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The Role of an Online Community in Supporting Diabetes Self-Management in Thailand

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# The Role of an Online Community in Supporting Diabetes Self-Management in Thailand

Nittaya Boonchum

A thesis submitted in partial fulfilment of the requirements of Sheffield Hallam University for the degree of Doctor of Philosophy

December 2023

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I hereby declare that:

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- 2. None of the material contained in the thesis has been used in any other submission for an academic award.
- 3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.
- 4. The work undertaken towards the thesis has been conducted in accordance with the SHU Principles of Integrity in Research and the SHU Research Ethics Policy.
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Director(s) of Studies	Dr. Kathy Doherty

#### Nittaya Boonchum

A thesis submitted in partial fulfilment of the requirements of Sheffield Hallam University for the degree of Doctor of Philosophy

### Thesis title:

The Role of an Online Community in Supporting Diabetes Self-Management in Thailand

### Abstract

One of the greatest health issues facing the world today is diabetes mellitus (diabetes), and Thailand is no exception. Even though diabetes cannot be cured, those who manage their illness well can have normal lives. To effectively monitor and regulate their blood sugar levels, people with diabetes must spend a significant amount of time working on self-management outside of medical settings. Most patients fail to complete this procedure because it is patient-centred, meaning that patients must complete it primarily on their own. Since questions or problems with their diabetes treatment could arise at any time, they search online for support. In addition to providing users with constant access to information about diabetes self-management, online forums allow users the chance to connect with others, exchange stories, ask questions, and seek assistance. The aim of this thesis is to examine the ways in which people use the online community Pantip to exchange their knowledge and experience as part of the self-management of diabetes and as carers, as part of an overall strategy of managing diabetes, and to explore the cultural context for diabetes self-management in Thailand. The analysis examines 992 individual posts in 177 message threads during a period of 6 months on a message board on Pantip and the interviews with 15 members of the forum. A thematic analysis was conducted to identify major themes related to the diabetes self-management. According to the study, the site helps users with peer support, informational support, and emotional support, particularly when it comes to lifestyle management, which is the self-manager's main area of the problem. Users of Pantip also consider how Thai culture either encourages or discourages self-management. While Thai cuisine can be a barrier to diet control, which may lead people with diabetes to utilize complementary and alternative therapies, Thai family structures promote the adult child's role as a carer in Thailand. Even though Thailand permits the use of both conventional medicine and complementary and alternative medicine (CAM), most patients never discuss their use of CAM with their doctors; they choose to discuss it online. Pantip acts as a resource for individuals, helping them understand why they use it, assisting in rechecking it, and providing advice to caution against latent advertising. For carers, Pantip is a place to learn about the responsibilities of caring for people with diabetes and how to deal with crises or struggles by receiving both informational and emotional support. Overall, the community supports patient-centred approaches that are the cornerstone of diabetes management by sharing experiences that provide insights into how people with diabetes deal with their diseases and how Thai culture affects self-management. Pantip, an online community, can help people with diabetes and their carers practice better self-management, which may improve their health outcome.

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## **Chapter 1: Diabetes in the Thai Health Care Context**

## **1.1 Introduction**

This study examines the experience of people in Thailand living with diabetes mellitus (diabetes) focusing on the role of the online community Pantip. com in supporting selfmanagement and well-being, including its use by carers and family members. Diabetes is a health condition whose prevalence has increased globally. For many countries, the diabetes epidemic is a huge concern. In Thailand, Non-Communicable Diseases (NCDs) continue to be the country's biggest health issue in terms of both the number of deaths and the overall illness burden, with diabetes ranking as the sixth leading cause of death for Thai people (Division of Non-Communicable Disease, 2019).

Diabetes self-management (DSM) is a critical component of diabetes therapy where people with diabetes take responsibility for caring for themselves. When first diagnosed, people with diabetes are given management instructions by medical specialists. Some of these responsibilities include testing procedures, medication, diet, and exercise. Diabetes is a chronic condition so people who have it must adapt to some quite difficult lifestyle modifications that are frequently emotionally stressful. Health- care facilities cannot be available 24 hours a day to respond to questions or difficulties, which can happen at any time. People who are managing their diabetes may find it difficult to comprehend or adapt to new routines. Their friends and family may find themselves in a new and potentially stressful role of caring for and monitoring the person with diabetes in their new role as a "family health volunteer" (as now defined by the Ministry of Public Health in Thailand). People with diabetes and members of their support network may therefore desire to seek assistance, advice, and social support outside of clinics and official resources.

This study explores the role that the online community Pantip.com plays in supporting DSM for people with diabetes in Thailand, and members of their support network.Drawing on interviews with people adjusting to and living with diabetes and analysis of talk about diabetes on Pantip.com (Pantip) itself, it considers the reasons why people go to Pantip for help and support and the ways that the online community responds. In the context of Thailand, it also explores how and why people with diabetes and their carers may turn to the Pantip online community for advice about traditional Thai approaches to diabetes management considered to be complimentary, alternative, or even contrary to the self-care regimes recommended by their clinicians and official education materials.

This program of research aims to examine the ways in which people use the online community Pantip to exchange their knowledge and experience as part of the self-management of diabetes and as carers, as part of an overall strategy of managing diabetes, and to explore the cultural context for diabetes self-management in Thailand. The main objectives are:

1. To explore how Pantip.com supports self-management and control of diabetes by analysing the interactions on the forum and the topics of discussion that members bring to the online community.

- 2. To explore how Pantip.com supports family members and carers of people living with diabetes by analysing the interactions on the forum and the topics of discussion that members bring to the online community.
- 3. To consider the significance of Thai culture in discussions about living with diabetes on Pantip. com, including consideration of the popularity of complementary and alternative medicine.
- 4. To explore members' accounts of the experience of adjusting to and living with diabetes or caring for someone living with diabetes in Thailand including the reasons for visiting Pantip.com

## **1.2 Overview of chapters**

In Chapter one, the prevalence and effects of diabetes are explored both globally and in Thailand. The literature review of Thailand's healthcare system, diabetes care, and national diabetes policy are presented. A discussion of the healthcare systems in Thailand and the United Kingdom is then shown to help the viewer understand and grasp the overall picture of Thailand's healthcare system. The patient path in the Thai clinic that follows illustrates how individuals move through the healthcare system from getting a diagnosis to self-managing diabetes. The Thai setting for conventional complementary and alternative approaches to healthcare and diabetes self-management is examined. The chapter then moves on to define and discuss diabetes self-management, which persons with diabetes must undertake and take responsibility for outside of the clinic, as they adjust to living with diabetes, and considers the role that peer support and carers might play in supporting self-management.

Chapter two discusses self-management in long-term ailments. The chapter begins with an overview of literature which examines the lived experience of long-term illness and the difficulty of self-management in general for chronic illness. The chapter then examines research literature on the role of internet communities for people with diabetes. Finally, the specific research questions are outlined.

Chapter three is devoted to a discussion of the research methodology and methods used in this investigation. The chapter begins with an explanation of the research design and data collecting, followed by a discussion of case selection of the site. Then, the considerations the ethical considerations surrounding this research. Following that, it explains how to select samplings and gather data both threads and interview. Finally, a description of how to analyse the data is given.

