literacy in diabetes self-care empowerment, other healthcare providers', for example, doctors, dietitians and nurses, perceptions need to be explored too. This will provide us with the overall understanding of what needs to be improved in the healthcare system to increase accessibility and support required by diabetes patients especially those with low health literacy.

The HLQ used in this study to evaluate patients' health literacy comprised of 44 items, with participants spending approximately 12 minutes to complete it online. Among the 15 patients recruited from the two health clinics, 7 patients chose to complete the questionnaire online at their own time. Addressing the responses from the pharmacists in this study, the tools or questionnaire used for assessing patients' health literacy in practical settings should be simple and easy to administer. This is important to ensure patients are comfortable to be assessed without taking a lot of their time and feel that they are being judged. Nevertheless, the HLQ results obtained from this study provide us with better insights into the health literacy strengths and limitations of the newly diagnosed diabetes patients in this study. The data obtained can be used to develop and select suitable response strategies to improve equity in diabetes outcomes and access. However, due to the small sample size and the lack of focus on the association between the HLQ scores and the demographic characteristics of the patients in this study, the results obtained may make it difficult to determine if a particular outcome is a true finding. This limitation not only affects the generalisability of the results to the larger population but also restricts the opportunity for triangulation with the qualitative findings of this study. Therefore, the limitations of this study mentioned above may have opened up potential areas that could be explored and researched in the future.

6.7 Practical implications and recommendations

The findings of this study provide insight into key areas in which diabetes patients can be supported to access, understand and use diabetes information for self-care empowerment, and have implications for pharmacists and pharmacy practice seeking to improve patients' diabetes outcomes and increase diabetes awareness among the public. This section discusses the implications of this study for diabetes patients, healthcare providers and the healthcare system, as well as what else can be done to improve diabetes self-care management in Malaysia.

6.7.1 Implications and recommendations for the practice

From this study, it was found that several patients struggled to maintain their glycaemic control and practice self-care due to various reasons including low health literacy. As they were newly diagnosed with T2DM or pre-diabetes, many patients in this study also struggled to accept the diagnosis which led them to feel scared and worried about their future. This may have negative consequences as patients might feel unsupported and no empowerment to self-care management. Additionally, some of the patients mentioned that they lack accessibility to reliable health information and health services required to help in controlling their blood glucose levels in terms of diet, exercise and medication adherence. Because of this, many patients solely rely on the information received from one source and faced difficulties to apply the health information received in their day-to-day life.

Limited access and understanding of diabetes and its management could lead to treatment failure and the development of diabetes complications. This consequently can affect diabetes patients' quality of life, increase hospitalisation and healthcare cost as well as higher mortality rate. Therefore, all newly diagnosed patients should be offered psychological support to help them cope with the diagnosis and the complex management of diabetes. Diabetes education from different diabetes educators such as the doctors, pharmacists, dietitians, podiatrists, nurses and ophthalmologists should be offered at the earliest opportunity after diagnosis to support and educate patients on diabetes management to make patients aware of the progressive nature of T2DM and the importance of self-care management.

Services such as DMTAC (Iqbal et al., 2021; Lee et al., 2015; Lim & Lim, 2010) has been proven by various studies to be a highly effective resource that has benefited many diabetes patients who struggled to maintain good glycaemic control. Therefore, the service should be expanded to include patients who are newly diagnosed with T2DM and pre-diabetes, regardless of their HbA1c status, and also to patients who have low health literacy. This can be achieved by changing the criteria set by the Pharmacy Service Division on who can be referred to DMTAC or introduce a new programme which focuses only on newly diagnosed patients. Additionally, public-private partnership collaborating with community pharmacies can be established to deliver the service, thereby alleviating the burden on public healthcare facilities. Another effective approach that has also proved to be beneficial in diabetes management by several studies (Brownson & Heisler, 2009; Mohebi et al., 2013; Shariff-Ghazali et al., 2015; Siopis et al., 2021; Van der Wulp et al., 2012) would be to introduce a peer support programme in clinics and hospitals to provide additional support to newly diagnosed diabetes patients especially those with low health literacy as they navigate their diabetes journey. By connecting them with individuals who have experiences dealing with the similar challenges and successes in managing diabetes, these individuals can be empowered to practise self-care in their daily lives.

6.7.2 Implications and recommendations for the healthcare system

Health literacy is recognised as an important indicator of outcomes and costs in healthcare (Osborne et al., 2013; Sørensen et al., 2012). Patients with adequate and high health literacy can access, understand and apply health information better compared to patients who possess low health literacy. With adequate to high health literacy, diabetes patients may be empowered to adopt self-care measures as they are able to understand and interpret information given to them by healthcare providers. It is not easy to change patients' health literacy levels as we need to take into consideration patients' socio-demographic status such as level of education, age, gender, ethnicity and employment status. As recommended in NHMS 2019, health literacy enhancement and intervention programme should focus on those with no formal or lower education levels, unemployed, the elderly and B40 (lower) income groups (Institute for Public Health (IPH), 2020). However, to implement this requires extensive and collaborative work from various government agencies such as the Ministry of Health, Ministry of Education and Ministry of Women, Family and Community Development.

In NHMS 2015, it was recommended that healthcare providers must be knowledgeable, aware and responsive to patients with low health literacy levels, and there is a need to intensify multidisciplinary research and health promotion on the importance of adequate health literacy (Institute for Public Health (IPH), 2015). Due to difficulty of assessing patients' health literacy without a standardised assessment tool in practice, healthcare providers need to communicate with patients without pre-conceived judgement of their health literacy to ensure patients are receiving sufficient access to and understanding of health information. All healthcare providers should be trained to communicate with patients using literacy-sensitive techniques as discussed in section 5.3.3 so that they are aware and responsive to the needs of the patients regardless of their health literacy status.

The impact of treating uncontrolled diabetes and diabetes complications on both the healthcare system and the economy are hugely substantial (Ganasegeran et al., 2020). It is reported that the national economic burden for T2DM in Malaysia was estimated to be USD 600 million and it is said that the estimation was underestimated due to limited studies conducted (Ganasegeran et al., 2020). As discussed in section 4.3.2, most patients in this study were unaware that they have diabetes until they went to have a blood glucose check or developed symptoms that they recognised. As a result, most patients have developed hyperglycaemia by the time they seek for medical assistance. In order to increase public awareness, a nationwide campaign to recognise the signs and symptoms of diabetes and the benefits of early detection and intervention should be conducted in all healthcare facilities including the pharmacies. This will consequently increase public awareness to blood glucose screening in the primary healthcare level. Early detection of high blood glucose level can help to prevent diabetes progression and therefore, reducing the costs and burden to the healthcare system.

6.7.3 Implications and recommendations for the pharmacy profession

Pharmacists are seen as highly accessible and well-trained healthcare provider, but they are underutilised by the public (Smith, 2009). The findings in this study showed that patients perceived pharmacists as experts in medicines and only capable of giving advice on medications. Pharmacists who were interviewed in this study also expressed the similar view where they felt that the public perception of their role is limited to dispensing medications only. However, it is evident from this study that pharmacists could do more than just dispensing medicines. Pharmacists who are working in public health clinics and hospitals are providing various services such as diabetes counselling and education.

Community pharmacies are easily accessible by everyone, and they have different services offered such as blood glucose, blood pressure and cholesterol checks, medicines reviews and provide minor ailments advice. In Malaysia, most anti-diabetic agents are classed as Group B which is equivalent to prescription only medicine in UK, and some agents for example, metformin, gliclazide and insulin are classed as Group C, which is equivalent to pharmacy medicine in UK. Practically community pharmacists are able to supply metformin or gliclazide to patients or customers after a blood glucose screening and provide diabetes counselling when they visit the pharmacy. Despite that, the public still perceived community pharmacists as “retailers” and will not go into community pharmacies for health advice. A study that explored the views of patients on the role of community pharmacists in diabetes support and education found that generally patients were receptive to the involvement of community pharmacists in diabetes management (Lee et al., 2018). Nevertheless, several challenges were identified in implementing such services such as cost for the service, the scepticism of the accuracy of information provided by community pharmacists and lack of awareness of the roles and responsibilities of a community pharmacist (Lee et al., 2018). The misconception of the role of pharmacists especially community pharmacists among public observed in this study and other studies conducted raised the importance to develop an intervention to improve public awareness of the role of pharmacists in Malaysia.

With the increasing prevalence of NCDs in Malaysia, the Ministry of Health has responded by developing and implementing the "National Strategic Plan for Non-Communicable Diseases (NSP-NCD) 2010 – 2014" with an updated version which is called NSP-NCD 2016 – 2025. In the plan, the MOH has initiated an intervention programme to empower Malaysians through KOSPEN (*KOmuniti Sihat PEmbina Negara* – Healthy Communities, Building the Nation) where the aim was to empower the Malaysian population to take more responsibility on their own health status by creating trained health volunteers who will function as "agents of change" that facilitate healthy living practices amongst their respective community (Ministry of Health Malaysia, 2016). To make this programme successful, the involvement of community pharmacists should be included as they are resourceful and easily accessible by the community. However, none of the community pharmacists interviewed in this study mentioned this programme or their involvement to empower their communities. In March 2023, the Diabetes Lifestyle Programme (DLP) was launched as an integral part of standard diabetes management practices to improve treatment outcome and reduce diabetes burden on patients, families, healthcare system and the economy. The objectives of the programme are to train healthcare providers to become diabetes lifestyle advocates, to empower patients with the knowledge, skills, attitudes and self-awareness to change their lifestyle and to facilitate the implementation of the programme in all healthcare settings especially at the primacy care level (Ignatius, 2023). Though it is a new programme that has just been launched, it is imperative that all and future national health programmes should incorporate pharmacists especially community pharmacists as they are at the heart of the communities that they served.

Pharmacists in this study recognised their capacity to provide quality diabetes care, but they also acknowledged that more support and training in self-care management and health literacy is needed for them to provide more holistic care to diabetes patients.

6.8 Future work

The findings of this study have helped to understand the dynamics involved in counselling and educating newly diagnosed T2DM and pre-diabetes patients in Malaysia to self-care empowerment. It has also highlighted the inadequacy in our healthcare system in supporting diabetes patients throughout their treatment journey. As a result, there is a need to further explore these shortcomings and further research is required to measure and evaluate diabetes counselling sessions conducted by other healthcare providers such as dietitians and doctors. In addition, the introduction of DMTAC service in community pharmacies conducted by community pharmacists should be explored and investigated to assess its impact to patient access and overall diabetes outcomes. This will contribute valuable insights into gaps, challenges and effectiveness of the service in community pharmacies.

Furthermore, as reported by Abdullah et. al (2020), published articles in the field of health literacy in Malaysia especially among T2DM patients are still limited and hence, more research is required in this field (Abdullah et al., 2020). There is also the need to develop a locally well-validated health literacy assessment tool appropriate for the Malaysian population to enable better measurement of the health literacy levels and comparison across countries (Abdullah et al., 2020; Institute for Public Health (IPH), 2020). This will enable us to gather accurate data and insights that can inform effective healthcare strategies and interventions that meet the unique needs of Malaysian population. The development of a simple to use, and accessible assessment tool is required for all healthcare providers to have access to and use in their daily interactions with patients to enable them to conduct an effective patient-centred counselling. The tool or questionnaire developed also needs to be simple, user-friendly, and, importantly, it should be designed to be non-time-consuming and unbiased.

Improving health literacy levels among Malaysians is also key to improve people's quality of life and to reduce the prevalence of NCDs such as diabetes, hypertension and obesity in Malaysia. Health literacy research requires collaboration from different stakeholders as it involves complex interaction between patients, healthcare providers, educators and policymakers. With the input of various experiences and knowledge from different stakeholders, conducting health literacy research can help in identifying gaps in health literacy among Malaysian population, developing interventions to address these gaps, and evaluating the effectiveness of these interventions in practice.

Another area worthy of research is digital health literacy. In recent years, the rise of mobile health (mHealth) and the growing utilisation of digital health services by healthcare organisations have expanded people's access to health services and health information online or electronically (Smith & Magnani, 2019). However, as seen in this study, not everyone possesses the ability and skills to access, understand and use digital health services effectively. Inadequate digital health literacy can lead to difficulties in navigating online healthcare services, resulting in disparities in healthcare access and outcomes (Smith & Magnani, 2019). Therefore, further research is needed in the field of digital health literacy to evaluate the feasibility of digital health services for all individuals. The assessment of patients' digital health literacy also requires investigation to address challenges and disparities experienced by individuals, thereby improving access to digital health services for everyone.

Lastly, as indicated by the pharmacists in this study, more work needs to be done to educate them and other healthcare providers on health literacy and diabetes self-care management. The introduction of a health literacy theme both in pharmacy undergraduate programmes and continuing pharmacist education needs to be implemented and researched to provide pharmacy students and professionals with the exposure to recognise patients with low health literacy and to communicate effectively using literacy sensitive techniques. The advancement of continuing pharmacist education on diabetes self-care management especially in diet and exercise also needs to be investigated to upskill pharmacists in delivering diabetes care confidently.

6.9 Conclusion

This study has helped to identify the needs of newly diagnosed T2DM and pre-diabetes patients to empower them to self-care behaviours. It has also identified the expanding role of pharmacists in motivating and empowering diabetes patients to practise self-care in managing their diabetes. The voices of the patients heard in this study needs to be considered by policymakers to improve the quality of diabetes care provided in the country. With the increasing trend of overall diabetes prevalence in Malaysia, the enhancement of support and education for newly diagnosed T2DM and pre-diabetes patients is required to improve self-awareness and to prevent the progression of the condition. The exploration of health literacy strengths and limitations among the patients in this study has highlighted the necessity to improve access to diabetes care in Malaysia. Improving the accessibility of diabetes patients to health information and health services, for example, allowing them to choose their preferred healthcare providers or encouraging patients to ask questions, is crucial. This not only promotes patient-centred care and self-care empowerment but also helps in enhancing patient knowledge. The ability to access information and make informed choices about their diabetes care contributes significantly to patients' understanding of their condition and active participation in their health management.

Regarding pharmacists, the study highlights the significant role of pharmacists in empowering newly diagnosed diabetes patients to self-care management. Their involvement in the multidisciplinary healthcare team especially community pharmacists should be recognised and supported in order to increase the accessibility of patients to diabetes care at primary care level. Overall, pharmacists are well positioned to help in reducing the prevalence of diabetes through patient empowerment and improving patient's health literacy. However, they require support, resources and training in self-care and health literacy to maximise their impact. The misconceptions of the public towards the role of pharmacists also needs to be addressed and improved through health promotion campaigns that highlight the role of pharmacist in diabetes screening and education.

In conclusion, the findings of this study offer valuable insights contributing to a more holistic understanding of the challenges and opportunities in diabetes care, particularly among newly diagnosed patients and the crucial role of pharmacists. The recommendations provided emphasise the potential for positives change in healthcare practices, focusing on patient empowerment, improved health literacy and enhanced collaboration with healthcare providers, particularly community pharmacists, to effectively tackle the growing burden of diabetes.

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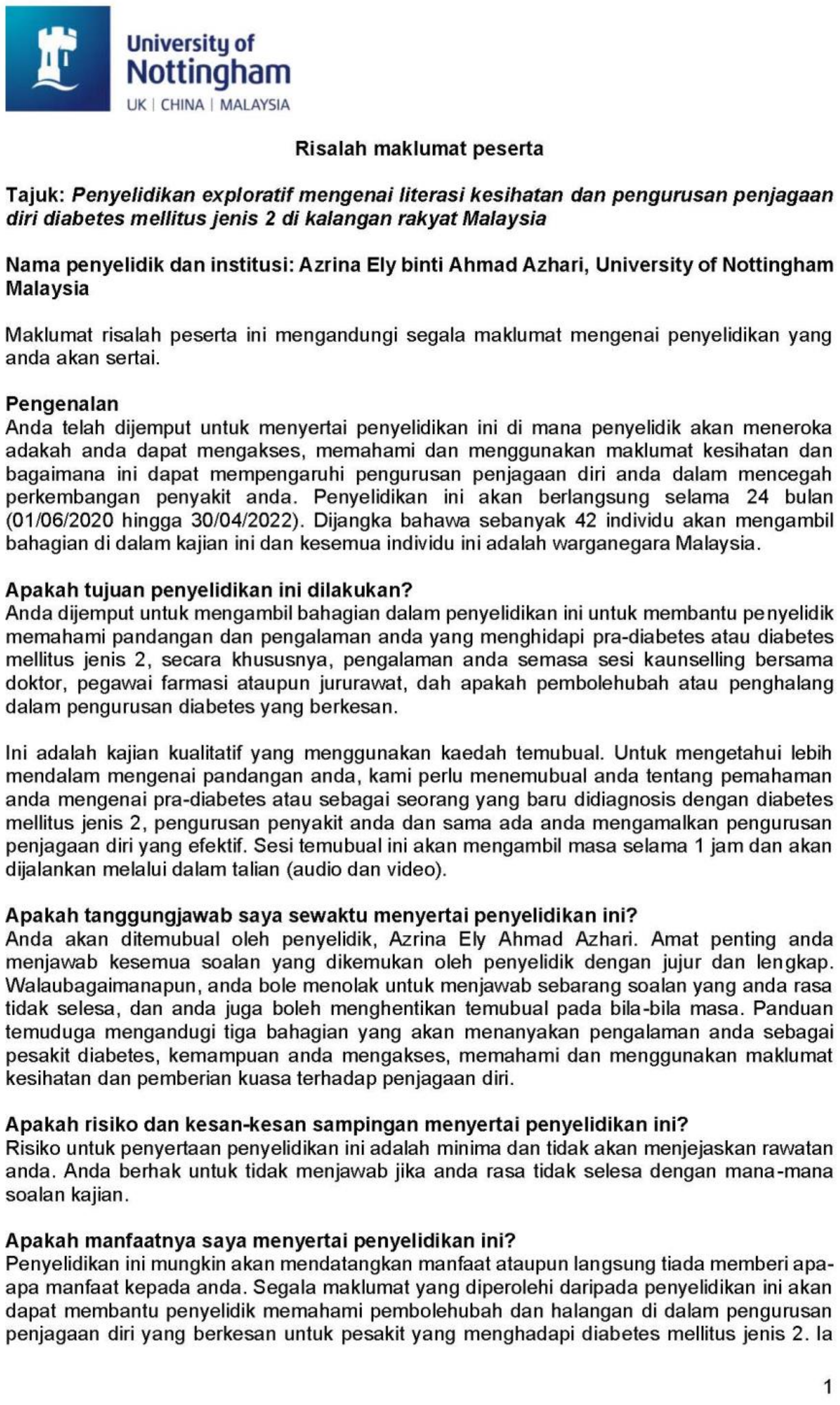
Appendices

Appendix 1: Patient information sheet (Malay)



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Risalah maklumat peserta

Tajuk: *Penyelidikan exploratif mengenai literasi kesihatan dan pengurusan penjagaan diri diabetes mellitus jenis 2 di kalangan rakyat Malaysia*

Nama penyelidik dan institusi: Azrina Ely binti Ahmad Azhari, University of Nottingham Malaysia

Maklumat risalah peserta ini mengandungi segala maklumat mengenai penyelidikan yang anda akan sertai.