The analyses and findings of are presented in Chapters four, five, six, and seven. Chapter four considers how people use Pantip even before being diagnosed with diabetes and considers the topics and concerns they bring to the Pantip community in the early stages of the disease and adjustment to being a person with diabetes, and how the community responds. In chapter five the role of Pantip in site users' daily self-management of their diabetes is examined and findings in chapters four and five are also supported by interview data. In chapter six, the significance of the online community as a source of knowledge and assistance about Thai traditional complementary medicine (CAM) and alternative approaches to health

care and DSM is discussed. The analysis explores threads in which members actively consider the potential merits of such approaches in relation to 'official regimes' and seek advice from the community and community responses. The status of the community as a target for selling CAM approaches is also discussed. In chapter seven, the importance of carers in diabetes selfmanagement, their experience of caring and using online communities and the function of forums in assisting them to aid self-managers is explored.

Chapter eight draws the main findings from the study together and discusses the main contributions to knowledge. Practical implications and suggestions for future research are also addressed.

## 1.3 What is diabetes mellitus?

Diabetes mellitus (diabetes) is a chronic illness that has no cure. The World Health Organization (WHO) defines diabetes as a condition in which the pancreas fails to generate enough insulin, or the body is unable to efficiently use the insulin it does produce. Insulin controls blood glucose so if diabetes is not adequately managed, a person's blood sugar levels can be too high causing hyperglycaemia - a fasting blood sugar level over 130 mg/dL which is damaging to the body. Hypoglycaemia, or too little blood sugar (a fasting blood sugar level below 70 mg/ dL), is frequently a side effect of blood sugar- lowering medication (InformedHealth.org, 2020).

Diabetes can be caused by inherited, epigenetic, and environmental factors (International Diabetes Federation [IDF], 2011). Diabetes is divided into four types. Type 1 Insulindependent diabetes, also known as juvenile or childhood-onset diabetes, is characterized by inadequate insulin production, and required daily insulin delivery (Tripathi et al., 2016). Type 1 diabetes has an unknown cause. Some scientists believe it is caused by a genetic mutation (DiabetesInfo, 2015). Type 2 diabetes, also known as non-insulin-dependent diabetes or adult-onset diabetes, is caused by the body's inefficient use of insulin. Type 2 diabetes affects 90% of diabetic patients worldwide. Pregnant women can develop gestational diabetes. During pregnancy, sufferers experience hyperglycaemia, which is defined as blood glucose levels that are higher than normal. Various types of diabetes caused by other causes, such as exocrine pancreas illnesses, monogenetic diabetes syndrome, and drug-induced diabetes, are the fourth category (Tripathi et al., 2016b). Patients with diabetes symptoms from other causes, such as pancreas abnormalities, endocrine system problems, or the use of steroids, may develop the last form of diabetes (DiabetesUK, 2015). Diabetes can also lead to major complications such as heart disease, stroke, cardiovascular illness, amputation, blindness, and kidney disease (World Health Organization [WHO], 2016).

## 1.4 The prevalence and impact of diabetes

In the 21<sup>st</sup> century, diabetes is one of the global health emergencies, data shows that there are 463 million people living with diabetes and there will be 578 million adults with diabetes by 2030, and 700 million by 2045 (IDF, 2019). 4.2 million people aged 20–79 years were estimated to die from diabetes-related causes in 2019 (IDF, 2019). Due to global health

emergencies, the expenditure in healthcare around the world is growing faster than gross domestic product and more rapidly in low and middle-income countries (Xu et al., 2018).

In 2017, it was predicted that the mortality among people 20–99 years old from diabetes was 5.0 million people. Globally, diabetes represented 9.9% of all-causes of mortality among individuals in this age range (Cho et al., 2018). The estimated number of deaths from diabetes among adults aged 20 to 99 in 2017 was 5.0 million. Around the world, diabetes accounted for 9.9% of deaths from all causes among people in this age group (Cho et al., 2018).

The Western Pacific Region has the highest number of people living with diabetes of any region of the globe with approximately 158.8 million adults (IDF, 2019). Thailand is in the Western Pacific Region, which has the highest number of people living with diabetes and the highest number of deaths among the IDF countries. In addition, this zone has more than half (54%) of the people living with diabetes that have not been diagnosed and has a higher risk of other complications and costly problems. Thailand is in the group of top 5 countries for the number of people living with diabetes in this region, which comprises China, Indonesia, Japan, Thailand, and the Philippines respectively. There were 4,426,959 people living with diabetes in Thailand in 2017 (Cho et al., 2018) and it is expected that this will increase to 5.3 million people in 2040 (Novonordisk Thailand, 2017).

In Thailand, more than 70% of mortality is caused by non-communicable diseases (NCDs) including diabetes, with the result that more than 200 people per day died because of diabetes in Thailand in 2017. Furthermore, Thailand is now an ageing society, and it is predicted that the population aged more than 60 years old is 14.4 million people (more than 20% of total population). One in five people in the elderly population, will be diagnosed with diabetes (Novonordisk Thailand, 2017).

Thailand has made a substantial commitment to controlling NCDs and achieving global goals to lower the mortality rate from NCDs by a third by 2030 Novonordisk Thailand, 2017). As a result of this commitment, the Ministry of Public Health (MoPH) has designated diabetes as one of the diseases that counts in terms of prevention and treatment, as specified in the National Strategic Plan for Public Health in next 20 years, which was organized by the Policy and Strategy in 2017. The Cabinet also adopted the premise of a five- year National Noncommunicable Disease Prevention and Control Strategic Plan (2017–2021), which is a continuation of Thailand's Healthy Lifestyle Strategic Plan 2011–2020.

The Bureau of Non-Communicable Diseases and the Office of Healthy Lifestyle Management have been designated as the primary responsible parties, with the goal of ridding the country of the avoidable burden of NCDs by 2021, to ensure that the population is in good health, to optimize the productivity of all age groups, and to ensure that these NCDs do not impede the quality of life and economic development (MOPH, 2018).

As explained above, diabetes is part of the major disease problem of NCDs and has a direct impact to patients and their families due to illness and disability and significant adjustments to lifestyle. In term of the economy, the government invests a large amount in healthcare for NCDs. In 2016, the average cost was 3,128 Bath per person per year (approximately 70 GBP)

excluding the burden such as needles for blood sugar test in people who are government officers that individuals need to pay by themselves at around 1,750 Bath per person per year (around 40 GBP). Another impact on society is premature death in people with NCDs, affecting a loss of productivity in the population. At the individual level, NCDs and risk factors are related to poverty because individuals who have poor economic status eat unhealthy food, consume tobacco and alcohol, and are often obese (MOPH, 2016).

## 1.5 Symptoms, diagnosis, and treatment

There are four types of diabetes (the interviewees in this study covered all categories) as stated in section 1.3: Type 1 Diabetes, Type 2 Diabetes, gestational diabetes, and other kinds of diabetes due to various causes. The following are the symptoms and diagnoses for all types:

Type 1 Diabetes affects people of all ages, though it is most common in children and adolescents. Because type 1 diabetes is difficult to identify, it necessitates the use of additional tests to confirm the diagnosis. This kind of diabetes requires daily insulin injections, as well as regular blood glucose testing and a healthy lifestyle. Type 1 diabetes accounts for about 10% of people with diabetes. Being thirsty and having a dry mouth, losing weight without trying, frequent going to the toilet, especially at night, exhaustion, blurred eyesight, continual hunger, genital itching and wounds taking longer to heal are some of the most typical symptoms (Diabetes.org, 2020; DiabetesUK, 2020; IDF, 2020).