Pengenalan

Anda telah dijemput untuk menyertai penyelidikan ini di mana penyelidik akan meneroka adakah anda dapat mengakses, memahami dan menggunakan maklumat kesihatan dan bagaimana ini dapat mempengaruhi pengurusan penjagaan diri anda dalam mencegah perkembangan penyakit anda. Penyelidikan ini akan berlangsung selama 24 bulan (01/06/2020 hingga 30/04/2022). Dijangka bahawa sebanyak 42 individu akan mengambil bahagian di dalam kajian ini dan kesemua individu ini adalah warganegara Malaysia.

Apakah tujuan penyelidikan ini dilakukan?

Anda dijemput untuk mengambil bahagian dalam penyelidikan ini untuk membantu penyelidik memahami pandangan dan pengalaman anda yang menghidapi pra-diabetes atau diabetes mellitus jenis 2, secara khususnya, pengalaman anda semasa sesi kaunselling bersama doktor, pegawai farmasi ataupun jururawat, dah apakah pembolehubah atau penghalang dalam pengurusan diabetes yang berkesan.

Ini adalah kajian kualitatif yang menggunakan kaedah temubual. Untuk mengetahui lebih mendalam mengenai pandangan anda, kami perlu menemubual anda tentang pemahaman anda mengenai pra-diabetes atau sebagai seorang yang baru didiagnosis dengan diabetes mellitus jenis 2, pengurusan penyakit anda dan sama ada anda mengamalkan pengurusan penjagaan diri yang efektif. Sesi temubual ini akan mengambil masa selama 1 jam dan akan dijalankan melalui dalam talian (audio dan video).

Apakah tanggungjawab saya sewaktu menyertai penyelidikan ini?

Anda akan ditemubual oleh penyelidik, Azrina Ely Ahmad Azhari. Amat penting anda menjawab kesemua soalan yang dikemukan oleh penyelidik dengan jujur dan lengkap. Walaubagaimanapun, anda bole menolak untuk menjawab sebarang soalan yang anda rasa tidak selesa, dan anda juga boleh menghentikan temubual pada bila-bila masa. Panduan temuduga mengandugi tiga bahagian yang akan menanyakan pengalaman anda sebagai pesakit diabetes, kemampuan anda mengakses, memahami dan menggunakan maklumat kesihatan dan pemberian kuasa terhadap penjagaan diri.

Apakah risiko dan kesan-kesan sampingan menyertai penyelidikan ini?

Risiko untuk penyertaan penyelidikan ini adalah minima dan tidak akan menjejaskan rawatan anda. Anda berhak untuk tidak menjawab jika anda rasa tidak selesa dengan mana-mana soalan kajian.

Apakah manfaatnya saya menyertai penyelidikan ini?

Penyelidikan ini mungkin akan mendatangkan manfaat ataupun langsung tiada memberi apa-apa manfaat kepada anda. Segala maklumat yang diperolehi daripada penyelidikan ini akan dapat membantu penyelidik memahami pembolehubah dan halangan di dalam pengurusan penjagaan diri yang berkesan untuk pesakit yang menghadapi diabetes mellitus jenis 2. Ia

1

juga dapat membantu dalam meningkatkan kualiti penyampaian kaunselling bagi mencegah atau menangguhkan perkembangan penyakit, dan juga meningkatkan tahap pengurusan penyakit.

Siapakah yang membiayai penyelidikan ini?
Penyelidikan ini adalah ditaja sendiri. Anda akan diberi token di dalam bentuk baucar bernilai RM40.00 sebagai tanda penghargaan penyertaan anda dalam penyelidikan ini.

Adakah saya perlu mengambil bahagian?
Penyertaan anda dalam penyelidikan ini adalah secara sukarela. Anda tidak perlu menyertai penyelidikan ini sekiranya anda tidak mahu. Anda juga mempunyai hak untuk tidak menjawab mana-mana soalan yang anda tidak mahu jawab. Anda juga boleh menarik diri daripada penyelidikan ini pada bila-bila masa sahaja. Jika anda menarik diri, segala maklumat yang telah diperolehi sebelum anda menarik diri tetap akan digunakan dalam penyelidikan ini. Jika anda tidak mahu menyertai ataupun menarik diri dari penyelidikan ini, tindakan anda tidak akan menjejaskan segala hak dan keistimewaan perubatan kesihatan yang selayaknya anda terima.

Penyertaan penyelidikan ini melibatkan anda ditemubual oleh penyelidik, dan ini akan mengambil masa sekitar 1 jam. Temubual akan direkodkan secara rakaman audio dan video dan akan ditranskripsikan. Maklumat daripada temubual anda akan dimasukkan ke dalam pernerbitan seperti laporan penyelidikan tanpa mendedahkan identiti anda. Anda bebas untuk menarik diri daripada temubual ini pada bila-bila masa tanpa memberi sebarang alasan. Sekiranya anda bersetuju untuk mengambil bahagian, anda akan menerima maklumat risalah ini untuk disimpan dan anda diminta untuk menandatangani borang persetujuan penyertaan.

Bolehkah penyelidikan ataupun penyertaan saya ditamatkan lebih awal daripada yang dirancang?
Penyelidik boleh menamatkan penyelidikan ini ataupun menamatkan penyertaan anda dalam penyelidikan ini pada bila-bila masa, jika ia perlu demi keselamatan anda atau kekurangan dalam pengambilan individu untuk ditemubual atau ketidakupayaan untuk menjalankan kajian. Jika penyelidikan ini dihentikan terlebih awal, di atas sebab-sebab tertentu, anda akan dimaklumkan dan rawatan yang bakal anda terima selepas itu tidak akan terjejas.

Adakah maklumat yang dikumpul akan dirahsiakan?
Segala maklumat anda yang diperolehi dalam penyelidikan ini akan disimpan dan dikendalikan secara sulit, bersesuaian dengan peraturan-peraturan dan/atau undang-undang yang berkenaan. Hanya penyelidik yang akan mempunyai akses kepada maklumat peribadi anda dan data kajian. Sekiranya hasil penyelidikan ini diterbitkan atau dibentangkan kepada orang ramai, identiti anda tidak akan didedahkan tanpa kebenaran anda terlebih dahulu. Transkripsi maklumat akan disimpan di dalam laci dan pejabat berkunci dan akan disimpan selama enam tahun untuk rujukan masa hadapan bagi tujuan penerbitan laporan sahaja, di mana selepas tempoh ini, maklumat transkripsi ini akan dimusnahkan dengan sewajarnya. Pihak-pihak tertentu seperti individu yang terlibat dalam penyelidikan ini, juruaudit dan jurupantau yang terlatih, pihak berkuasa kerajaan atau undang-undang, boleh memeriksa maklumat atau data kajian jika diperlukan.

Perkongsian maklumat kesihatan anda
Doktor anda atau mana-mana pihak ketiga tidak akan menerima sebarang maklumat daripada penyelidikan ini. Maklumat yang diperolehi dari penyelidikan ini tidak akan dimasukkan ke

dalam rekod perubatan anda atau digunakan untuk rawatan perubatan anda kecuali jika ia dinyatakan.

Apakah akan berlaku kepada data kajian?
Maklumat yang dikumpul akan digunakan untuk membantu kami merancang penyelidikan dan penyediaan perkhidmatan pada masa hadapan. Anda juga boleh mendapatkan ringkasan kajian jika anda mahu,

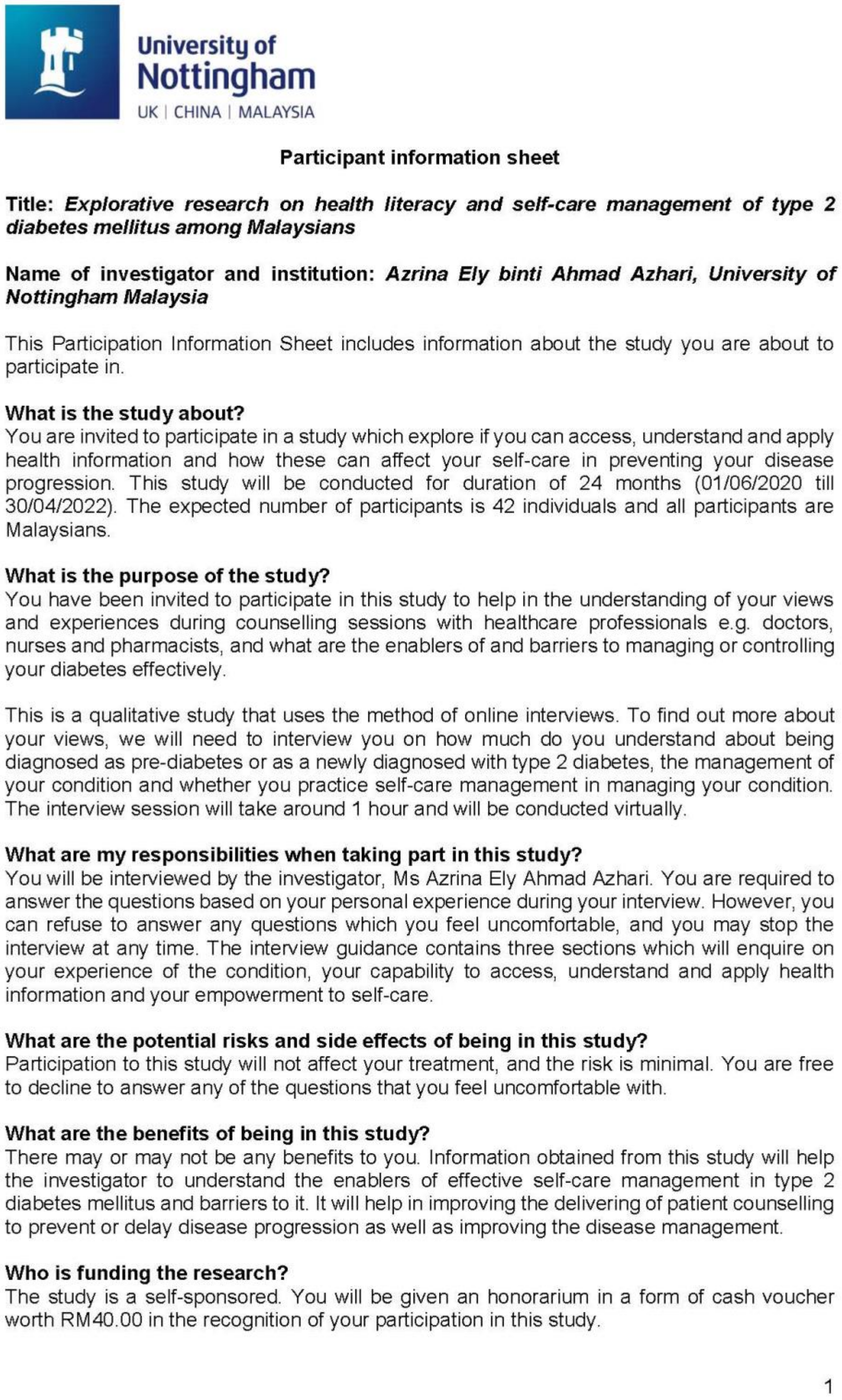
Apakan prosedurnya?
Anda perlu menandatangani 'Borang Persetujuan Peserta' dan memastikan bahawa anda telah membaca and memahami semua maklumat yang telah diberikan kepada anda dan anda bersetuju untuk mengambil bahagian dalam penyelidikan ini. 'Borang Penyertaan Peserta' akan disimpan dan dikendalikan secara sulit.

Terima kasih terlebih dahulu diatas bantuan anda terhadap penyelidikan ini.

Siapakah yang perlu saya hubungi sekiranya saya mempunyai sebarang pertanyaan?
Jika anda mempunyai sebarang pertanyaan mengenai penyelidikan ini, sila hubungi penyelidik, Azrina Ely Ahmad Azhari, melalui emel di *hyxaa1@nottingham.edu.my* atau melalui talian telefon di 017-2553005; atau penyelia penyelidik, Dr Jim Chai, melalui emel di *Jim.Chai@nottingham.edu.my*

Jika anda mempunyai sebarang pertanyaan berkaitan hak-hak anda sebagai peserta dalam penyelidikan ini, sila hubungi Setiausaha, Jawatankuasa Etika & Penyelidikan Perubatan, Kementerian Kesihatan Malaysia, melalui talian telefon di 03-3362 8407/8205/8888.

Appendix 2: Patient information sheet (English)



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Participant information sheet

Title: ***Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians***

Name of investigator and institution: ***Azrina Ely binti Ahmad Azhari, University of Nottingham Malaysia***

This Participation Information Sheet includes information about the study you are about to participate in.

What is the study about?
You are invited to participate in a study which explore if you can access, understand and apply health information and how these can affect your self-care in preventing your disease progression. This study will be conducted for duration of 24 months (01/06/2020 till 30/04/2022). The expected number of participants is 42 individuals and all participants are Malaysians.

What is the purpose of the study?
You have been invited to participate in this study to help in the understanding of your views and experiences during counselling sessions with healthcare professionals e.g. doctors, nurses and pharmacists, and what are the enablers of and barriers to managing or controlling your diabetes effectively.

This is a qualitative study that uses the method of online interviews. To find out more about your views, we will need to interview you on how much do you understand about being diagnosed as pre-diabetes or as a newly diagnosed with type 2 diabetes, the management of your condition and whether you practice self-care management in managing your condition. The interview session will take around 1 hour and will be conducted virtually.

What are my responsibilities when taking part in this study?
You will be interviewed by the investigator, Ms Azrina Ely Ahmad Azhari. You are required to answer the questions based on your personal experience during your interview. However, you can refuse to answer any questions which you feel uncomfortable, and you may stop the interview at any time. The interview guidance contains three sections which will enquire on your experience of the condition, your capability to access, understand and apply health information and your empowerment to self-care.

What are the potential risks and side effects of being in this study?
Participation to this study will not affect your treatment, and the risk is minimal. You are free to decline to answer any of the questions that you feel uncomfortable with.

What are the benefits of being in this study?
There may or may not be any benefits to you. Information obtained from this study will help the investigator to understand the enablers of effective self-care management in type 2 diabetes mellitus and barriers to it. It will help in improving the delivering of patient counselling to prevent or delay disease progression as well as improving the disease management.

Who is funding the research?
The study is a self-sponsored. You will be given an honorarium in a form of cash voucher worth RM40.00 in the recognition of your participation in this study.

Do I have to participate?
Your participation is entirely voluntary, and it is up to you to decide whether or not to take part. You do not have to participate in this study if you do not want to. You may also refuse to answer any questions you do not want to answer. If you volunteer to be in this study, you may withdraw at any time. If you withdraw, any data collected from you up to your withdrawal will still be used for the study. Your refusal to participate or withdrawal will not affect any medical or health benefits to which you are otherwise entitled.

Participation in this study involve being interviewed by the researcher, and it will take around 1 hour. The interview will be audio or video recorded and later transcribed and you may be quoted anonymously in publications e.g. reports and published papers. Even if you decide to be interviewed and recorded, you are free to withdraw at any time, without giving any reason. If you decide to take part, you will receive this information sheet to keep and you will be asked to sign a consent form.

Can the research or my participation be terminated early?
The investigator may due to concerns for your safety or lack of recruitment or inability to sustain or further manage the study, stop the study or your participation at any time. If the study is stopped early for any reason you will be informed, and this will not in any way affect your medical care.

Will the collected data be treated confidentially?
All information collected from you will be kept strictly confidential and stored in a database which will be password protected. Only the principal investigator will have access to your personal information and study data. Any information about you which leaves the research unit will be anonymous (all identifying information removed). Your data will be saved under a number (ID), which cannot be tracked back to you. Transcription will be stored in a locked office belonging to the researcher and maintained for six years for future reference for the purpose of publication of reports or peer reviewed publications, whereby after this period it will be professionally destroyed. When publishing or presenting the study results, your identity will not be revealed without your expressed consent. Individuals involved in this study, qualified monitors and auditors, and governmental or regulatory authorities may inspect study data, where appropriate and necessary.

Sharing your health information with others
Neither your doctor nor any third party will receive information from this study. Research information from this study will not be placed in your medical record or used for your medical care unless specifies by the project.

What will happen to the study data?
The information that you provide will be used to help us plan future research and service provision in this area. You will also be able to request a summary of the study.

What is the procedure?
Sign the 'Participant Consent Form' ensuring that you have read and understood all the information provided to you and that you agree to participate in this study. The 'Participant Consent Form' will be held securely and all information contain therein will be kept strictly confidential.

Thank you in advance for your interest and assistance with this research.

Who should I call if I have questions?

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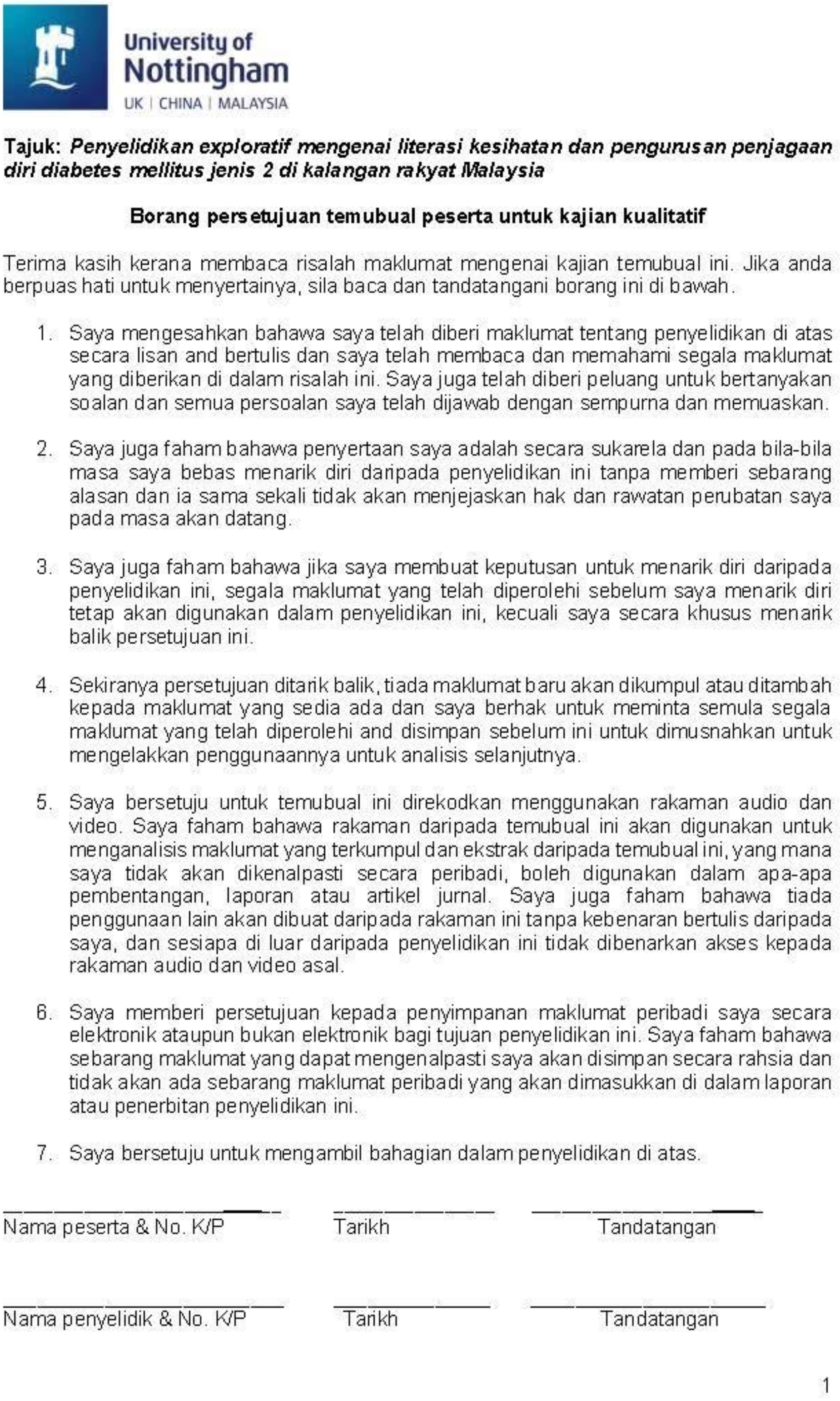
If you have any questions regarding this research, please contact the researcher, Azrina Ely Ahmad Azhari, via email at hyxaa1@nottingham.edu.my or via telephone at 017-2553005; or the supervisor, Dr Jim Chai, via email at Jim.Chai@nottingham.edu.my

If you need further information about your rights as a participant in this study, or if you have any concerns about the study, you can contact The Secretary, Medical Research Ethics Committee, Ministry of Health Malaysia via telephone at 03-3362 8407/8205/8888.

Appendix 3: Consent form (Malay)



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Tajuk: ***Penyelidikan exploratif mengenai literasi kesihatan dan pengurusan penjagaan diri diabetes mellitus jenis 2 di kalangan rakyat Malaysia***

Borang persetujuan temubual peserta untuk kajian kualitatif

Terima kasih kerana membaca risalah maklumat mengenai kajian temubual ini. Jika anda berpuas hati untuk menyertainya, sila baca dan tandatangani borang ini di bawah.

1. Saya mengesahkan bahawa saya telah diberi maklumat tentang penyelidikan di atas secara lisan and bertulis dan saya telah membaca dan memahami segala maklumat yang diberikan di dalam risalah ini. Saya juga telah diberi peluang untuk bertanyakan soalan dan semua persoalan saya telah dijawab dengan sempurna dan memuaskan.

2. Saya juga faham bahawa penyertaan saya adalah secara sukarela dan pada bila-bila masa saya bebas menarik diri daripada penyelidikan ini tanpa memberi sebarang alasan dan ia sama sekali tidak akan menjejaskan hak dan rawatan perubatan saya pada masa akan datang.

3. Saya juga faham bahawa jika saya membuat keputusan untuk menarik diri daripada penyelidikan ini, segala maklumat yang telah diperolehi sebelum saya menarik diri tetap akan digunakan dalam penyelidikan ini, kecuali saya secara khusus menarik balik persetujuan ini.

4. Sekiranya persetujuan ditarik balik, tiada maklumat baru akan dikumpul atau ditambah kepada maklumat yang sedia ada dan saya berhak untuk meminta semula segala maklumat yang telah diperolehi and disimpan sebelum ini untuk dimusnahkan untuk mengelakkan penggunaannya untuk analisis selanjutnya.

5. Saya bersetuju untuk temubual ini direkodkan menggunakan rakaman audio dan video. Saya faham bahawa rakaman daripada temubual ini akan digunakan untuk menganalisis maklumat yang terkumpul dan ekstrak daripada temubual ini, yang mana saya tidak akan dikenalpasti secara peribadi, boleh digunakan dalam apa-apa pembentangan, laporan atau artikel jurnal. Saya juga faham bahawa tiada penggunaan lain akan dibuat daripada rakaman ini tanpa kebenaran bertulis daripada saya, dan sesiapa di luar daripada penyelidikan ini tidak dibenarkan akses kepada rakaman audio dan video asal.

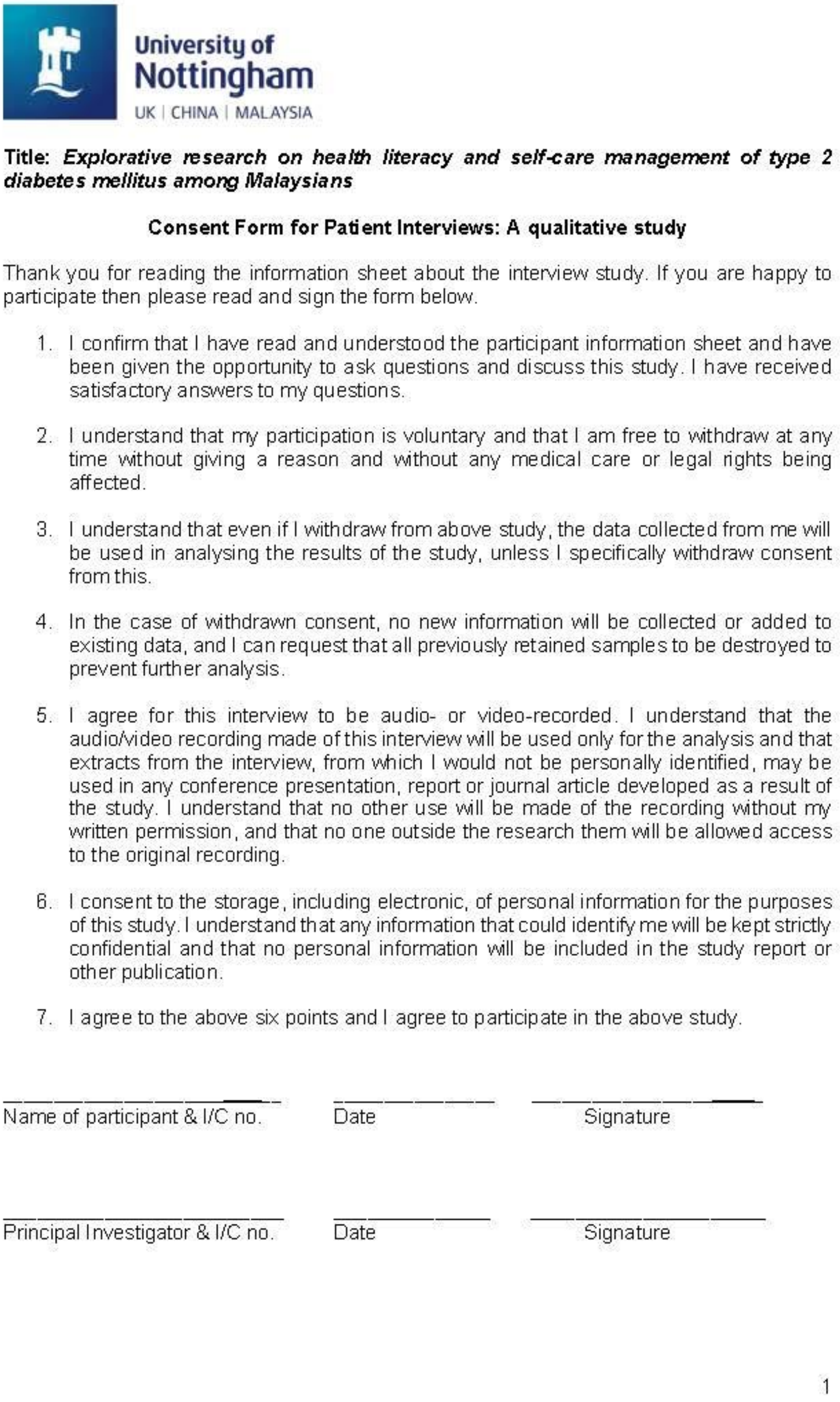
6. Saya memberi persetujuan kepada penyimpanan maklumat peribadi saya secara elektronik ataupun bukan elektronik bagi tujuan penyelidikan ini. Saya faham bahawa sebarang maklumat yang dapat mengenalpasti saya akan disimpan secara rahsia dan tidak akan ada sebarang maklumat peribadi yang akan dimasukkan di dalam laporan atau penerbitan penyelidikan ini.

7. Saya bersetuju untuk mengambil bahagian dalam penyelidikan di atas.

____________________________	________________	______________________
Nama peserta & No. K/P	Tarikh	Tandatangan
____________________________	________________	______________________
Nama penyelidik & No. K/P	Tarikh	Tandatangan

1

Appendix 4: Consent form (English)



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Title: ***Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians***

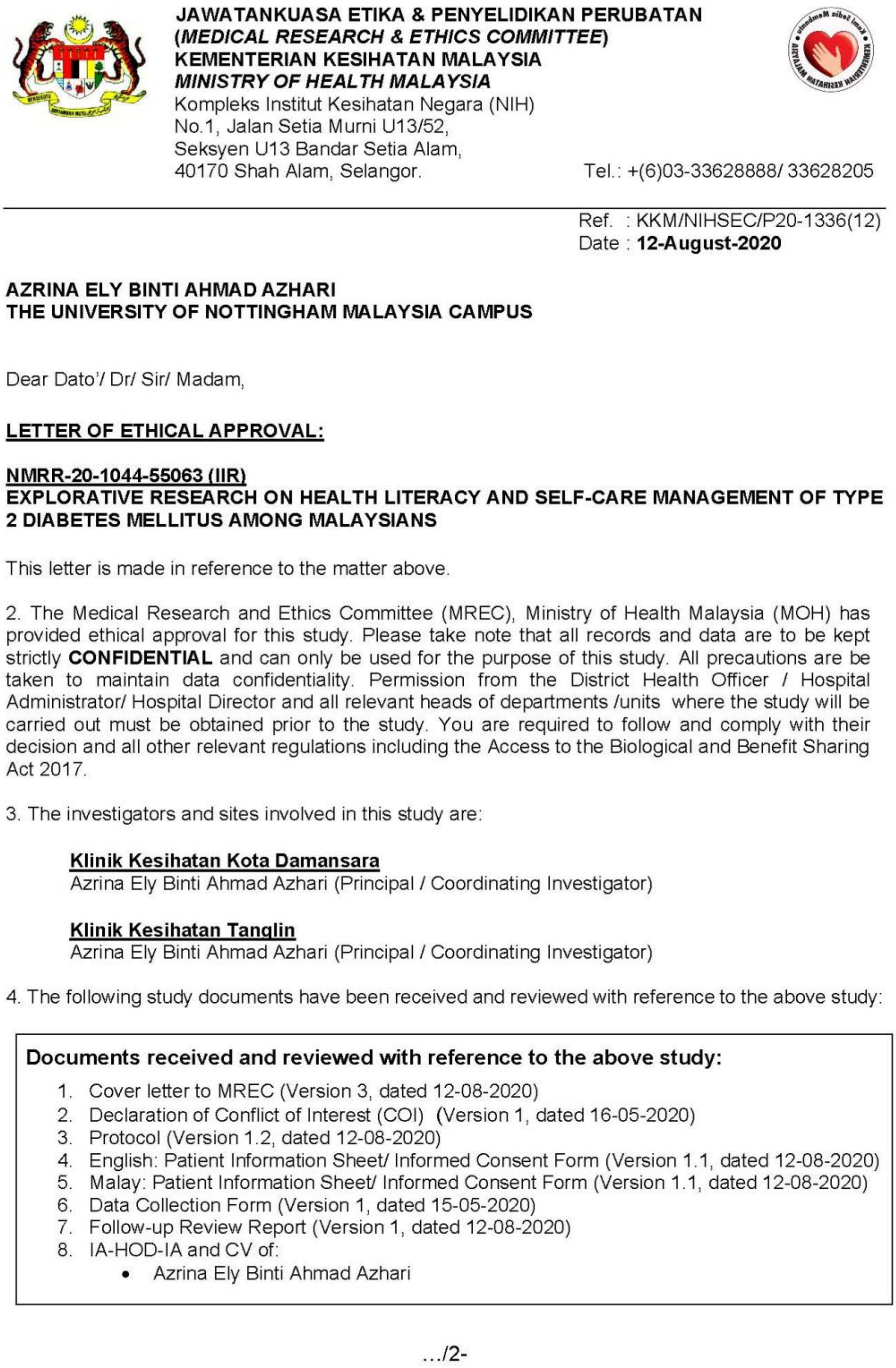
Consent Form for Patient Interviews: A qualitative study

Thank you for reading the information sheet about the interview study. If you are happy to participate then please read and sign the form below.

1. I confirm that I have read and understood the participant information sheet and have been given the opportunity to ask questions and discuss this study. I have received satisfactory answers to my questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without any medical care or legal rights being affected.
3. I understand that even if I withdraw from above study, the data collected from me will be used in analysing the results of the study, unless I specifically withdraw consent from this.
4. In the case of withdrawn consent, no new information will be collected or added to existing data, and I can request that all previously retained samples to be destroyed to prevent further analysis.
5. I agree for this interview to be audio- or video-recorded. I understand that the audio/video recording made of this interview will be used only for the analysis and that extracts from the interview, from which I would not be personally identified, may be used in any conference presentation, report or journal article developed as a result of the study. I understand that no other use will be made of the recording without my written permission, and that no one outside the research them will be allowed access to the original recording.
6. I consent to the storage, including electronic, of personal information for the purposes of this study. I understand that any information that could identify me will be kept strictly confidential and that no personal information will be included in the study report or other publication.
7. I agree to the above six points and I agree to participate in the above study.

______________________	______________	____________________
Name of participant & I/C no.	Date	Signature
______________________	______________	____________________
Principal Investigator & I/C no.	Date	Signature

Appendix 5: MREC Letter of Ethical Approval



JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN
(*MEDICAL RESEARCH & ETHICS COMMITTEE*)
KEMENTERIAN KESIHATAN MALAYSIA
MINISTRY OF HEALTH MALAYSIA
Kompleks Institut Kesihatan Negara (NIH)
No.1, Jalan Setia Murni U13/52,
Seksyen U13 Bandar Setia Alam,
40170 Shah Alam, Selangor.
Tel.: +(6)03-33628888/ 33628205

Ref. : KKM/NIHSEC/P20-1336(12)
Date : **12-August-2020**

AZRINA ELY BINTI AHMAD AZHARI
THE UNIVERSITY OF NOTTINGHAM MALAYSIA CAMPUS

Dear Dato'/ Dr/ Sir/ Madam,

LETTER OF ETHICAL APPROVAL:

NMRR-20-1044-55063 (IIR)
EXPLORATIVE RESEARCH ON HEALTH LITERACY AND SELF-CARE MANAGEMENT OF TYPE 2 DIABETES MELLITUS AMONG MALAYSIANS

This letter is made in reference to the matter above.