Type 2 Diabetes is the most common type of diabetes, affecting over 90% of people with the disease. It is most diagnosed in the elderly, but as the number of obese people rises, it is becoming more common among children, adolescents, and young adults. The indications and symptoms are identical to Type 1 Diabetes, however in many people there are initially no symptoms, thus they go unnoticed, and some people may have Type 2 diabetes for up to ten years before being recognized. To help regulate their glycemia, oral medicine and insulin are usually provided, along with daily blood sugar tests and self-management of diet and exercise (see section 1.7 below for detailed discussion of self-management practices). People with Type 2 Diabetes who can maintain their blood glucose at normal levels (HbA1c level of 48mmol/mol or 6.5 percent or below) do not need to take diabetes medication, which is known as remission diabetes. This is quite difficult to achieve because diabetes can reappear at any time (Diabetes.org, 2020; DiabetesUK, 2020; IDF, 2020).

## 1.6 Psychosocial consequences of diabetes

People adjusting to and living with diabetes may experience issues with their emotional or psychological well-being (Kalra et al., 2018). Psychosocial issues, according to the American Diabetes Association, include complicated environmental, social, behavioral, and emotional aspects (Young-Hyman et al., 2016).

Evidence reveals that at least four out of ten people with diabetes suffer from emotional issues such as depression, anxiety, and fear problems (DiabetesUK, 2016), which can influence and be caused by diabetes self-management and lifestyle changes (see more detail in section 2.3) and have negative health repercussions (Bateman, 2018). The American Diabetes

Association (Young-Hyman et al., 2016) position statement underlines the importance of integrating psychosocial and medical care for all people with diabetes.

Individuals with diabetes are responsible for maintaining their glycemia within a prescribed range, but irritation and emotional suffering during self-management may become a barrier to achieving this (Weinger & Jacobson, 2001). Dietary restrictions, blood glucose self-monitoring, insulin injection, and a lack of support from family and healthcare providers are among the challenges they may face as a result of their diabetes (Rubin & Peyrot, 2001). Furthermore, there is no guarantee that persons with diabetes will have near-normal blood glucose levels or avoid other issues if they follow that treatment program (Rubin & Peyrot, 2001).

People living with diabetes are therefore likely to require psychological help throughout their lives as they cope with managing the disease. Positive emotional well-being may help individuals cope more effectively in the long run, shield them from negative repercussions, and improve their physical health (Chew, 2014). High stress levels are associated with the quality of life of individuals living with type 2 diabetes in Thailand, and patients may be advised to participate in skill-building programs to help cope with their stress (Duangchinda, 2015).

Diabetes UK (2016) employs a pyramid model to categorize the psychological and emotional needs of persons living with diabetes into five levels, ranging from mild to severe, as illustrated below (figure 1). They note that general coping difficulties associated with the consequences for lifestyle are common for most people receiving a diagnosis and can develop into more severe difficulties including anxiety and difficulty complying with self-care and, in more severe cases, depression or severe and complex mental illness:

#### LEVEL 5 Severe and complex

mental illness, requiring specialist psychiatric intervention(s).

#### LEVEL 4

More severe psychological problems that are diagnosable and require biological treatments, medication and specialist psychological interventions.

#### LEVEL 3

Psychological problems which are diagnosable/classifiable but can be treated solely through psychological interventions, e.g. mild and some moderate cases of depression, anxiety states and obsessive/compulsive disorders.

#### LEVEL 2

More severe difficulties with coping, causing significant anxiety or lowered mood, with impaired ability to care for self as a result.

LEVEL 1 General difficulties coping with diabetes and the perceived consequences of this for the person's lifestyle etc. Problems at a level common to many or most people receiving the diagnosis.

#### Figure 1: Pyramid of psychological problems (Diabetes UK, 2016)

Nonetheless, the majority of diabetes care guidelines focus on the medical components of initial management, leaving psychosocial support to those with diabetes unmet (Kalra et al. 2013 as cited in Kalra et al., 2018). "Identifying and supporting patients with psychosocial problems early in the course of diabetes may promote psychosocial well-being and improve their ability to adjust or take adequate responsibility in diabetes self-management" because of the difficulty of diabetes self-management and the needs of people living with diabetes (Kalra et al., 2018, p. 696). This unmet need for support in adjusting to and taking responsibility for DSM may be one reason why people seek out advice and reassurance from online health communities. Bateman argues that psychologists should be part of the primary care team since psychological difficulties associated to diabetes have an impact on the quality of life of people living with it and influence successful daily self-management. They can help diabetics achieve better physical outcomes (Bateman, 2018).

In Thailand, the Department of Disease Control, Ministry of Public Health, has written in the manual of NCDs Clinic plus quality evaluation work year 2018, 2019, and 2020 that health professionals should ask two questions from the depression screen form or 2Q form, expressing concern about the psychosocial health of people living with diabetes. If the patients say no, it suggests they are not at risk of becoming depressed. If they answer yes to both questions, they are at risk of developing depression, and healthcare providers will utilize

the depression evaluation form, also known as the 9Q form, to analyze the patient's behavior over the previous two weeks. The result will be converted into a scale of 0-27 points, with a score of less than 7 indicating little or very limited depression distress, and a score of more than 27 indicating severe depression distress. A score of 7 to 12 indicates mild depression, 13 to 18 indicates moderate depression, and a score of more than 19 indicates severe depression. Health practitioners will proceed to the next stage for those who have severe depression by using a suicide evaluation form, also known as an 8Q form, which has eight questions to analyze an individual's suicide trend. If a person's score is higher than 17, he or she will be referred to a psychiatrist immediately (Department of Disease Control, 2020; Department of Disease Control, 2018).

Since the number of Thai people who commit suicide has gradually increased, worry about depression has grown in Thailand, and it is now one of the top 10 health problems in Thailand and around the world. Depression affects 39% of Thai diabetes patients (Jarassaeng et al., 2012) As previously stated, the depression screen form is used to determine whether persons in Thailand are at risk of developing depression.

## 1.7 Healthcare in Thailand

### 1.7.1 Healthcare Systems in Thailand and services for diabetes care

To provide some context for the investigations in the thesis, this section discusses the services in Thailand's public health system that are relevant to the experience and care of people with diabetes. Thailand has attained a high standard of healthcare services and governance, including, "substantial health benefits at a relatively moderate cost in terms of total health expenditure per capita". Despite this, the Government has failed to ensure that all citizens have equal access to public health infrastructure and personnel. They are still restricted to the capital and other major cities (Pongpirul et al., 2009).

Thailand's Ministry of Public Health, like mainland China, Taiwan, and Malaysia, is responsible for developing and implementing public policies throughout the country, including collecting and storing health-care data (Aljunid et al., 2012). The major purpose of Thailand's 12th National Development Plan, which runs from 2017 to 2021, is to improve quality and universal security for all Thais (Ministry of Public Health, 2017).

The healthcare system in Thailand is a mix of public and private sectors in terms of both supply and financing of healthcare (Aljunid et al., 2012) and support for people with diabetes might come in the form of behavioural, educational, psychosocial, or clinical services (Powers et al., 2016). The majority of healthcare services are provided by the public sector, which comprises 1,303 hospitals with in-patient services (Ministry of Public Health, 2017) and 61,418 health stations (Ministry of Public Health, 2012). In the private sector, there are 347 hospitals and medical specialty clinics. The majority of private healthcare facilities are centred in Bangkok (National Statistical Office, 2017).

In accordance with the Geographic Information System, the Office of Permanent Secretary of Thailand's Ministry of Public Health divides the healthcare service system into three tiers: primary care, secondary care, and tertiary care.

The primary care tier has responsibilities for health promotion, screening, disease prevention and healthcare services at the outpatient departments (OPD). The secondary care tier provides a health service with beds for the patients (In Patient Department or IPD) with common problems, more complex treatment or very complex treatment which require medical specialists in both major and minor specialism, such as ophthalmology, radiology, psychiatry, rehabilitation medicine, and medical crisis treatment. The tertiary care tier includes medical specialist and sub-specialists; and excellence centres, offering diseasespecific treatment centres such as heart centre, cancer centre, organ transplant centre, and trauma centre (see figure 2).



Figure 2: Hierarchy of health care service system in Thailand (Thai Health Coding Centre, 2015)

All Thai citizens have public health insurance that covers healthcare services in primary care, secondary care, and tertiary care levels respectively. There are three main public insurance programmes, including the universal health coverage scheme (UCS), making Thailand the first country in Southeast Asia to achieve this programme for its entire population, along with the civil servant medical benefit scheme (CSMBS), and the social security scheme (SSS). The UCS is financed through general taxation with benefits for the poor, children, the elderly, and the disabled. The CSMBS is financed through general tax and a non-contributory scheme, and the

SSS is financed through equal contributions from the government, employers, and employees. These three schemes cover 75%, 9%, and 16% of the Thai population respectively (Deerochanawong & Ferrario, 2013).

As previously stated, all Thai residents have access to public health insurance. However, recent evidence suggests that persons living with diabetes address unmet needs in diabetes care at multiple phases, including screening, diagnosis, treatment, and control. As a result, Thailand continues to require effective behavioural and structural interventions, particularly at the primary care level (Yan et al., 2020).

## 1.7.2 Healthcare system in Thailand and the UK

To help us understand further the elements of the Thai healthcare system, I compare it here to those of other developed countries, such as the United Kingdom, which has one of the largest and greatest healthcare systems in the world (Duncan & Jowit, 2018). The National Health System (NHS) in the United Kingdom oversees healthcare and reports to the government. Primary care, often known as community care, includes GPs, dentists, pharmacists, and other health professionals; secondary care, which includes hospital-based care is accessible through GP referral or emergency admission; and tertiary care. These three levels are comparable to Thailand's, with the exception that Thailand's primary care level lacks doctors, dentists, and pharmacists, at this level, only nurses and health educators' work.

Topics	Thailand	UK
Institute	МОРН	NHS by the central government
Healthcare service system	Primary, secondary, tertiary (No physicians at primary care level.)	Primary, secondary, tertiary (Doctors, dentist, pharmacists etc. work at primary level.)
Funding	Tax, a non-contributory, government, employee, employer	Tax and national contribution
The number of staff	Shortage	Increased
Patient Experience Feedback survey	Lack of data	Annually
Current health burden	Non-communicable disease, including diabetes	Non-communicable disease including diabetes

Table I: Comparison of the healthcare system of Thailand and the UK

Due to the lack of physicians at the primary care level, Thais must go to the secondary care level to visit a doctor. As a result, at the secondary care level, long lines form to see a doctor, and crowds of patients form.

## 1.8 Diabetes care in Thailand: the patient's journey

The diabetes treatment guidelines endorsed by the Thai Diabetes Association, the Endocrine Society of Thailand, and the MOPH, which are updated every three to four years, with the most recent version released in 2017, provide a comprehensive and effective system for patients to easily access services in a timely manner (Deerochanawong & Ferrario, 2013).

The chronic care model (CCM) by Wagner EH (Wagner, 2011) was used to establish the pattern of chronic NCD care and diabetic clinics in Thailand. The patient is at the centre of this CCM concept. From 2013 to 2016, the diabetes care clinic followed the Clinical Practice Guideline for Diabetes, and from 2017 to 2018, the Bureau of Non-Communicable Diseases prepared a manual on how to conduct quality assessments (Ministry of Public Health, 2017), with a revised edition due in 2020. In Thailand, the ministry of public health established a diabetic self-management standard, which was later replaced by the American Diabetes Association's standard.

## 1.8.1 Prediabetes screening in Primary Care

Pre-diabetes screening is accessed at the primary care level. The hope is that individuals can quickly control their disease if they detect the risk of diabetes early. The two main workers in primary care are health professionals and village health volunteers. The emphasis is on screening for diabetes for anyone aged 15 and up. Individuals take a screening test in which they answer six questions regarding their age, gender, BMI, waist circumference, hypertension, and family history of diabetes, and the results are translated into a diabetes risk score. The score is on a scale of 0 to 17. If a person's score is less than 6, they are followed up every 1–3 years with advice on how to exercise and maintain a healthy weight. If their score is equal to or more than 6, they will be identified as in the high-risk zone for diabetes. This group of people are followed up, which involves testing their blood glucose levels using a Dextrostrix (DTX). If their DTX is equal to or greater than 100mg/dl, they will be referred to a secondary care facility for a fasting blood glucose test (FPG). If their DTX (or FPG) is less than 100mg/dl, they will be scheduled for annual checks.

Individuals with FPG between 100 and 125 mg/dl receive a follow-up in the next 6 months, while those with FPG greater than 125 mg/dl have their FPG level checked again within one or two weeks. At the same time, they are offered education on how to maintain healthy blood glucose levels on their own, including how to eat healthy, exercise, and use a glucose monitoring program. Patients are diagnosed with diabetes and transferred to secondary care level if their results remain stable at above 125 mg/dl where they will be seen by doctors. When a person is newly diagnosed with diabetes, they will be asked questions about their medical history, age, and symptoms, all of which will be noted in the diabetes register.

Due to a scarcity of physicians and specialists, many Thais do not engage with primary care screening, accessing services when symptomatic at the secondary tier care.

Because Thailand's primary healthcare system is experiencing a physician shortage, patients are being directed to secondary care. Even though Thailand has universal health coverage,

there are still inequalities in access to treatment. Furthermore, individuals living in remote locations are unable to receive therapy or be monitored.

# **1.8.2** Secondary care services including self-management education and support

Patients may be transferred from screening or be diagnosed as newly diabetic in secondary care level if they have symptoms. A multidisciplinary team manages the overall operation of diabetes care, including medical diagnosis and registration, stages of diabetes assessment, risk factor prevention, disease control, and treatment, and the NCDs case manager/ coordinator oversees chronic disease management and patient care. The multidisciplinary team are responsible for delivery of self-management education.

Self-management is an intervention developed for patients to better manage their chronic conditions. It is defined as a day-to-day task and the ability of people with long-term illnesses to regulate or lessen the burden of disease which they have to deal with their physical health status (the symptoms, treatment, physical, social outcome, and lifestyle changes) and psychological problems (Richard & Shea, 2011; Barlow et al., 2002; Clark et al., 1991). This approach is considered significant and crucial in the management of chronic diseases that people living with them must handle on their own (Holman & Lorig, 2004). Thomas Creer was one of the first to coin the term "self-management" to describe how patients might take control of their own treatment (Lorig & Holman, 2003).

There is no gold standard for the self-management process, though Corbin and Strauss (1988) were the first to identify the processes of self-management, stating that there are three tasks of self-management that arise from having a long-term condition: medical management ( taking medications and attending medical appointments) , behavioural management ( lifestyle management) , and emotional management. Problem solving, decision making, accessing resources, engaging with healthcare providers, taking action, and building self-efficacy are six self-management strategies outlined by Lorig and Holman (2003).