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

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

Klinik Kesihatan Kota Damansara
Azrina Ely Binti Ahmad Azhari (Principal / Coordinating Investigator)

Klinik Kesihatan Tanglin
Azrina Ely Binti Ahmad Azhari (Principal / Coordinating Investigator)

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

Documents received and reviewed with reference to the above study:

1. Cover letter to MREC (Version 3, dated 12-08-2020)
2. Declaration of Conflict of Interest (COI) (Version 1, dated 16-05-2020)
3. Protocol (Version 1.2, dated 12-08-2020)
4. English: Patient Information Sheet/ Informed Consent Form (Version 1.1, dated 12-08-2020)
5. Malay: Patient Information Sheet/ Informed Consent Form (Version 1.1, dated 12-08-2020)
6. Data Collection Form (Version 1, dated 15-05-2020)
7. Follow-up Review Report (Version 1, dated 12-08-2020)
8. IA-HOD-IA and CV of:
    - Azrina Ely Binti Ahmad Azhari

…/2-

5. Please note that the approval is valid until **11-August-2021**. The following are to be reported upon receiving ethical approval. Required forms can be obtained from the National Medical Research Registry (NMRR) website.

i. **Continuing Review Form** has to be submitted to MREC within 2 months (60 days) prior to the expiry of ethical approval.
ii. **Study Final Report** upon study completion to the MREC.
iii. Ethical approval is required in the case of **amendments/ changes** to the **study documents/ study sites/ study team**. MREC reserves the right to withdraw ethical approval if changes to study documents are not completely declared.
iv. **Applicable for Clinical interventional Studies only:** Report occurrences of **all Serious Adverse Events (SAEs), Suspected Unexpected Serious Adverse Reaction (SUSARs)** and **Protocol Deviation/Violation** at all MREC approved sites to MREC. SAEs are to be reported within 15 calendar days from awareness of event by investigator. Initial report of SUSARs are to be reported as soon as possible but not later than 7 calendar days from awareness of event by investigator, followed by a complete report within 8 additional calendar days.

6. There will be **42 subjects/ patients/ respondents** targeted to be enrolled in this study within Malaysia.

7. Please take note that the reference number of this letter must be stated in all future correspondence related to this study to facilitate the administrative processes.

Project Sites:
KLINIK KESIHATAN KOTA DAMANSARA
KLINIK KESIHATAN TANGLIN

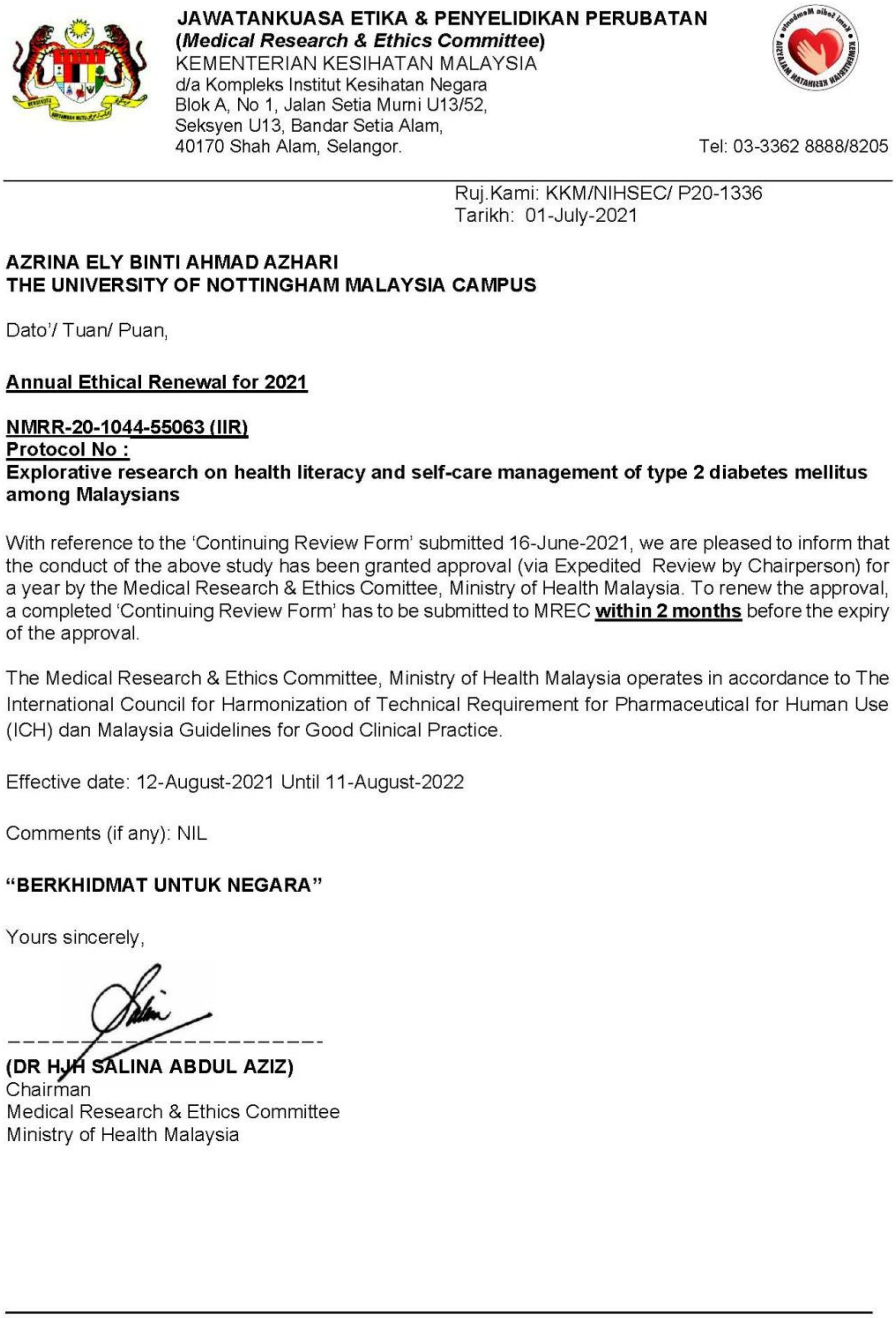
Decision by Medical Research & Ethics Committee:
(√) Approved
( ) Disapproved

Date of Approval : **12-August-2020**

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

CM\MREC_Share\Approval 2020\Expedited by Primary Reviewer\August 2020\55063

Appendix 6: MREC Annual Ethical Renewal for 2021



JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN
(*Medical Research & Ethics Committee*)
KEMENTERIAN KESIHATAN MALAYSIA
d/a Kompleks Institut Kesihatan Negara
Blok A, No 1, Jalan Setia Murni U13/52,
Seksyen U13, Bandar Setia Alam,
40170 Shah Alam, Selangor.
Tel: 03-3362 8888/8205

Ruj.Kami: KKM/NIHSEC/ P20-1336
Tarikh: 01-July-2021

AZRINA ELY BINTI AHMAD AZHARI
THE UNIVERSITY OF NOTTINGHAM MALAYSIA CAMPUS

Dato'/ Tuan/ Puan,

Annual Ethical Renewal for 2021

NMRR-20-1044-55063 (IIR)
Protocol No :
Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians

With reference to the 'Continuing Review Form' submitted 16-June-2021, we are pleased to inform that the conduct of the above study has been granted approval (via Expedited Review by Chairperson) for a year by the Medical Research & Ethics Comittee, Ministry of Health Malaysia. To renew the approval, a completed 'Continuing Review Form' has to be submitted to MREC **within 2 months** before the expiry of the approval.

The Medical Research & Ethics Committee, Ministry of Health Malaysia operates in accordance to The International Council for Harmonization of Technical Requirement for Pharmaceutical for Human Use (ICH) dan Malaysia Guidelines for Good Clinical Practice.

Effective date: 12-August-2021 Until 11-August-2022

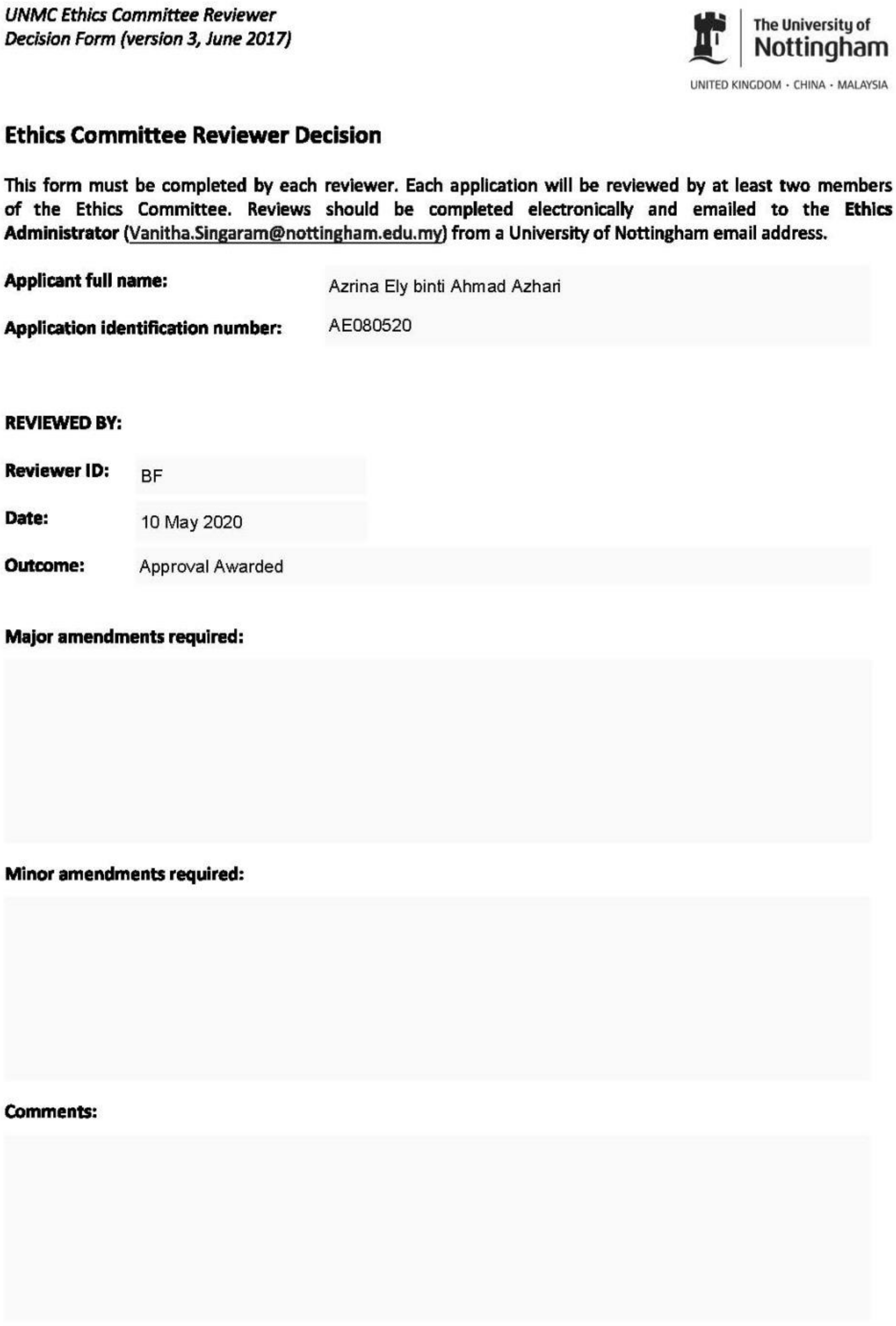
Comments (if any): NIL

"BERKHIDMAT UNTUK NEGARA"

Yours sincerely,

(DR HJH SALINA ABDUL AZIZ)
Chairman
Medical Research & Ethics Committee
Ministry of Health Malaysia

Appendix 7: SEREC Ethics Committee Reviewer Decision



UNMC Ethics Committee Reviewer
Decision Form (version 3, June 2017)

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Ethics Committee Reviewer Decision

This form must be completed by each reviewer. Each application will be reviewed by at least two members of the Ethics Committee. Reviews should be completed electronically and emailed to the Ethics Administrator (Vanitha.Singaram@nottingham.edu.my) from a University of Nottingham email address.

Applicant full name: Azrina Ely binti Ahmad Azhari

Application identification number: AE080520

REVIEWED BY:

Reviewer ID: BF

Date: 10 May 2020

Outcome: Approval Awarded

Major amendments required:

Minor amendments required:

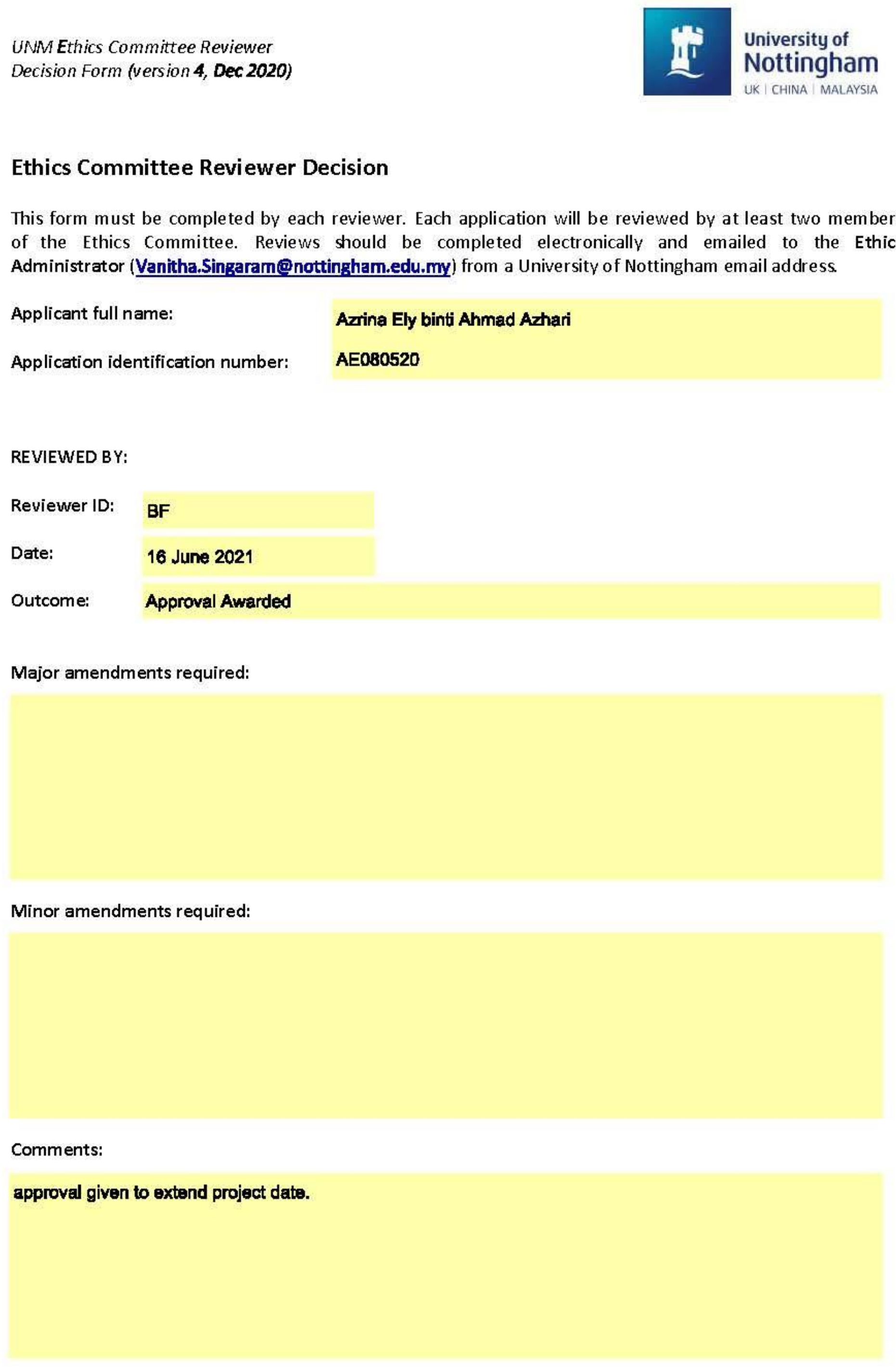
Comments:

Please note:

1. The approval only covers the participants and trials specified on the form and further approval must be requested for any repetition or extension to the investigation.
2. The approval covers the ethical requirements for the techniques and procedures described in the protocol but does not replace a safety or risk assessment.
3. Approval is not intended to convey any judgement on the quality of the research, experimental design or techniques.
4. Normally, all queries raised by reviewers should be addressed. In the case of conflicting or incomplete views, the ethics committee chair will review the comments and relay these to the applicant via email. All email correspondence related to the application must be copied to the Faculty research ethics administrator.
5. You have the right to appeal against a decision by the Research Ethics Committee. To do so please complete the appeal form (available on the Moodle Page) and submit it to Vanitha.Singaram@nottingham.edu.my

Any problems which arise during the course of the investigation must be reported to the Research Ethics Committee

Appendix 8: SEREC Ethics Committee Reviewer Decision (Amendment on end date)



UNM Ethics Committee Reviewer
Decision Form (version 4, Dec 2020)

University of Nottingham
UK | CHINA | MALAYSIA

Ethics Committee Reviewer Decision

This form must be completed by each reviewer. Each application will be reviewed by at least two members of the Ethics Committee. Reviews should be completed electronically and emailed to the Ethics Administrator (Vanitha.Singaram@nottingham.edu.my) from a University of Nottingham email address.