Schulman-Green et al., (2012) analysed 101 qualitative studies published between January 2000 and April 2011 that described self-management processes in long-term conditions and discovered three categories of self-management processes: focusing on illness needs (e.g., learning about conditions, recognising and meaning body response, and changing behaviours to minimize disease impact), activating resources (e.g., family members, friends, healthcare providers, and community resources and services), and living with a chronic illness (e.g., tasks and skills related to coping with the illness, transitioning from a focus on the illness needs to integrating the illness into the context of the individual's life).

People with chronic conditions who can take control with good self-management skills can improve clinical health outcomes, such as lessening pain, becoming more active, feeling stronger, feeling more in control of their health, and being better able to enjoy their family, friends, and favourite activities (WA Health, 2007), as well as reduce unnecessary health care utility and costs (Silva, 2011; Sawyer & Aroni, 2005).

However, patients may struggle to adapt to the responsibility and new routines, diet and regimes that are part of self-management (Kadirvelu et al., 2012) as seen by the large proportion of people with diabetes who are unable to control their blood glucose levels. In Thailand, 65 percent of diabetic individuals are unable to control their blood sugar levels (Rangsin & MedRes, 2014, as cited in Novonordisk Thailand, 2017). Physical barriers, such as the nature of their condition/ conditions, where people have different needs; financial barriers, such as physical limitations of access to services, time, location, and financial cost; and system barriers, such as different advice or a lack of collaborative working between healthcare and social care, are all potential barriers to self-management (Novonordisk Thailand, 2017).

The Diabetes Self-management Support program in Thailand is frequently held in locations that are easily accessible to the public, such as healthcare centres, churches, or community centres. DSMS has been found to improve clinical outcomes and quality of life while reducing hospital admissions and care costs due to a lower risk of complications in numerous trials (Suwannarat et al., 2019; Beck et al., 2017; Powers et al., 2016). Individuals with diabetes who process this information and have the motivation and capacity to control their disease on a regular basis will benefit from these programmes and may not need to access Tier 2 services (Gómez-Velasco et al., 2019)

Diabetes self-management education (DSME) is considered to be a crucial component of excellent diabetes care that generates favourable health outcomes (the American Diabetes Association, 2016; Hass et, al, 2014), and it is a standard of diabetes medical treatment all over the world. DSME is an ongoing process that aims to enhance clinical results, health status, and quality of life by facilitating the knowledge, skill, and ability required for diabetes treatment (Powers et al., 2017).

The ten topics that make up self-management education are as follows: (1) diabetes basics, (2) nutrition therapy, (3) exercise, (4) diabetes treatment, (5) blood glucose self-monitoring and interpretation of results, (6) prevention and treatment of hypoglycaemia and hyperglycaemia, (7) diabetes complications, (8) general health care, 9) foot care, and (10) diabetes at special times, such as illness, vacation, pregnancy, party, school, and work. Topics 1–5 and 8 are fundamental knowledge for all patients, although topics 6–7 and 9–10 will vary depending on the individual's concerns.

Posters, electronic media, and models/examples, such as food or exercise, are all provided by the health educators for diabetes management. After some education, the health professional team will use blood glucose testing to determine whether these self-management programs are appropriate for those patients and will encourage them to record their symptoms and self-management in a personal diary. Following their initial diagnosis, everyone will receive a diary. The objective of the diary is to measure one's understanding and track the patients' self-management. Most of the self-management education is done in groups rather than individually. If a patient's illness is under control and their FPG is less than 126 mg/dl, the secondary care level will refer them back to the primary care level, where they will continue to be monitored and access medication.

As a global standard, DSME is explained to all newly diagnosed patients and at all phases of diabetes symptoms, including Thailand (Berard et al., 2018; Ministry of Public Health, 2012). DSME is also started in Thailand once people are diagnosed with diabetes at the secondary care level. The ADA does, however, urge that healthcare practitioners continue to train DMSE and test self-management skills and understanding of diabetes least once a year (Care et al., 2002).

Prior research on DSME found that it reduced HbA1c levels, which are clinical markers in people with diabetes, improved biometrics and self-efficacy ratings, and lowered the risk of all-cause mortality (Hermanns et al., 2020; Chrvala et al., 2016; He et al. 2016). As a result, DSME can aid persons with diabetes in staying healthy and avoiding costly consequences.

However, the majority of those who take part in the DSME intervention did not reach optimum HbA1c levels (including in Thailand as explained previously in section 1.6). Because diabetes is a long-term illness, it may be difficult to maintain. According to Klein et al. (2013), most DSME programs are short-term (Funnell et al., 2007) and "rely heavily on rules and procedures to guide decisions about diet, exercise, and weight loss" (p.1), so, "DSME may need to include cognitive self-monitoring, diagnosis, and planning skills to help patients detect anomalies, identify possible causes, generate a treatment plan, and generate a treatment plan"(p.1).

There is evidence from the research that identified the obstacles to diabetes selfmanagement education and support from healthcare professionals' perspectives in Thailand and found that obstacles to diabetes education were a lack of time due to other duties, a lack of skills in assisting patients with behavior change, inadequate diabetes educator numbers, patient disinterest in diabetes education, and patient reluctance to change unhealthy behaviors (Preechasuk wt al., 2019).

Instead of focusing on knowledge and skills, the DSME concept has evolved to include more self-management and empowerment (Hermanns et al., 2020).

Figure 3 shows that the stage of practicing self-management at home is the stage in which diabetes management takes place outside of healthcare centres four times a year in Thailand (Ministry of Public Health, 2012) due to a lack of health experts. These two variables could be the reason why patients look for help elsewhere (Jansink et al., 2010, Kolasa & Rickett, 2010). Patients who are able to regulate their blood glucose (FPG126mg/dl) will be transferred back to primary care. This circumstance may serve to alleviate the scarcity of medical personnel, as well as help patients with diabetes live longer and healthier lives. As a result, initial and ongoing diabetes education must be extensive in scope while also being tailored to each person's unique needs.

## **1.8.3** Tertiary care level for treatment of complications

Patients who cannot control their diabetes and have other ailments such as kidney disease, cardiovascular disease, blindness, or who need to be referred for amputation will be transferred from the secondary care level to the tertiary care level or an excellence centre.



Figure 3: Diabetes self-management education system in Thailand

# 1.9 Complementary and alternative treatments for diabetes in Thai Traditional Medicine

In Thailand, individuals with chronic conditions commonly use Thai Traditional Medicine (TTM) instead of or as well as medical treatments prescribed within the health care system. In this section I will describe the context and background for complementary and alternative medicine (CAM), and in chapter six will explore the role of Pantip in supporting community members to access CAM as part of their self-management.

The usage of CAM by patients with diabetes ranges from 17 percent to 72.8 percent worldwide (Chang et al., 2007), with as many as nearly half (47.8 percent) of people with diabetes in Thailand using CAM (Moolasarn & Ms, 2005). According to Chang et al. (2007) nutritional supplements and herbal medicines are the most utilized CAM. Mindfulness, biofeedback, relaxation, qigong, massage treatment, yoga, alternative food, and lifestyle modification are some of the various types of CAM that have been reported in prior studies. However, little is known regarding the safety and efficacy of herbal, vitamin, and other dietary supplements for diabetes (Yeh et al., 2003).

Thailand's own medicine is known as Thai Traditional Medicine (TTM). TTM is a holistic medicine system that has been established, systematized, amended, recorded, and passed down from generation to generation throughout the country's history (Ministry of Public Health, 2005, p.98). Herbal medicine was first used in Thailand before 1238 A.D. for the treatment of various symptoms and ailments, as well as for health promotion (Ministry of Public Health, 2005).