Applicant full name: Azrina Ely binti Ahmad Azhari

Application identification number: AE080520

REVIEWED BY:

Reviewer ID: BF

Date: 16 June 2021

Outcome: Approval Awarded

Major amendments required:

Minor amendments required:

Comments:

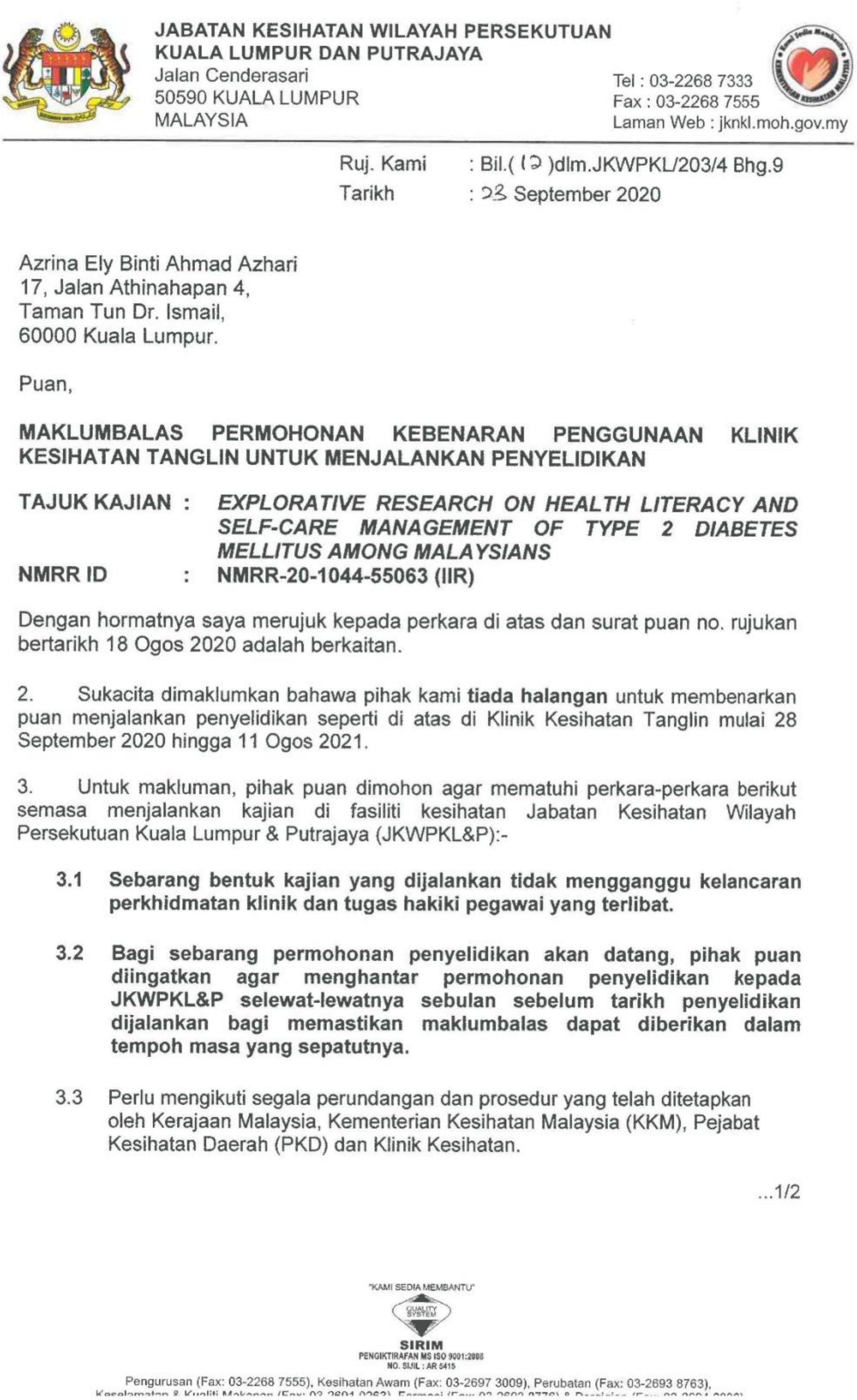
approval given to extend project date.

Please note:

1. The approval only covers the participants and trials specified on the form and further approval must be requested for any repetition or extension to the investigation.
2. The approval covers the ethical requirements for the techniques and procedures described in the protocol but does not replace a safety or risk assessment.
3. Approval is not intended to convey any judgement on the quality of the research, experimental design or techniques.
4. Normally, all queries raised by reviewers should be addressed. In the case of conflicting or incomplete views, the ethics committee chair will review the comments and relay these to the applicant via email. All email correspondence related to the application must be copied to the Faculty research ethics administrator.
5. You have the right to appeal against a decision by the Research Ethics Committee. To do so please complete the appeal form **(available on the Moodle Page)** and submit it to **Vanitha.Singaram@nottingham.edu.my**

Any problems which arise during the course of the investigation must be reported to the Research Ethics Committee

Appendix 9: Letter of permission to use THC as the study site



JABATAN KESIHATAN WILAYAH PERSEKUTUAN
KUALA LUMPUR DAN PUTRAJAYA
Jalan Cenderasari
50590 KUALA LUMPUR
MALAYSIA

Tel : 03-2268 7333
Fax : 03-2268 7555
Laman Web : jknkl.moh.gov.my

Ruj. Kami : Bil.(12)dlm.JKWPKL/203/4 Bhg.9
Tarikh : 23 September 2020

Azrina Ely Binti Ahmad Azhari
17, Jalan Athinahapan 4,
Taman Tun Dr. Ismail,
60000 Kuala Lumpur.

Puan,

MAKLUMBALAS PERMOHONAN KEBENARAN PENGGUNAAN KLINIK KESIHATAN TANGLIN UNTUK MENJALANKAN PENYELIDIKAN

TAJUK KAJIAN : ***EXPLORATIVE RESEARCH ON HEALTH LITERACY AND SELF-CARE MANAGEMENT OF TYPE 2 DIABETES MELLITUS AMONG MALAYSIANS***
NMRR ID : NMRR-20-1044-55063 (IIR)

Dengan hormatnya saya merujuk kepada perkara di atas dan surat puan no. rujukan bertarikh 18 Ogos 2020 adalah berkaitan.

2. Sukacita dimaklumkan bahawa pihak kami **tiada halangan** untuk membenarkan puan menjalankan penyelidikan seperti di atas di Klinik Kesihatan Tanglin mulai 28 September 2020 hingga 11 Ogos 2021.

3. Untuk makluman, pihak puan dimohon agar mematuhi perkara-perkara berikut semasa menjalankan kajian di fasiliti kesihatan Jabatan Kesihatan Wilayah Persekutuan Kuala Lumpur & Putrajaya (JKWPKL&P):-

3.1 **Sebarang bentuk kajian yang dijalankan tidak mengganggu kelancaran perkhidmatan klinik dan tugas hakiki pegawai yang terlibat.**

3.2 **Bagi sebarang permohonan penyelidikan akan datang, pihak puan diingatkan agar menghantar permohonan penyelidikan kepada JKWPKL&P selewat-lewatnya sebulan sebelum tarikh penyelidikan dijalankan bagi memastikan maklumbalas dapat diberikan dalam tempoh masa yang sepatutnya.**

3.3 Perlu mengikuti segala perundangan dan prosedur yang telah ditetapkan oleh Kerajaan Malaysia, Kementerian Kesihatan Malaysia (KKM), Pejabat Kesihatan Daerah (PKD) dan Klinik Kesihatan.

...1/2

"KAMI SEDIA MEMBANTU"
SIRIM
PENGIKTIRAFAN MS ISO 9001:2008
NO. SIJIL : AR 5415

Pengurusan (Fax: 03-2268 7555), Kesihatan Awam (Fax: 03-2697 3009), Perubatan (Fax: 03-2693 8763),

MAKLUMBALAS PERMOHONAN KEBENARAN PENGGUNAAN KLINIK KESIHATAN TANGLIN UNTUK MENJALANKAN PENYELIDIKAN

TAJUK KAJIAN : ***EXPLORATIVE RESEARCH ON HEALTH LITERACY AND SELF-CARE MANAGEMENT OF TYPE 2 DIABETES MELLITUS AMONG MALAYSIANS***
NMRR ID : NMRR-20-1044-55063 (IIR)

3. Untuk makluman, pihak puan dimohon agar mematuhi perkara-perkara berikut semasa menjalankan kajian di fasiliti kesihatan Jabatan Kesihatan Wilayah Persekutuan Kuala Lumpur & Putrajaya (JKWPKL&P):-

3.4 Membentangkan hasil kajian kepada pihak kami setelah kajian selesai.

3.5 Memberikan sesalinan hasil kajian kepada pihak kami sebagai bahan bacaan dan rujukan pegawai-pegawai di Jabatan ini.

3.6 Sebarang penerbitan atau diseminasi hasil penyelidikan tersebut sama ada melalui penulisan, pengiklanan, pembentangan atau untuk ke media perlu mendapat kelulusan Ketua Pengarah Kesihatan Malaysia terlebih dahulu.

Puan boleh merujuk kepada garis panduan Institut Kesihatan Negara mengenai penyelidikan di institusi dan fasiliti Kementerian Kesihatan Malaysia (Pindaan 01/2015).

4. Untuk perbincangan lanjut, pihak puan perlu berhubung terus dengan Pegawai Kesihatan Lembah Pantai (No. Telefon: 03-22687452) sebelum penyelidikan bermula bagi memastikan kelancaran penyelidikan tersebut. Perhatian dan kerjasama pihak tuan amat dihargai dan didahulukan dengan ucapan terima kasih.

Sekian.

"BERKHIDMAT UNTUK NEGARA"

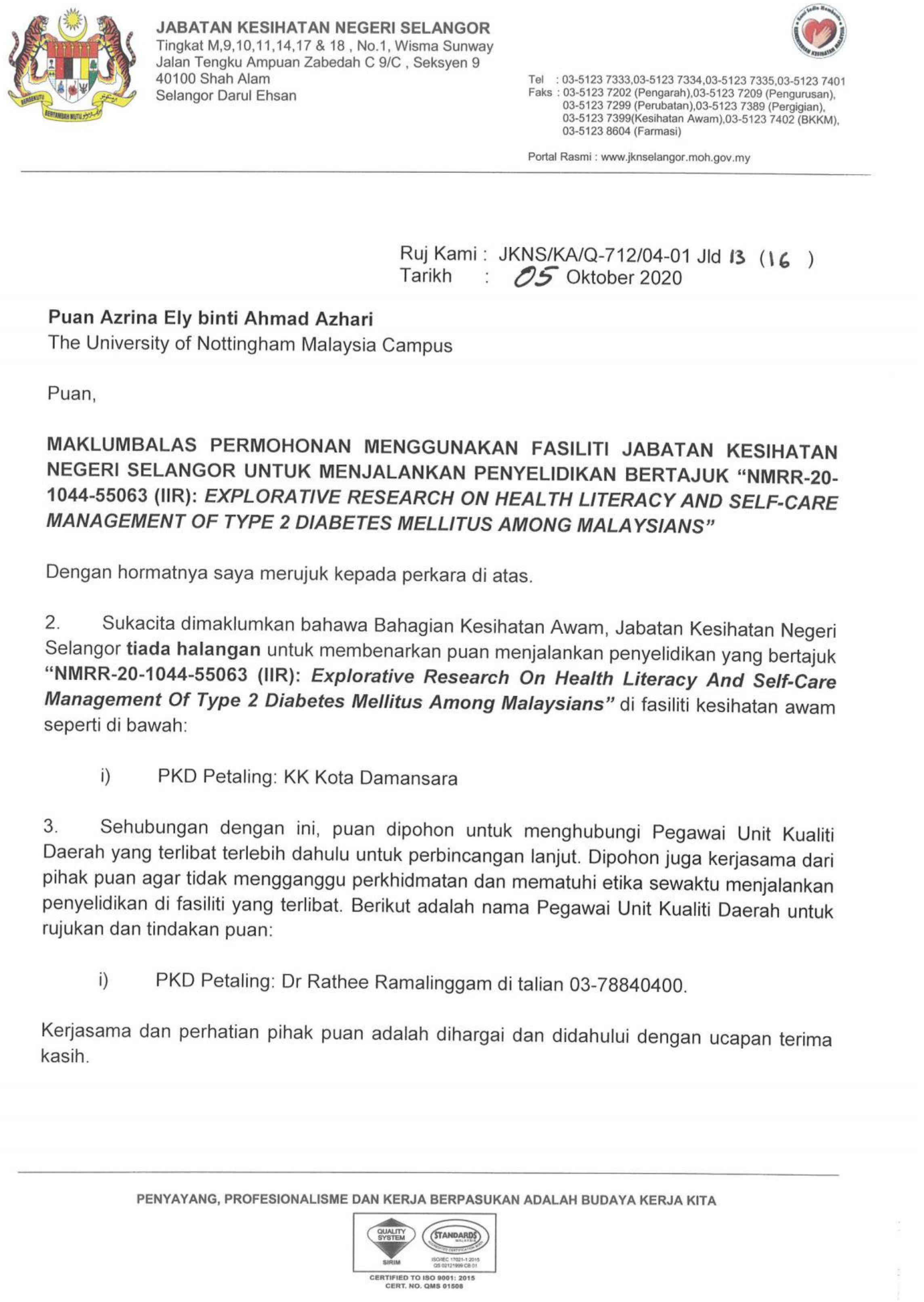
Saya yang menjalankan amanah,

(DR. PARAM JEETH SINGH A/L PAKAR SINGH)
No. MMC: 28133
Pengarah Kesihatan Negeri
Jabatan Kesihatan Wilayah Persekutuan
Kuala Lumpur & Putrajaya

s.k - Timbalan Pengarah Kesihatan Negeri (Kesihatan Awam)
- Pegawai Kesihatan Lembah Pantai
- Ketua Klinik Kesihatan Tanglin

AzeeyAminsuratkebenarankajian/22092020

Appendix 10: Letter of permission to use KDHC as the study site



JABATAN KESIHATAN NEGERI SELANGOR
Tingkat M,9,10,11,14,17 & 18 , No.1, Wisma Sunway
Jalan Tengku Ampuan Zabedah C 9/C , Seksyen 9
40100 Shah Alam
Selangor Darul Ehsan

Tel : 03-5123 7333,03-5123 7334,03-5123 7335,03-5123 7401
Faks : 03-5123 7202 (Pengarah),03-5123 7209 (Pengurusan),
03-5123 7299 (Perubatan),03-5123 7389 (Pergigian),
03-5123 7399(Kesihatan Awam),03-5123 7402 (BKKM),
03-5123 8604 (Farmasi)

Portal Rasmi : www.jknselangor.moh.gov.my

Ruj Kami : JKNS/KA/Q-712/04-01 Jld 13 (16)
Tarikh : 05 Oktober 2020

Puan Azrina Ely binti Ahmad Azhari
The University of Nottingham Malaysia Campus

Puan,

MAKLUMBALAS PERMOHONAN MENGGUNAKAN FASILITI JABATAN KESIHATAN NEGERI SELANGOR UNTUK MENJALANKAN PENYELIDIKAN BERTAJUK "NMRR-20-1044-55063 (IIR): *EXPLORATIVE RESEARCH ON HEALTH LITERACY AND SELF-CARE MANAGEMENT OF TYPE 2 DIABETES MELLITUS AMONG MALAYSIANS*"

Dengan hormatnya saya merujuk kepada perkara di atas.

2. Sukacita dimaklumkan bahawa Bahagian Kesihatan Awam, Jabatan Kesihatan Negeri Selangor **tiada halangan** untuk membenarkan puan menjalankan penyelidikan yang bertajuk **"NMRR-20-1044-55063 (IIR): *Explorative Research On Health Literacy And Self-Care Management Of Type 2 Diabetes Mellitus Among Malaysians*"** di fasiliti kesihatan awam seperti di bawah:

i) PKD Petaling: KK Kota Damansara

3. Sehubungan dengan ini, puan dipohon untuk menghubungi Pegawai Unit Kualiti Daerah yang terlibat terlebih dahulu untuk perbincangan lanjut. Dipohon juga kerjasama dari pihak puan agar tidak mengganggu perkhidmatan dan mematuhi etika sewaktu menjalankan penyelidikan di fasiliti yang terlibat. Berikut adalah nama Pegawai Unit Kualiti Daerah untuk rujukan dan tindakan puan:

i) PKD Petaling: Dr Rathee Ramalinggam di talian 03-78840400.

Kerjasama dan perhatian pihak puan adalah dihargai dan didahului dengan ucapan terima kasih.

PENYAYANG, PROFESIONALISME DAN KERJA BERPASUKAN ADALAH BUDAYA KERJA KITA

CERTIFIED TO ISO 9001: 2015
CERT. NO. QMS 01508

MAKLUMBALAS PERMOHONAN MENGGUNAKAN FASILITI JABATAN KESIHATAN NEGERI SELANGOR UNTUK MENJALANKAN PENYELIDIKAN BERTAJUK "NMRR-20-1044-55063 (IIR): *EXPLORATIVE RESEARCH ON HEALTH LITERACY AND SELF-CARE MANAGEMENT OF TYPE 2 DIABETES MELLITUS AMONG MALAYSIANS"*

Sekian.