When hospitals were built in 1182, herbs were employed in treatment until missionaries introduced western medicine, which employed quinine to treat malaria. Following that, in 1888, hospital treatment incorporated both western medicine and TTM. TTM was rejected and confined to a small area for 60 years because of the effects of modern medicine. TTM, on the other hand, was redesigned and reintroduced to the public in the late 1970s (Chokevivat & Chuthaputti, 2005). The National Institute of Thai Traditional Medicine was founded as a section of the Department of Medical Services on March 24, 1993. TTM had been introduced into health centres by 1999, particularly at the sub-district level.

Many institutes and colleges now provide a TTM curriculum, and traditional medical practitioners are registered with the Ministry of Public Health's Medical Registration (MOPH). Furthermore, Thailand's government established a committee to develop a five-year Master Plan for Thai Herbal Development (2017-2021) that includes four initiatives. The first approach will promote the production of Thai herbal plants in response to domestic and international market demand. The second plan aims to expand Thailand's herbal industry and market so that Thai herbs can compete in the global market. The third strategy is to encourage the use of herbal plants for medical purposes and to improve overall health. A framework for the development of herbal plants to contribute to the Thai economy will be established in the fourth strategy (Foreign Office, [the Government Public Relations], 2016).

TTM practice can be divided into four main categories: (1) medical practice involving the diagnosis and treatment of diseases or symptoms; (2) pharmacy practice involving the use of medicinal materials derived from plants, animals or minerals as traditional medicines and the art of compounding those ingredients into various dosage forms of TTM recipes; (3) traditional midwifery; and (4) traditional Thai massage.

Thai traditional medicine (TTM) includes acupuncture, Thai traditional massage, herbal steam baths, and traditional herbal medicines. TTM is defined by law as medical processes involving the examination, diagnosis, therapy, treatment, or prevention of diseases, as well as the promotion and rehabilitation of human or animal health, midwifery, Thai massage, and the preparation, production, and use of Thai traditional medicines, as well as the manufacture of medical devices and instruments. All of these are based on knowledge or textbooks that have been passed down through the generations (Thai Royal Gazette, 1999). Thai traditional medicine is popular as it is considered by some to be less toxic than modern medicine (Chokevivat & Chuthaputti, 2005), and consumers frequently have one or more chronic illnesses. However, the number of persons suffering from chronic renal failure as a result of using herbs has risen considerably. Health specialists suggest visiting a doctor before consuming herbs that can lower blood glucose levels because some herbs cannot be used every day and the negative effects can lead to kidney and liver problems. TTM has advantages and disadvantages, and herbal remedies must be administered and supervised by a skilled practitioner. Misuse can result in significant consequences.

In other countries, people living with diabetes have been documented to use CAM. For example, in Taiwan, diabetics use a combination of CAM and modern medication. Nutritional supplements are the most often utilized CAM before and after diagnosis. However, there is a low rate of disclosure of CAM use to healthcare professionals (Chang et al., 2011), which is like Thailand, people with diabetes who use CAM may not disclose their use to healthcare professionals because they are afraid of being blamed and because they feel they have no obligation to disclose because the healthcare providers have never asked about it. (Wanchai & Phrompayak; 2017; Wanchai & Phrompayak, 2016). While diabetic individuals in Palestine have seen great results from using it. More than 70% of individuals who utilized CAM reported a positive benefit, such as a feeling of disease progression being slowed, symptom relief, illness resolution, or a reduction in allopathic drug side effects (Ali-Shtayeh et al., 2012).

Additionally, online discussion forums appear to be a crucial mechanism for forum users to inquire about prior CAM experiences and seek knowledge regarding CAM use for diabetes. They also looking for information about the advantages of CAM, how frequently they should be used, or how long CAM take to start working, and any negative impacts they may have had (Alzahrani et al., 2022).

This programme of research therefore seeks to explore support for self-management of diabetes in Thailand in an online health community in a context where there may be unmet psychosocial needs for those adjusting to a diabetes diagnosis, the formal health care system may be difficult to access or people may be reluctant or unable to engage with screening and pre-diabetes health education, and where TTM is popular but may be a risky approach to managing diabetes.

## 1.10 The role of family, friends and peers in DSM

### 1.10.1 Family as a carer

In 2017, the Ministry of Public Health trained volunteers to care for their family members/close friends as "family health volunteers," with the goal of caring for elderly people and people with NCDs (such as kidney disease, diabetes, and hypertension) and assisting them in self-management and disease monitoring (Ministry of Public Health, 2017).

Because individuals with diabetes spend most of their time at home managing their condition, their family can have a significant impact on their behaviour and actions (Ory et al., 2013). Individuals receive support primarily from their spouses and children, who provided instrumental support (e.g., preparing healthy meals, reminding them to take medications, and encouraging and motivating them to fight for their health) as well as encouraging and motivating them to fight for their health.

Family members have the potential to provide constructive support to people with chronic illnesses, as well as flexibility and long-term adaptation to meet the challenge of chronic diseases in the family (Chesla 2010). Family members play an important role in promoting self-management of chronic disorders by creating a supportive and engaging atmosphere that promotes family cohesion, normalization, and contextualization of chronic diseases (Whitehead et al., 2018).

Family members can help people with diabetes enhance their self-management capability and capacity (Whitehead, 2009), as well as their motivation and confidence (Stamp et al., 2015). As a result, people are more likely to lower their blood glucose levels and monitor their blood glucose on a frequent basis, and both practical and emotional support have a good impact on overall diabetes self-management measures (Stamp et al., 2015).

Family members may take on the role of carer because of these benefits that improve the health outcomes of people with diabetes. A carer is responsible for looking for another person, such as someone with a handicap, someone who is ill, or someone who is very young (Collins, 2018). In some Asian nations, such as China, family members are the primary caregivers for their sick relatives (Chan & Yu, 2004). Furthermore, they serve a vital role in providing social support to persons with diabetes (Tang et al., 2015).

In Thailand, family members play an important role as carers, caring for and assisting their sick relatives. In Thai society, adult children are the primary carers. Thai society is hierarchical, with people's places determined by their age, gender, wealth, power, and education (Burnard & Gill, 2008, as cited in Yuennan, 2015). Family care for the elderly and disabled is valued in Thai society, and it plays an important role in aiding members of the medical team caring for their relatives in the hospital. Families will, however, require government help and augmentation to provide sufficient care for the expanding populations of crippled and elderly (Chunharas & Boonthamcharoen, nd).

Furthermore, not everyone in Thailand has a pension. Individuals who work for government agencies or companies that provide pension benefits will be eligible for it. People aged 60 and up who do not have any pensions or privileges will receive a social pension from the

government in the following amounts: aged 60–69 receive 600 Bath (approximately GBP14), aged 70–79 receive 700 Bath (approximately GBP 16.6), aged 80–89 receive 800 Bath (approximately GBP 19), and aged 90 or over receive 1,000 Bath (approximately GBP 23.8) per month (Phetkong, n.d.).

Another source of income for the elderly in Thailand is financial support for families, with families with one adult child receiving at least 10,000 Baht (approximately GBP 222) each year, and families with more than one adult child receiving at least 30,000 Baht (approximately GBP 666) each year. In Thailand, the family, particularly children or childrenin-law, continues to play a major role in personal care. The main carer among these groups is the daughter (42%), followed by spouses (around 30%) (Knodel et al., 2017). As a result, the family, particularly adult children, play an important role in providing care and support for their aging relatives (Knodel et al., 2013).