"BERKHIDMAT UNTUK NEGARA"

Saya yang menjalankan amanah,

(DR. B. VENUGOPALAN, NO. MPM: 27418)
Pakar Perunding Perubatan Kesihatan Awam
Timbalan Pengarah Kesihatan Negeri (Kesihatan Awam)
b.p. Pengarah Kesihatan Negeri
Jabatan Kesihatan Negeri Selangor
UPKA

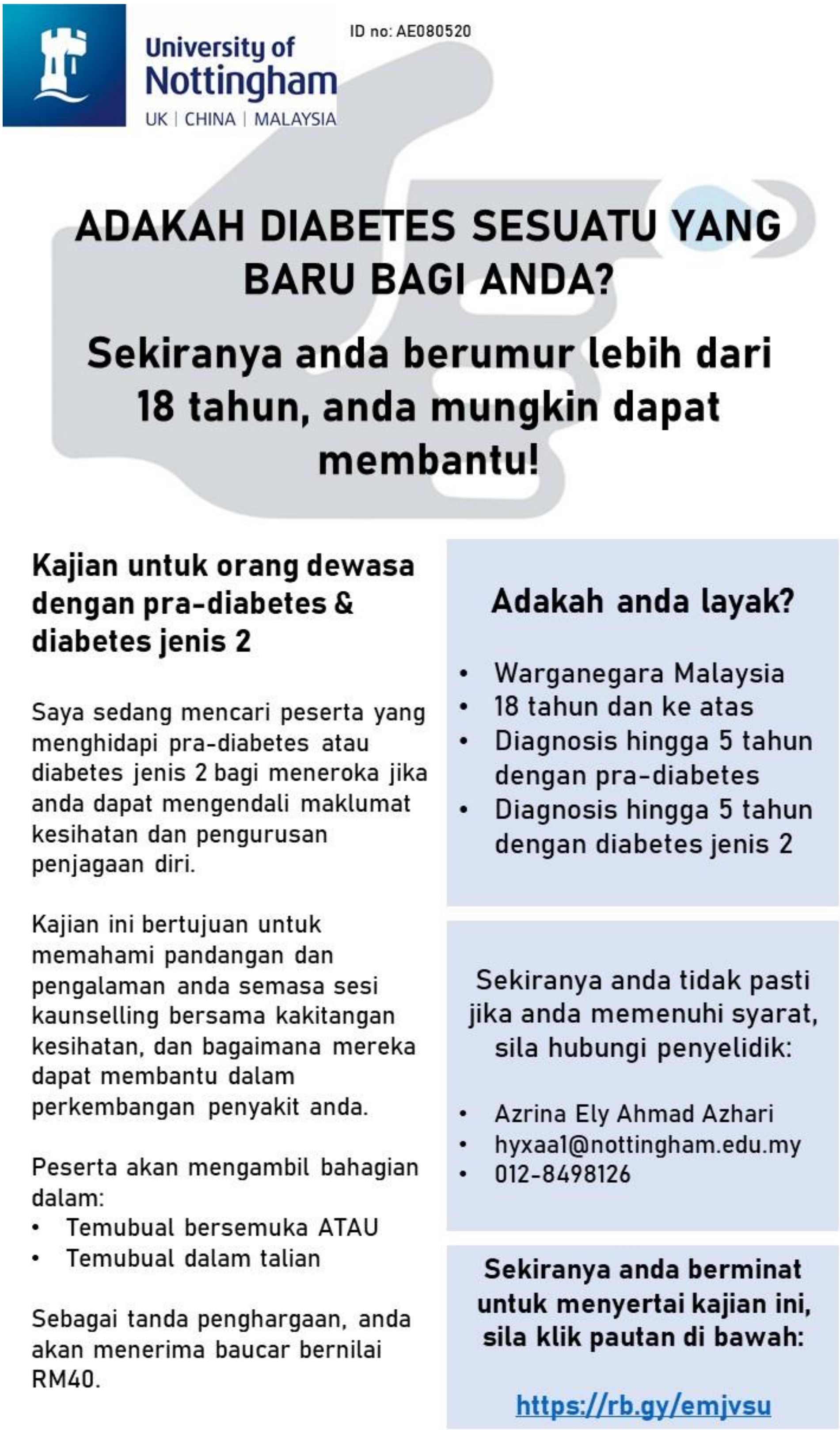
s.k:

Ketua Unit Perkembangan Kesihatan Awam,
Bahagian Kesihatan Awam, JKNS

Ketua Unit Kawalan Penyakit Tidak Berjangkit,
Bahagian Kesihatan Awam, JKNS

Pegawai Kesihatan Daerah
Pejabat Kesihatan Daerah Petaling

Appendix 11: Patient recruitment poster (Malay)



University of Nottingham
UK | CHINA | MALAYSIA

ID no: AE080520

ADAKAH DIABETES SESUATU YANG BARU BAGI ANDA?

Sekiranya anda berumur lebih dari 18 tahun, anda mungkin dapat membantu!

Kajian untuk orang dewasa dengan pra-diabetes & diabetes jenis 2

Saya sedang mencari peserta yang menghidapi pra-diabetes atau diabetes jenis 2 bagi meneroka jika anda dapat mengendali maklumat kesihatan dan pengurusan penjagaan diri.

Kajian ini bertujuan untuk memahami pandangan dan pengalaman anda semasa sesi kaunselling bersama kakitangan kesihatan, dan bagaimana mereka dapat membantu dalam perkembangan penyakit anda.

Peserta akan mengambil bahagian dalam:
- Temubual bersemuka ATAU
- Temubual dalam talian

Sebagai tanda penghargaan, anda akan menerima baucar bernilai RM40.

Adakah anda layak?

- Warganegara Malaysia
- 18 tahun dan ke atas
- Diagnosis hingga 5 tahun dengan pra-diabetes
- Diagnosis hingga 5 tahun dengan diabetes jenis 2

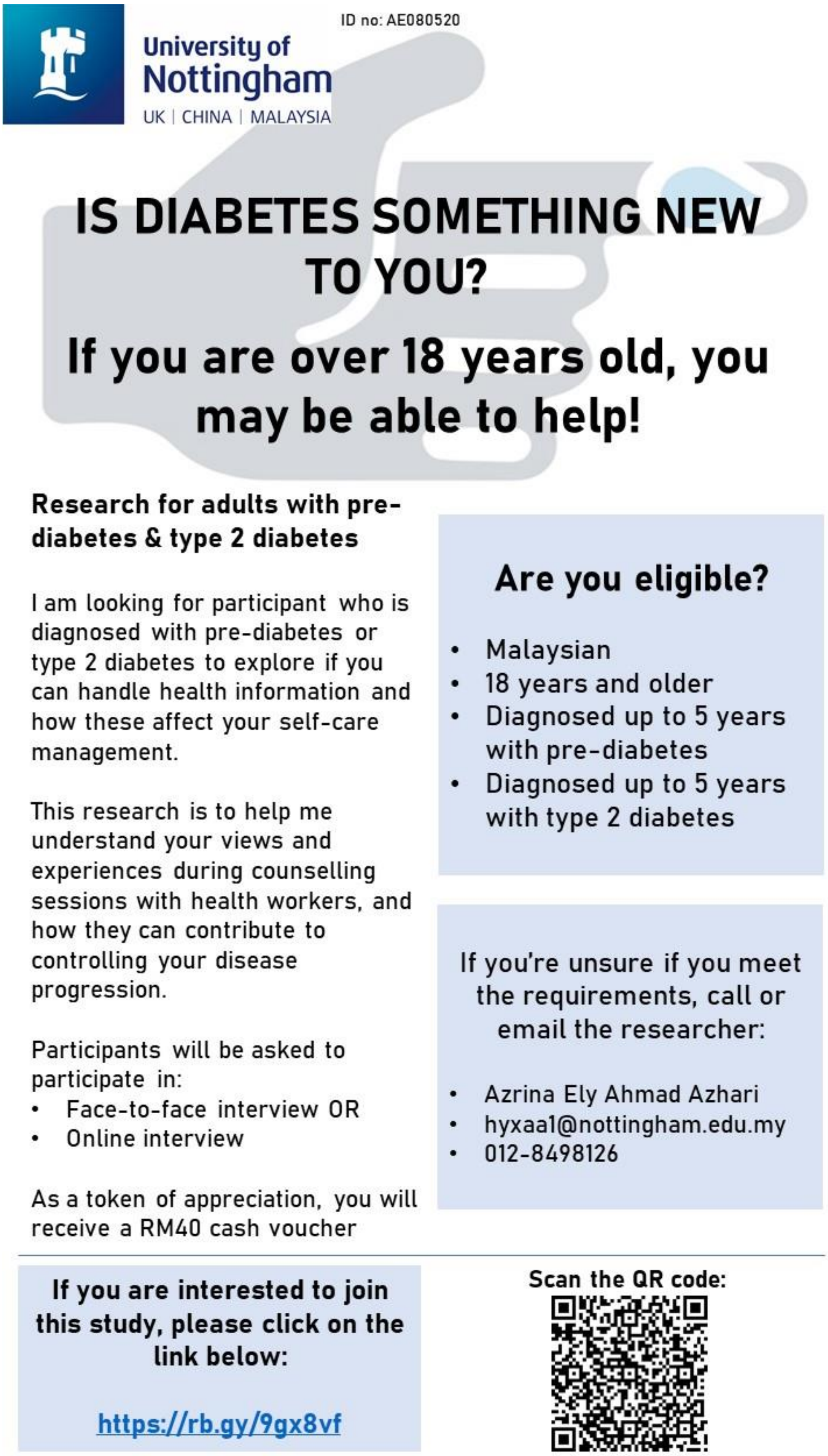
Sekiranya anda tidak pasti jika anda memenuhi syarat, sila hubungi penyelidik:

- Azrina Ely Ahmad Azhari
- hyxaa1@nottingham.edu.my
- 012-8498126

Sekiranya anda berminat untuk menyertai kajian ini, sila klik pautan di bawah:

https://rb.gy/emjvsu

Appendix 12: Patient recruitment poster (English)



ID no: AE080520

University of Nottingham
UK | CHINA | MALAYSIA

IS DIABETES SOMETHING NEW TO YOU?

If you are over 18 years old, you may be able to help!

Research for adults with pre-diabetes & type 2 diabetes

I am looking for participant who is diagnosed with pre-diabetes or type 2 diabetes to explore if you can handle health information and how these affect your self-care management.

This research is to help me understand your views and experiences during counselling sessions with health workers, and how they can contribute to controlling your disease progression.

Participants will be asked to participate in:
- Face-to-face interview OR
- Online interview

As a token of appreciation, you will receive a RM40 cash voucher

Are you eligible?

- Malaysian
- 18 years and older
- Diagnosed up to 5 years with pre-diabetes
- Diagnosed up to 5 years with type 2 diabetes

If you're unsure if you meet the requirements, call or email the researcher:

- Azrina Ely Ahmad Azhari
- hyxaa1@nottingham.edu.my
- 012-8498126

If you are interested to join this study, please click on the link below:

https://rb.gy/9gx8vf

Scan the QR code:

Appendix 13: Pharmacist recruitment poster

University of Nottingham
UK | CHINA | MALAYSIA

AE080520

PARTICIPANTS NEEDED

Looking for dedicated Pharmacists who are working in:

- Community Pharmacy
- Hospital Pharmacy
- Health Clinic

To participate in a research focusing on how you interact with newly diagnosed pre-diabetes or type 2 diabetes patients and how pharmacists can contribute in preventing or delaying their disease progression.

If you are interested to join this study, please click on the link below:

https://rb.gy/knkfxj

Alternatively, scan the QR code:

Appendix 14: Participant information sheet (Pharmacist focus group)

University of Nottingham
UK | CHINA | MALAYSIA

Participant information sheet (Pharmacists Focus Group)

Title: ***Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians***

Name of investigator and institution: ***Azrina Ely binti Ahmad Azhari, University of Nottingham Malaysia***

This Participation Information Sheet includes information about the study you are about to participate in.

What is the study about?
Based on the National Health and Morbidity Survey 2015, the prevalence of diabetes in Malaysia has increased from 15.2% in 2011 to 17.5% in 2015. Numerous researches have been conducted on diabetes to help diabetes patients control and manage their condition. As a pharmacist, we play a major role in educating patients in disease management as well as disease prevention. You are invited to participate in this study to explore the pharmacists' perception on type 2 diabetes mellitus patients' health literacy and self-care behaviours, and how we as healthcare professionals can contribute in improving their understanding of the condition and effective self-care management. The expected number of participants participating in this study is 42 individuals and they are all Malaysians.

What is the purpose of the study?
You have been invited to participate in this study to help in the understanding of your views and experiences during counselling sessions with pre-diabetes and newly diagnosed T2DM patients, particularly on how you interact and communicate with these patients to ensure enhancement in patients' disease knowledge and self-care management.

What are the potential risks of being in this study?
There are no known or anticipated risks associated with participation in this study. If a question, or the discussion, makes you uncomfortable, you may choose not to answer.

What are the benefits of being in this study?
There may or may not be any benefits to you. Information obtained from this study will help the investigator to understand your views in the barriers of effective self-care management in pre-diabetes and newly diagnosed T2DM patients. It will help in improving the roles of pharmacists in delivering quality patient counselling to prevent or delay disease progression.

Who is funding the research?
The study is a self-sponsored. You will be given an honorarium in a form of AEON® voucher worth RM40.00 in the recognition of your participation in this study.

What does participation involve?
Participation in this study will consist of attending one focus group with 3 to 4 other people who are also working as a pharmacist either in a hospital or community settings. The session is expected to last about 60 – 90 minutes. The focus group will be conducted virtually at a time and date convenient for the participants. You will first complete a short demographic survey e.g. age, gender, length of service, etc., and then investigator will guide a discussion on the health literacy and self-care behaviours on pre-diabetes patients and T2DM newly diagnosed patients. The session will be audio/video recorded to ensure an accurate transcript of the focus group. With your permission, you may be quoted anonymously in publications e.g. reports and

published papers. Given the format of this session, I will ask you to refrain from mentioning any confidential information that may identify or could potentially identify any patient.

Can the research or my participation be terminated early?
The investigator may due to concerns for your safety or lack of recruitment or inability to sustain or further manage the study, stop the study or your participation at any time. If the study is stopped early for any reason you will be informed.

Do I have to participate?
Your participation is entirely voluntary, and it is up to you to decide whether or not to take part. You may decide to leave the study at any time by communicating this to the focus group facilitator. The focus group discussion will be audio/video recorded and later transcribed and you may be quoted anonymously in publications e.g. reports and published papers. Even if you decide to be interviewed and audio/video recorded, you are free to withdraw at any time, without giving any reason. If you decide to take part, you will receive this information sheet to keep and you will be asked to sign a consent form.

Will the collected data be treated confidentially?
All information collected from you will be kept strictly confidential and stored in a database which will be password protected. Any information about you which leaves the research unit will be anonymous (all identifying information removed). Your data will be saved under a number (ID), which cannot be tracked back to you. Transcription will be stored in a locked office belonging to the researcher and maintained for six years for future reference for the purpose of publication of reports or peer reviewed publications, whereby after this period it will be professionally destroyed. When publishing or presenting the study results, your identity will not be revealed without your expressed consent. Individuals involved in this study, qualified monitors and auditors, and governmental or regulatory authorities may inspect study data, where appropriate and necessary.

What will happen to the study data?
The information that you provide will be used to help us plan future research and service provision in this area. You will also be able to request a summary of the study.

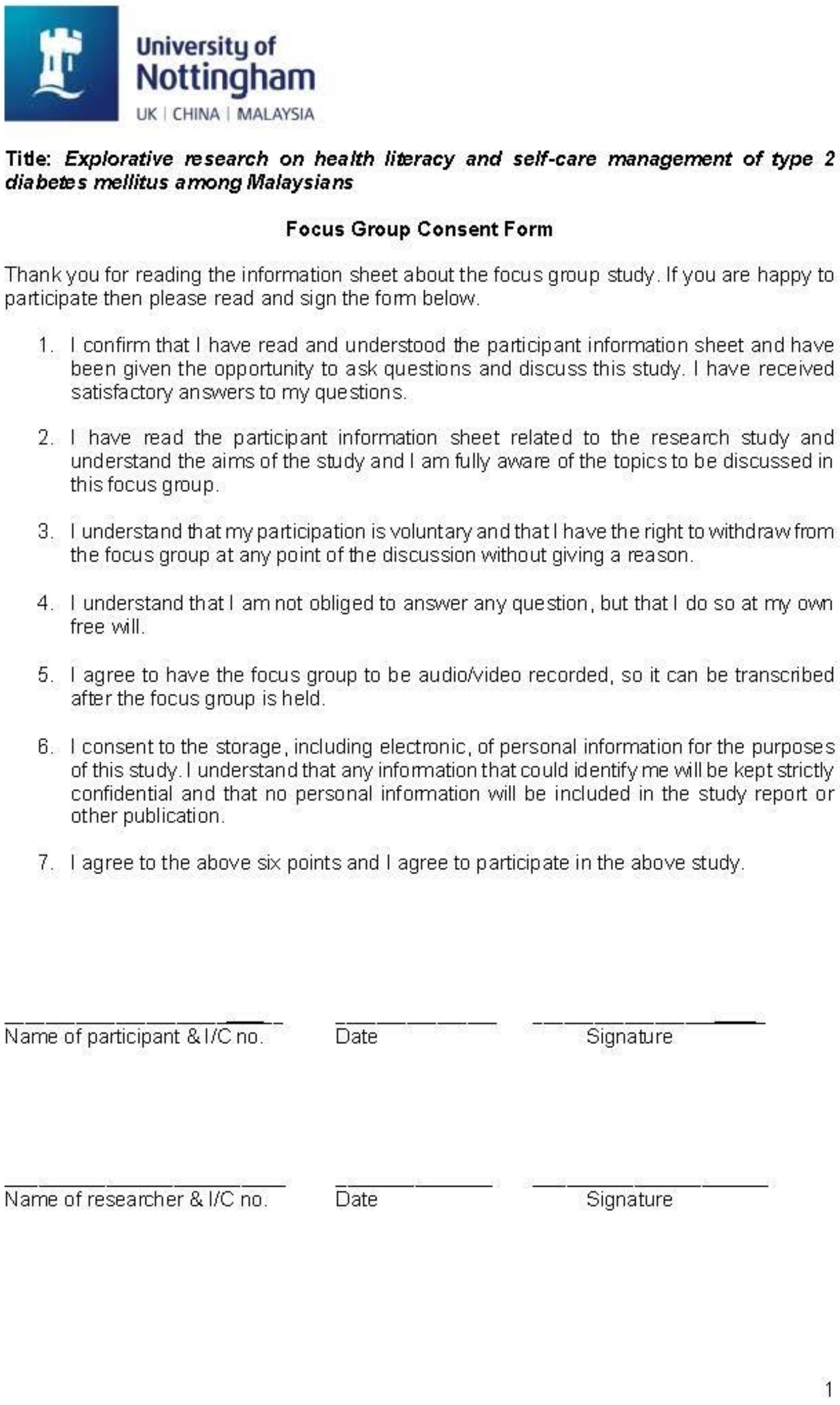
What is the procedure?
Sign the 'Participant Consent Form' ensuring that you have read and understood all the information provided to you and that you agree to participate in this study. The 'Participant Consent Form' will be held securely and all information contain therein will be kept strictly confidential.