Preparing and serving medication, including insulin injections, was the most common daily care action performed by Thai carers for people with type 2 diabetes. Dietary control was critical, and most caregivers assisted their clients in changing their eating habits by reducing their intake of sugary, fried, and salty foods, as well as coconut milk. Many carers encouraged their relatives to exercise, and they even did it with them at times. Most carers accompany people with diabetes to medical appointments since they are older and have issues walking or seeing, and they will immediately listen to the doctors' recommendations and question about the patient's atypical symptoms (Suparee et al., 2017).

Nonetheless, there is evidence that patients with diabetes and their carers have a limited understanding of the disease. Carers claim that they never received any diabetes information from health experts, thus they must have a basic understanding of how to care for people with diabetes (Sinclair et al., 2010). This data is comparable to findings from a study in Thailand that looked at carers' experiences with Thai elderly people and discovered that one of the negative effects of caretakers is worried is a result of a lack of information (Gray et al., 2016). It has been suggested that Thai caregivers need to be properly educated about type 2 diabetes (Suparee et al., 2017).

Because Thai carers have played such an important part in caring for relatives with diabetes, and because the majority of them are informal carers, the internet is one of the technologies that carers are interested in using to get more knowledge and support them in their caregiving job (Shaffer et al., 2018).

## 1.10.2 Peer support

Another place where people managing long term conditions can access support is from one another. Peer support does not have a standard definition (Fisher et al, 2012). Peer is a Latin word that means "equal" and is defined by the Oxford dictionary as "a person of the same age, status, or ability as another designated person". "Support" describes the feelings of empathy, encouragement, and assistance that people with similar experiences can provide to one another in a proportional connection (Penny, 2018). Peer support is defined as "the provision of emotional, appraisal, and informational assistance by a created social network member who has experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person" in the health care context" (Dennis, 2003, p.321).

The benefit of peer support among persons with similar chronic diseases is that it combines receiving and offering social support (Dennis, 2003), which is linked to mutual understanding, identity sharing, supply of relevant counsel and information, and mutual action (Fisher et al., 2015; Heisler et al., 2010 as cited in Fisher et al., 2017). When people seek emotional support and a quick fix for a common health problem, they turn to fellow patients, friends, and family for information (Fox, 2011).

Dale et al., (2012) examined a systematic review from 1966 to 2011 that looked at the impact and effectiveness of peer support in improving the outcomes of persons with diabetes. Peer support was linked to improvements in glycaemic control, blood pressure, cholesterol, BMI/ weight, physical activity, self- efficacy, depression, and perceived social support in twenty-five studies that met the study's criteria.

With the key functions of daily management assistant, social and emotional support, linkage to clinical care, and on-going availability of support, peers can provide sustainable support and effective management for people with diabetes, with the main goal of improving diabetes and other complications outcomes (Fisher et al., 2012). This is significant since many people with chronic conditions lack adequate social support, which is a risk factor for poor self-care behaviours and increased morbidity and death, according to the study (Brownson & Heisler, 2009).

Individuals must be empowered to control their own lives through social support, which is a sort of interpersonal exchange in which people feel loved, esteemed, accepted, respected, or motivated (Teoh et al., 2009). A higher level of social support has been linked to better health self-management in several studies. According to Schiøtz et al. (2012), people diagnosed with type 2 diabetes will experience less emotional stress if they have a sense of social support and practice better health self-management. Improve diabetes control and providing assistance for improvements in lifestyle behaviours such as physical activity and nutritional adjustments" through social assistance for people with diabetes (Goetz et al. 2012).

Psychological well-being is also linked to social support; 41% of adults with diabetes have low psychosocial well-being, and 46% of patients have had bad emotional, psychological, and social experiences as a result of their illness. For effective or bad diabetic self-management, people with diabetes must think and react in certain ways. It can be difficult for those living with diabetes to manage their condition. People with diabetes who maintain a positive attitude find it easier to live with their condition (Stuckey et al., 2014).

Community groups, mentoring, befriending, self-help groups, online communities, and support groups are all examples of peer assistance. The agreement to share experiences is the reason for each group's meeting (Challis, 2016).

## 1.10.3 Peer Support in Online communities

The internet offers opportunities for DSMES (Hermanns et al., 2020). The interaction, education, and support offered by peers with the same condition to encourage health-enhancing change. (Litchman et al., 2019)

When patient resources and access to care are limited, or primary care resources are insufficient, technology can help (Glasgow et al, 2012). From 2008 to 2013, Hunt (2015) did a literature review and examined data on the types of technology used to aid diabetic self-management and the impact of that technology on self-management and diabetes outcomes for persons with type 2 diabetes. It has been discovered that internet-based technological therapies provide just-in-time information and help people with diabetes control their condition better, he discovered.

For the benefit of educators and individuals with diabetes, virtual environments offer a practical and advantageous platform for diabetes instruction and support (Pereira et al., 2015; Cotter et al., 2014; as cited in Sherifali et al., 2018, p. s37). Research suggests that peer support in the form of online forums offers several advantages to its members, particularly to those who are facing serious health issues or who are lacking in acceptance and social support in their offline lives (Rains et al., 2015). Previous research has found that diabetes online groups are extremely beneficial with few negative repercussions, which can be classified as clinical, behavioural, psychological, and community outcomes (Litchman et al., 2019).

Due to the high number of uncontrolled diabetics and associated psychosocial needs, the question of how and whether internet platforms can support people with diabetes and their careers in Thailand is an important one.

## 1.11 Summary

This chapter has presented an overview of the prevalence and effects of diabetes, and the number of people living with diabetes worldwide, including in Thailand, is predicted to rise. Furthermore, non-communicable diseases (NCDs), which include diabetes, are one of the leading causes of death globally. Thailand lies in the Western Pacific Region, which has the largest number of individuals with diabetes and the highest number of deaths of any region. NCDs have a direct economic impact, resulting in the government investing a significant amount of money in NCDs healthcare, and the impact on society is premature death among those with NCDs, resulting in a loss of productivity.

Thailand has a robust plan in place to prevent and combat NCDs. Thailand's Ministry of Public Health (MoPH) is responsible for establishing public policies across the country, and all Thai people are covered by public health insurance. Thailand has developed a strategic plan and has supported a diabetes guideline that is based on a global standard that is patient centred.

In theory, most Thai diabetics can obtain diabetes self-management education (DSME) and diabetes self-management support (DSMS), which includes psychological assistance which are an essential component for people with diabetes to achieve positive health outcomes.

People with diabetes will only see their doctors 2 to 4 times a year, and there is evidence that 99 percent of chronic disease management, such as diabetes, is done by people with the disease or their caregivers, indicating that the needs of people with diabetes are still unmet, as evidenced by most people who are unable to control their blood glucose levels. Thai diabetics are looking for additional sources of support to help them better manage their chronic disease. Family and friends, peers, and internet networks can all provide alternate support. Family members in Thailand place a high emphasis on providing care for the elderly and disabled, and they play a vital role in supporting members of the health-care team caring for their relatives in hospitals. For patients with diabetes to accomplish self-management, peer support will be essential.

In Chapter 2, I will examine research on self- management and online health communities in greater depth, to explore how people with diabetes use health forums as part of diabetes self-management.