Thank you in advance for your interest and assistance with this research.

If you have any questions regarding this research, please contact the researcher, Azrina Ely Ahmad Azhari, via email at hyxaa1@nottingham.edu.my or via telephone at 017-2553005; or the supervisor, Dr Jim Chai, via email at Jim.Chai@nottingham.edu.my

If you need further information about your rights as a participant in this study, or if you have any concerns about the study, you can contact The Secretary, Medical Research Ethics Committee, Ministry of Health Malaysia via email at nihsec@moh.gov.my or via telephone at 03-3362 8888/8205/8407/8100.

Appendix 15: Consent form (Pharmacist focus group)



University of Nottingham
UK | CHINA | MALAYSIA

Title: ***Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians***

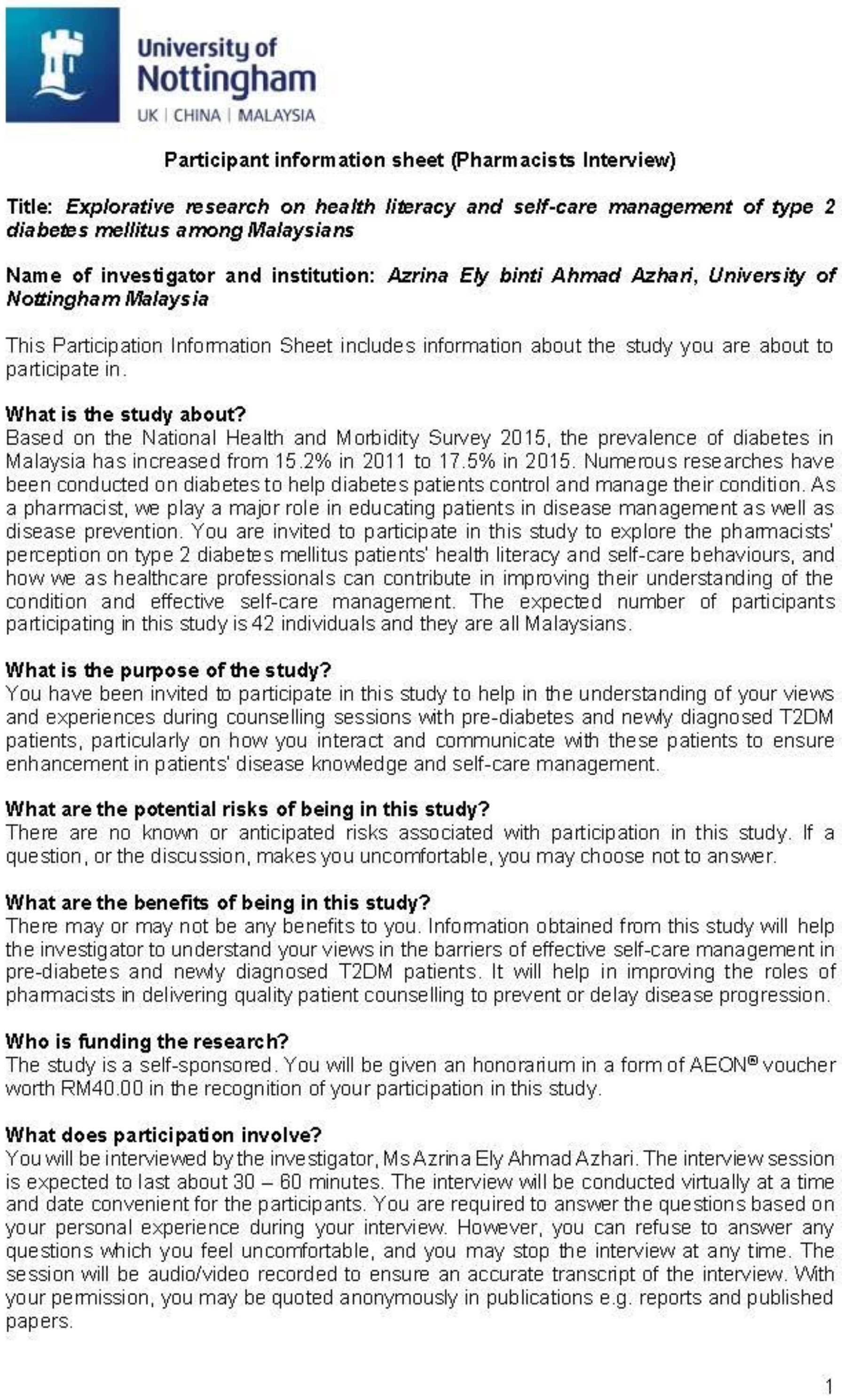
Focus Group Consent Form

Thank you for reading the information sheet about the focus group study. If you are happy to participate then please read and sign the form below.

1. I confirm that I have read and understood the participant information sheet and have been given the opportunity to ask questions and discuss this study. I have received satisfactory answers to my questions.
2. I have read the participant information sheet related to the research study and understand the aims of the study and I am fully aware of the topics to be discussed in this focus group.
3. I understand that my participation is voluntary and that I have the right to withdraw from the focus group at any point of the discussion without giving a reason.
4. I understand that I am not obliged to answer any question, but that I do so at my own free will.
5. I agree to have the focus group to be audio/video recorded, so it can be transcribed after the focus group is held.
6. I consent to the storage, including electronic, of personal information for the purposes of this study. I understand that any information that could identify me will be kept strictly confidential and that no personal information will be included in the study report or other publication.
7. I agree to the above six points and I agree to participate in the above study.

______________________	______________	____________________
Name of participant & I/C no.	Date	Signature
______________________	______________	____________________
Name of researcher & I/C no.	Date	Signature

Appendix 16: Participant information sheet (Pharmacist interview)



University of Nottingham
UK | CHINA | MALAYSIA

Participant information sheet (Pharmacists Interview)

Title: ***Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians***

Name of investigator and institution: ***Azrina Ely binti Ahmad Azhari, University of Nottingham Malaysia***

This Participation Information Sheet includes information about the study you are about to participate in.

What is the study about?
Based on the National Health and Morbidity Survey 2015, the prevalence of diabetes in Malaysia has increased from 15.2% in 2011 to 17.5% in 2015. Numerous researches have been conducted on diabetes to help diabetes patients control and manage their condition. As a pharmacist, we play a major role in educating patients in disease management as well as disease prevention. You are invited to participate in this study to explore the pharmacists' perception on type 2 diabetes mellitus patients' health literacy and self-care behaviours, and how we as healthcare professionals can contribute in improving their understanding of the condition and effective self-care management. The expected number of participants participating in this study is 42 individuals and they are all Malaysians.

What is the purpose of the study?
You have been invited to participate in this study to help in the understanding of your views and experiences during counselling sessions with pre-diabetes and newly diagnosed T2DM patients, particularly on how you interact and communicate with these patients to ensure enhancement in patients' disease knowledge and self-care management.

What are the potential risks of being in this study?
There are no known or anticipated risks associated with participation in this study. If a question, or the discussion, makes you uncomfortable, you may choose not to answer.

What are the benefits of being in this study?
There may or may not be any benefits to you. Information obtained from this study will help the investigator to understand your views in the barriers of effective self-care management in pre-diabetes and newly diagnosed T2DM patients. It will help in improving the roles of pharmacists in delivering quality patient counselling to prevent or delay disease progression.

Who is funding the research?
The study is a self-sponsored. You will be given an honorarium in a form of AEON® voucher worth RM40.00 in the recognition of your participation in this study.

What does participation involve?
You will be interviewed by the investigator, Ms Azrina Ely Ahmad Azhari. The interview session is expected to last about 30 – 60 minutes. The interview will be conducted virtually at a time and date convenient for the participants. You are required to answer the questions based on your personal experience during your interview. However, you can refuse to answer any questions which you feel uncomfortable, and you may stop the interview at any time. The session will be audio/video recorded to ensure an accurate transcript of the interview. With your permission, you may be quoted anonymously in publications e.g. reports and published papers.

Can the research or my participation be terminated early?
The investigator may due to concerns for your safety or lack of recruitment or inability to sustain or further manage the study, stop the study or your participation at any time. If the study is stopped early for any reason you will be informed.

Do I have to participate?
Your participation is entirely voluntary, and it is up to you to decide whether or not to take part. You do not have to participate in this study if you do not want to. You may also refuse to answer any questions you do not want to answer. If you volunteer to be in this study, you may withdraw at any time. If you withdraw, any data collected from you up to your withdrawal will still be used for the study. Your refusal to participate or withdrawal will not affect any medical or health benefits to which you are otherwise entitled.

Participation in this study involve being interviewed by the researcher, and it will take around 1 hour. The interview will be audio/video recorded and later transcribed and you may be quoted anonymously in publications e.g. reports and published papers. Even if you decide to be interviewed and recorded, you are free to withdraw at any time, without giving any reason. If you decide to take part, you will receive this information sheet to keep and you will be asked to sign a consent form.

Will the collected data be treated confidentially?
All information collected from you will be kept strictly confidential and stored in a database which will be password protected. Any information about you which leaves the research unit will be anonymous (all identifying information removed). Your data will be saved under a number (ID), which cannot be tracked back to you. Transcription will be stored in a locked office belonging to the researcher and maintained for six years for future reference for the purpose of publication of reports or peer reviewed publications, whereby after this period it will be professionally destroyed. When publishing or presenting the study results, your identity will not be revealed without your expressed consent. Individuals involved in this study, qualified monitors and auditors, and governmental or regulatory authorities may inspect study data, where appropriate and necessary.

What will happen to the study data?
The information that you provide will be used to help us plan future research and service provision in this area. You will also be able to request a summary of the study.

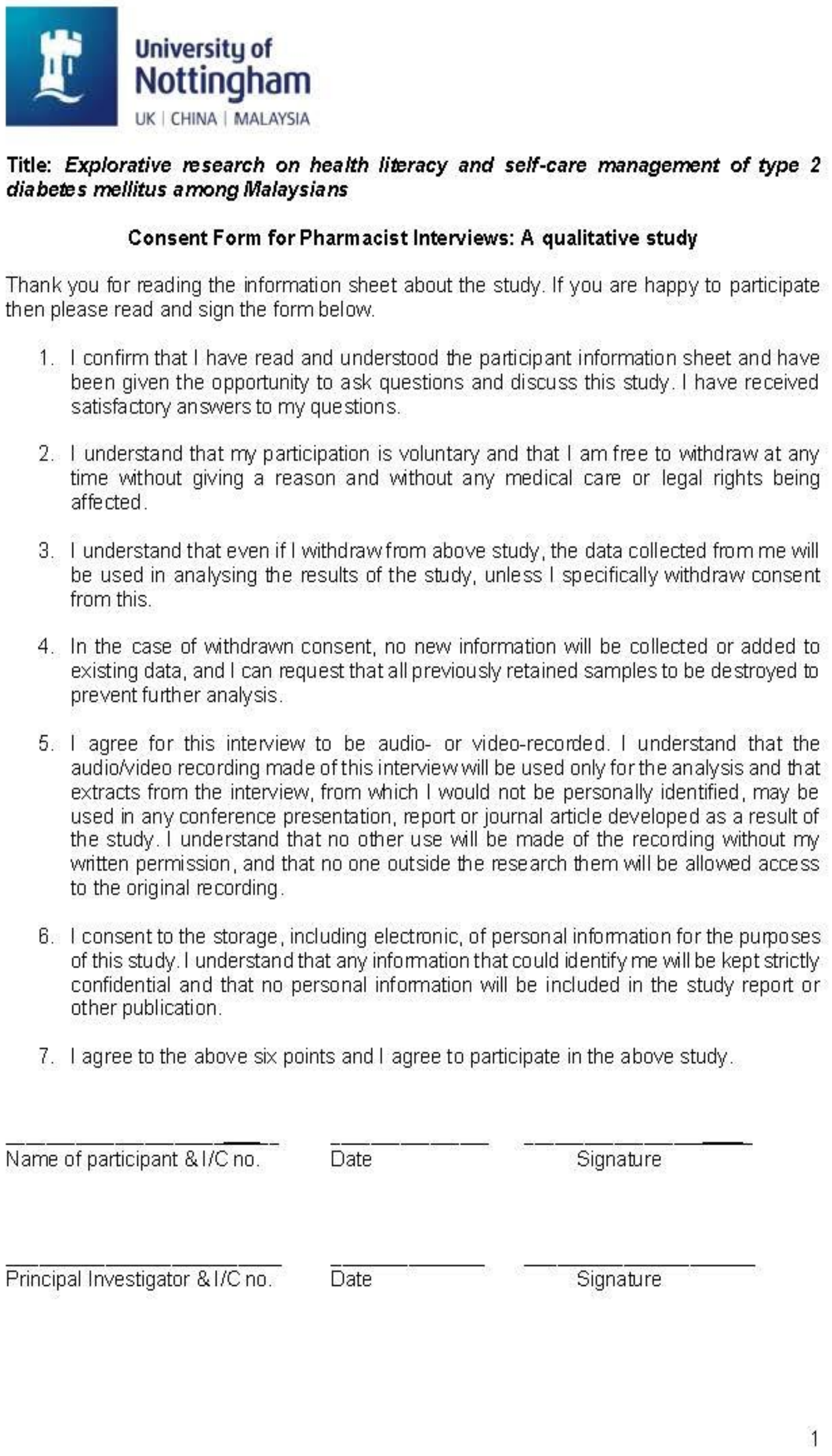
What is the procedure?
Sign the 'Participant Consent Form' ensuring that you have read and understood all the information provided to you and that you agree to participate in this study. The 'Participant Consent Form' will be held securely and all information contain therein will be kept strictly confidential.

Thank you in advance for your interest and assistance with this research.

If you have any questions regarding this research, please contact the researcher, Azrina Ely Ahmad Azhari, via email at hyxaa1@nottingham.edu.my or via telephone at 017-2553005; or the supervisor, Dr Jim Chai, via email at Jim.Chai@nottingham.edu.my

If you need further information about your rights as a participant in this study, or if you have any concerns about the study, you can contact The Secretary, Medical Research Ethics Committee, Ministry of Health Malaysia via email at nihsec@moh.gov.my or via telephone at 03-3362 8888/8205/8407/8100.

Appendix 17: Consent form (Pharmacist interview)



University of Nottingham
UK | CHINA | MALAYSIA

Title: ***Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians***

Consent Form for Pharmacist Interviews: A qualitative study

Thank you for reading the information sheet about the study. If you are happy to participate then please read and sign the form below.

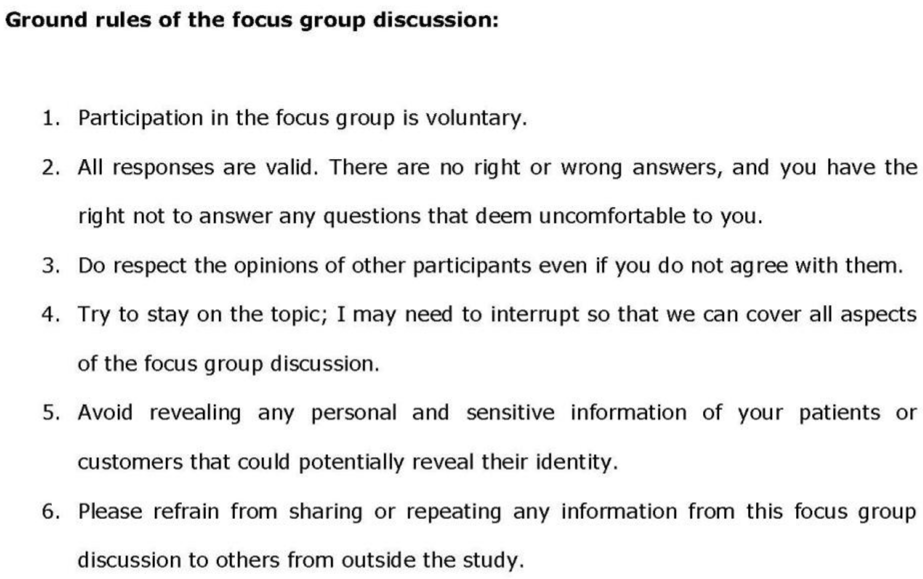
1. I confirm that I have read and understood the participant information sheet and have been given the opportunity to ask questions and discuss this study. I have received satisfactory answers to my questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without any medical care or legal rights being affected.
3. I understand that even if I withdraw from above study, the data collected from me will be used in analysing the results of the study, unless I specifically withdraw consent from this.
4. In the case of withdrawn consent, no new information will be collected or added to existing data, and I can request that all previously retained samples to be destroyed to prevent further analysis.
5. I agree for this interview to be audio- or video-recorded. I understand that the audio/video recording made of this interview will be used only for the analysis and that extracts from the interview, from which I would not be personally identified, may be used in any conference presentation, report or journal article developed as a result of the study. I understand that no other use will be made of the recording without my written permission, and that no one outside the research them will be allowed access to the original recording.
6. I consent to the storage, including electronic, of personal information for the purposes of this study. I understand that any information that could identify me will be kept strictly confidential and that no personal information will be included in the study report or other publication.
7. I agree to the above six points and I agree to participate in the above study.

______________________ ____________ __________________
Name of participant & I/C no. Date Signature

______________________ ____________ __________________
Principal Investigator & I/C no. Date Signature

1

Appendix 18: Pharmacist focus group ground rules



Ground rules of the focus group discussion:

1. Participation in the focus group is voluntary.
2. All responses are valid. There are no right or wrong answers, and you have the right not to answer any questions that deem uncomfortable to you.
3. Do respect the opinions of other participants even if you do not agree with them.
4. Try to stay on the topic; I may need to interrupt so that we can cover all aspects of the focus group discussion.
5. Avoid revealing any personal and sensitive information of your patients or customers that could potentially reveal their identity.
6. Please refrain from sharing or repeating any information from this focus group discussion to others from outside the study.

Appendix 19: Patient interview topic guide

Patient interview

First Question

What is the experience of the condition?

The first research question is to develop an understanding of what patients experience and feel when they have been diagnosed with pre-diabetes or diabetes.

Guiding Questions

- How did you find out about having diabetes?
- How was the information been passed on?
- What did you feel about being diagnosed with diabetes?
- What do you know about the disease before the diagnosis? How was your lifestyle before the diagnosis?

Second Question

How does patient access, understand or apply health information?

The second research question is to explore if patients can access, understand, appraise, and apply health information they obtained from healthcare providers, families and friends and the internet. This is to find out whether they have the capacity to find health information and if they do, whether they apply it to their everyday lives.

Guiding Questions

- How and where do you access or find information about your disease?
- What do you understand about the information you have been told or read?

- What kind of information do you usually look for?
- What do you do with the information you have received?
- How do you feel about health information on the internet and social media?
- If you received health information from healthcare providers or other sources e.g., social media, friends, or families, what language was used, and was the information useful?
- How do you feel about having the choice to choose who you see during your visit to healthcare facilities?
- What other training and guidance do you require to help in accessing or understanding health information?
- Have you use community pharmacy to get advice on self-care, medicines, and supplements?
- What do you understand about the role of a pharmacist?

Third Question

How does your understanding of the condition and its management affect your self-care?

The third research question is to find out what empower patients to self-care management or behaviours. This is to explore whether poor health literacy can affect the empowerment to self-care management or behaviours.

Guiding Questions

- What empowers you to manage your disease?
- What do you know about self-care?
- What self-care activities have you undertaken in managing your disease?
- What do you think is important during patient training to empower self-care behaviours?
- How do you feel about practising self-care?

Appendix 20: Pharmacist interview topic guide

Pharmacist interview

This interview is conducted to find out the perspective of pharmacists on the health literacy and self-care behaviours of pre-diabetes and newly diagnosed T2DM patients. This is to understand how pharmacists interact and communicate with individual patients to promote self-care behaviours in preventing disease progression.

Guiding Questions

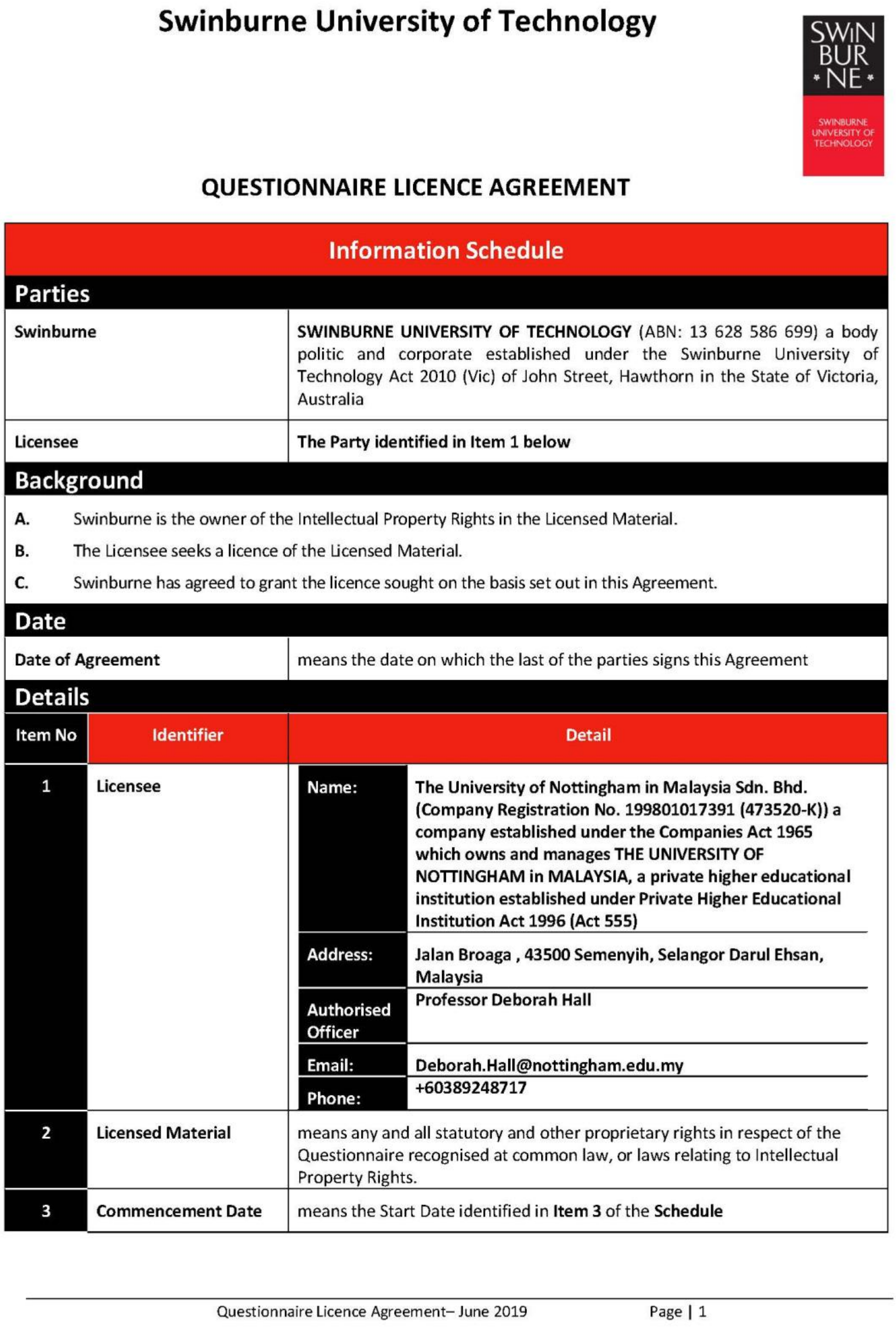
- Tell me about your experience counselling pre-diabetes and newly diagnosed T2DM patients? How is it done, what is discussed?
- In your own words, what do you understand about health literacy and self-care?
- How do you communicate health or medicine information to patients?
- How do you communicate with individual patient based on his/her health literacy level? For example, using laymen terms or diagrams/charts.
- How do you assess patient's health literacy level before any counselling or training? What assessment or communication tool or method used by you to assess patient's health literacy level?
- What do you think about incorporating topics on self-care and health literacy in pharmacy undergraduate programmes, in pre-registration training or at continuing professional development (CPD) level?
- What type of technique or training do you use to help increase patient's empowerment to self-care during patient counselling?
- How can you help to improve the health literacy and self-care management in these group of patients?

- What do you feel when dealing with patients with no knowledge or no empowerment to self-care?
- What is your opinion on the health information available on the internet and social media?
- Have you encounter any experience where patient wanted to clarify health information they received from family and friends/internet/other HCPs?
- Do you think the role of pharmacist is visible enough to the public? Why?

Appendix 21: The 44 items in the HLQ

Part 1 - Scales 1 to 5: How strongly you disagree or agree with the following statements (Strongly disagree/Disagree/Agree/Strongly agree).			
Scale number	**Scale name and abbreviation**	**Question in HLQ**	**Item**
1	**Feeling understood and supported by healthcare providers (HPS)**	Part 1 Q2	I have at least one healthcare provider who knows me well
		Part 1 Q8	I have at least one healthcare provider I can discuss my health problems with
		Part 1 Q17	I have the healthcare providers I need to help me work out what I need to do
		Part 1 Q22	I can rely on at least one healthcare provider
2	**Having sufficient information to manage my health (HSI)**	Part 1 Q1	I feel I have good information about health
		Part 1 Q10	I have enough information to help me deal with my health problems
		Part 1 Q14	I am sure I have all the information I need to manage my health effectively
		Part 1 Q23	I have all the information I need to look after my health
3	**Actively managing my health (AMH)**	Part 1 Q6	I spend quite a lot of time actively managing my health
		Part 1 Q9	I make plans for what I need to do to be healthy
		Part 1 Q13	Despite other things in my life, I make time to be healthy
		Part 1 Q18	I set my own goals about health and fitness
		Part 1 Q21	There are things that I do regularly to make myself more healthy
4	**Social support for health (SS)**	Part 1 Q3	I can get access to several people who understand and support me
		Part 1 Q5	When I feel ill, the people around me really understand what I am going through
		Part 1 Q11	If I need help, I have plenty of people I can rely on
		Part 1 Q15	I have at least one person who can come to medical appointments with me
		Part 1 Q19	I have strong support from family or friends
5	**Appraisal of health information (CA)**	Part 1 Q4	I compare health information from different sources
		Part 1 Q7	When I see new information about health, I check up on whether it is true or not
		Part 1 Q12	I always compare health information from different sources and decide what is best for me
		Part 1 Q16	I know how to find out if the health information I receive is right for me or not
		Part 1 Q20	I ask healthcare providers about the quality of the health information I find
Part 2 - Scales 6 to 9: How easy or difficult the following tasks are for you to do now (Cannot do or always difficult/usually difficult/sometimes difficult/usually eas			
6	**Ability to actively engage with healthcare providers (AE)**	Part 2 Q2	Make sure that healthcare providers understand your problems properly
		Part 2 Q4	Feel able to discuss your health concerns with a healthcare provider
		Part 2 Q7	Have good discussions about your health with doctors
		Part 2 Q15	Discuss things with healthcare providers until you understand all you need to
		Part 2 Q20	Ask healthcare providers questions to get the health information you need
7	**Navigating the healthcare system (NHS)**	Part 2 Q1	Find the right health care
		Part 2 Q8	Get to see the healthcare providers you need to
		Part 2 Q11	Decide which healthcare provider you need to see
		Part 2 Q13	Make sure you find the right place to get the health care you need
		Part 2 Q16	Find out what healthcare services you are entitled to
		Part 2 Q19	Work out what is the best care for you
8	**Ability to find good health information (FHI)**	Part 2 Q3	Find information about health problems
		Part 2 Q6	Find health information from several different places
		Part 2 Q10	Get information about health so you are up to date with the best information
		Part 2 Q14	Get health information in words you understand
		Part 2 Q18	Get health information by yourself
9	**Understand health information well enough to know what to do (UHI)**	Part 2 Q5	Confidently fill medical forms in the correct way
		Part 2 Q9	Accurately follow the instructions from healthcare providers
		Part 2 Q12	Read and understand written health information
		Part 2 Q17	Read and understand all the information on medication labels
		Part 2 Q21	Understand what healthcare providers are asking you to do

Appendix 22: Questionnaire Licence Agreement



Swinburne University of Technology

QUESTIONNAIRE LICENCE AGREEMENT

Information Schedule

Parties

Swinburne	**SWINBURNE UNIVERSITY OF TECHNOLOGY** (ABN: 13 628 586 699) a body politic and corporate established under the Swinburne University of Technology Act 2010 (Vic) of John Street, Hawthorn in the State of Victoria, Australia
Licensee	**The Party identified in Item 1 below**

Background

A. Swinburne is the owner of the Intellectual Property Rights in the Licensed Material.

B. The Licensee seeks a licence of the Licensed Material.

C. Swinburne has agreed to grant the licence sought on the basis set out in this Agreement.

Date

Date of Agreement	means the date on which the last of the parties signs this Agreement

Details

Item No	Identifier	Detail	
1	**Licensee**	**Name:**	**The University of Nottingham in Malaysia Sdn. Bhd. (Company Registration No. 199801017391 (473520-K)) a company established under the Companies Act 1965 which owns and manages THE UNIVERSITY OF NOTTINGHAM in MALAYSIA, a private higher educational institution established under Private Higher Educational Institution Act 1996 (Act 555)**
		Address:	**Jalan Broaga , 43500 Semenyih, Selangor Darul Ehsan, Malaysia**
		Authorised Officer	**Professor Deborah Hall**
		Email:	**Deborah.Hall@nottingham.edu.my**
		Phone:	**+60389248717**
2	**Licensed Material**	means any and all statutory and other proprietary rights in respect of the Questionnaire recognised at common law, or laws relating to Intellectual Property Rights.	
3	**Commencement Date**	means the Start Date identified in **Item 3** of the **Schedule**	

Schedule

Licence Number: L20025IS

Item 1 – The Questionnaire	HLQ – the health literacy questionnaire developed by Richard Osborne, Rachelle Buchbinder, Gerald Elsworth and Roy Batterham and more fully described in "The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)" *BMC Public Health* 2013, 13:658.

Item 2 – Licence Fee	
	Waived (for the duration of the Term)

Item 3 – Approved Purpose	
Purpose	Use of the HLQ in the English & Malaysian Languages for the project "Explorative research on health literacy and self-care management of type 2 diabetes mellitus among Malaysians"
Number of Authorised Implementations	40
Project Start Date	1st June 2020
Project End Date	30th April 2022

Item 4 – Duration of Licence	
	1 year, 11 months

Item 5 – Territory	
	Malaysia

Item 6 – Cultural Adaptation and/or Translation Rights	
	[***The Licensee does not have a right to prepare or obtain a cultural adaptation of the Questionnaire***] [***The Licensee does not have a right to obtain a translation of the Questionnaire***]
Language of Translation	[***N/A***]

The following Questions must be completed within 3 months before the end of the Term. The response to the questions should not exceed one side of an A4 page.

1) Please provide information on the particular purposes for which the questionnaires have been administered in the past 12 months?

2) What challenges (if any) have you encountered in the administration and collection of responses to the questionnaires in the last 12 months?

3) What benefits have accrued through the administration of the questionnaires in the past 12 months? (this may include but not limited to new interventions, re-alignment of practices, input to strategic plans and policy, presentation to stakeholders and broader audiences, publications etc)

4) Did the questionnaire serve your specific needs and purpose? Do you have any suggestions on ways in which the questionnaires may better serve your specific requirements?

Appendix 23: Demographic data of the participated patients

Patient	Age	Gender	Race	State of residence	Diagnosis	Years diagnosed	Medication	Interview	Recruitment site
SA	31	Female	Malay	Selangor	T2DM	2	Oral tablet and insulin	Yes	Online
ZE	35	Female	Malay	Pahang	T2DM	2	Oral tablet	Yes	Online
KA	34	Male	Malay	Pahang	T2DM	<1	Oral tablet	Yes	Online
SL	36	Male	Bumiputera Sarawak	Sarawak	T2DM	2	Not on medication	Yes	Online
S	43	Female	Malay	Johor	T2DM	4	Oral tablet and insulin	Yes	Online
KCK	45	Male	Chinese	Selangor	T2DM	4	Oral tablet	Yes	Online
NS	31	Female	Malay	Selangor	T2DM	2	Insulin	Yes	Online
NL	36	Female	Malay	Kuala Lumpur	T2DM	5	Oral tablet and insulin	Yes	THC
NA	52	Female	Malay	Selangor	T2DM	2	Oral tablet	Yes	THC
JK	21	Female	Chinese	Kuala Lumpur	T2DM	1	Oral tablet	Yes	Online
AR	51	Male	Malay	Selangor	T2DM	5	Oral tablet and insulin	Yes	THC
NHZ	38	Female	Malay	Kuala Lumpur	T2DM	1	Oral tablet and insulin	Yes	THC
MN	43	Male	Malay	Pulau Pinang	T2DM	<1	Not on medication	Yes	Online
CPC	53	Female	Chinese	Selangor	T2DM	<1	Oral tablet	Yes	KDHC
NSS	62	Female	Malay	Selangor	Pre-diabetes	<1	Not on medication	Yes	KDHC

NK	43	Female	Bumiputera Sarawak	Selangor	T2DM	5	Oral tablet	Yes	KDHC
NHA	56	Female	Malay	Kedah	T2DM	2	Oral tablet	Yes	Online
NJ	24	Female	Malay	Labuan	Pre-diabetes	<1	Not on medication	Yes	Online
MRO	42	Male	Malay	Selangor	T2DM	3	Oral tablet	Yes	KDHC
AA	36	Male	Malay	Selangor	T2DM	2	Oral tablet and insulin	Yes	KDHC
AH	51	Male	Malay	Kuala Lumpur	Pre-diabetes	<1	Not on medication	Yes	Online
IS	46	Female	Malay	Selangor	Pre-diabetes	1	Not on medication	Yes	Online
NH	-	Female	Malay	Kedah	T2DM	3	-	No	KDHC
ZW	43	Female	Malay	Selangor	T2DM	2	-	No	KDHC
H	-	Female	Malay	Selangor	T2DM	2	-	No	KDHC
NHM	-	Female	Malay	Selangor	T2DM	3	-	No	KDHC
GA	62	Male	Indian	Selangor	Pre-diabetes	<1	Not on medication	No	KDHC
MI	48	Female	Malay	Selangor	Pre-diabetes	<1	Not on medication	No	KDHC

Appendix 24: Demographic data of the participated pharmacists

Pharmacist	Gender	Race	State	Health sector	Type of pharmacy	Years of service
AK	Male	Malay	Kuala Lumpur	Public	Hospital	8
HN	Female	Malay	Selangor	Public	Health clinic	*Missing data*
CYT	Female	Chinese	Negeri Sembilan	Public	Health clinic	13
KLE	Male	Chinese	Sabah	Public	Hospital	8
RG	Female	Chinese	Selangor	Private	Community pharmacy	12
RI	Female	Malay	Kuala Lumpur	Private	Hospital	1
JO	Female	Chinese	Selangor	Private	Community pharmacy	5
LSP	Female	Chinese	Selangor	Private	Community pharmacy	5
MH	Male	Malay	Selangor	Private	Hospital	3
MR	Female	Indian	Negeri Sembilan	Private	Community pharmacy	10
NO	Female	Malay	Selangor	Private	Community pharmacy	15
CT	Female	Chinese	Selangor	Private	Community pharmacy	10
H	Female	Malay	Negeri Sembilan	Public	Health clinic	2
TN	Female	Malay	Selangor	Public	Hospital	2