## Chapter 2: Adjusting to life with Diabetes, Self-Management and Online Health Communities

## 2.1 Introduction

The thesis has thus far discussed the prevalence and problem of diabetes, as well as the diabetic journey of the patient in Thailand. As the sixth most common cause of death in Thailand, diabetes is currently a significant issue with 3.2 million registered patients in Thailand database (Department of Control Disease, 2021). After being diagnosed, patients will be offered self-management training and monitoring from healthcare professionals but are expected to take responsibility for managing their condition on a day-to-day basis. Evidence shows that many patients struggle or are unable to control their blood glucose levels consistently or make the recommended lifestyle adjustments. Because diabetes is a long-term illness that requires people with diabetes to manage their health daily outside of the clinic, people with diabetes may seek advice and practical and emotional support from a range of sources, including family and friends, peers, and internet forums such as Pantip.com (Pantip).

In this chapter, the content is focused on a review of existing research examining the lived experience of chronic illness and diabetes and psychosocial adjustment to diabetes, self-management in long- term conditions and diabetes in particular, the challenges of self-management for people with diabetes, and the use of online health communities including why individuals use them, the potential benefits that forum participants obtain, as well as research on how and why carers use online communities. Finally, the chapter will recap the study's aims and objectives.

## 2.2 Adjusting to life with chronic illness

How do people with chronic illness cope with their illness in daily activities, how do their bodies change, and how do they express their struggle? We may learn about these challenges, barriers, needs, and support through research that explores experiences of becoming ill and adjusting to illness. Researchers into lived experience of illness argue that storytelling can help people identify their needs, gaps of knowledge and skills (Gucciardi et al., 2016). It can also promote positive behaviour change, potentially increasing the use of health services and improving an individual's ability to visualise outcomes and realise more fully the implications of their health condition. Frank argues that "People tell stories not just to work out their own changing, but also to guide others who will follow them" (Frank, 1995 p.17), which is a theme we will return later in this chapter when we explore research on online communities. We may learn from these tales and help people with chronic conditions improve their quality of life and overcome obstacles (Cheng et al., 2019; Brown, 2018; Ho et al., 2016; Wu et al., 2016).

Living with chronic disease is challenging. A long-term illness can make individuals feel like it is a never- ending story and may face the possibility of unavoidable deterioration; and responsibility of coping with and managing the disease (Wu et al., 2016; Hopkins et al., 2006). Prior studies found that people managing chronic conditions experience several changes and restrictions to day- to- day life and regular multidisciplinary monitoring which impacts an individual's lifestyle (Forestier et al., 2019). For example, people living with chronic hepatitis B perceived the disease to have a broad impact on their lives as a result of personal and social factors (Tu et al., 2020).

In atrial fibrillation patients' experiences, their life changes were related to symptoms and concerns about limiting life and activities (Strid et al., 2019). Ho et al. (2018) found that patients with diabetes cannot maintain their hobbies, which can lead to psychological distress and impact to their quality of life. Furthermore, even if individuals learn to live with chronic disease and change their lives to it, they may still have doubts about their sickness and symptoms, whether psychological or physical. At first, they were frustrated because they had to rely on doctors to determine what was wrong and how to fix it. Even once the symptoms were under control, the fear of the treatment failing and the illness worsening lingered and their impact on daily living, coping, or managing that may have an impact on their quality of life (Brown et al., 2020).

The majority of people with diabetes were terrified of losing their feet and struggled to cope with the condition. They expected health providers to understand the difficulties they were experiencing (Meriç et al., 2019).

According to Ambrosio et al, living with chronic illness is a complicated, cyclical, dynamic, and ever-changing process that includes five characteristics: acceptance of the condition, coping, self-management, integration, and adjustment, all of which affect people in various aspects of their lives (Ambrosio et al., 2015). Acceptance of a chronic illness occurs when people become aware of their situation and is also the result of a movement toward increased knowledge of the illness and adaption to it, as well as a better understanding of how to recognize and manage their health. People with chronic illnesses reported adjusting their daily routines and retraining their thoughts to accept their new normal (Brown et al., 2020). Changes in habits cause difficulty controlling diabetes and it has an impact on people's quality of life, risk of complications, and treatment or self-management challenges (Hernandez et al., 2020; Slightam et al., 2018; Silva et al., 2018).

In the early stages, the process of learning to live with diabetes is difficult. Individuals with diabetes must comprehend their new condition as well as their new self and body capacity in their current circumstance. The learning process also necessitates the development of key routines; routines provided a feeling of security, but they were also recognized as a source of vulnerability if something unexpected occurred and they could not be followed. People with diabetes have a new experience with their body and the self. The feeling about a new condition with an unknown situation is created. The diagnosis becomes an issue to consider in daily life such as traveling abroad, going to a business conference, or having dinner at home as monitoring and remembering the insulin injection must be built into existing routines and activities. They need to plan and prepare.

In addition, in the beginning of their new situation with the illness, people with diabetes may feel like they do not have enough knowledge and experience. Therefore, they may look for diabetes information from health professionals and assume that they are accessible and have the capacity to focus on their specific needs. However, health care staff may generally pay more attention to dose and glucose level (HbA1c) than to an individual's questions, issues

relating to adjustment or their emotional experience. Negative feeling may be created and consequently, the relationship between the health care providers and people living with diabetes is not so good since the patients feel like they do not get support from them (Hernandez et al., 2020; Kneck et al., 2011). Because of these resource difficulties and prioritisation of clinical monitoring, it would be ideal to address people's demands for self-management services on their own terms. Furthermore, at different stages of the disease, persons with diabetes require different forms of assistance. Individual needs for self-management on one's own terms should be satisfied by a technological service that can reach and connect a huge number of people while remaining person-centred. (Gardsten et al., 2018).

Research therefore suggests that a sense of control is an important aspect of adjusting to chronic conditions like diabetes. People living with diabetes who can acquire control over their illness feel they can lead a normal life and felt healthier as a result. As a result, people pushed on with their treatment goals, maintained their spirits by positive lifestyle choices, and maintained their dignity and self-control (Kato et al., 2020; Cheng et al., 2019; Ho, et al., 2016). Furthermore, having some control was frequently accompanied by a desire to make their own health decisions in order to contribute to self-management and approach to managing their illness, which could influence experiences of living with a chronic condition, and the majority of people who felt this way were active in self-management (Olson, et al., 2018).

Chronic illness is typically accompanied by a perceptual change, in which life shifts from a previously "normal" path to one that appears 'fundamentally abnormal and inwardly damaging' (Bury, 1982: 171). A powerful reference point is normality, or life before sickness. Normal life can serve as a goal, a metric for development, or a sorrowful reminder of what has been lost. When symptoms or physical limits disrupt some component of perceived normality, disease takes on a new meaning for many people (Porter et al., 2020). Some people may really struggle for "normalcy" because of physical loss, such as the lived experiences of diabetic lower extremity amputation and post-amputation wounds (Zhu et al., 2020). The research shows that diagnosis has a negative influence on physical, psychological, and social elements of life right away (Due-Christensen et al., 2018). Participants discussed how they had to constantly adapt to their changing health and the numerous losses that came with it (e.g., functional abilities, relationships, confidence). This requires a difficult balancing act between independence and seeking assistance, all while dealing with a mismatch between their needs and available resources (Brighton et al., 2020).

In Thailand, 70% of those living with chronic illness have more than one chronic condition, with hypertension and diabetes being the most frequent. Research suggests that they are limited in their daily lives because of the symptoms of their chronic illnesses. They were physically and emotionally affected by their disease conditions since they didn't know how to deal with it. However, they accepted and understood it because of their belief in the Law of Karma and life after death, rather than seeing it as a long-term genetic disorder linked to lack of exercise, poor diet, smoking, and alcohol consumption. Finally, they adjusted their
emotions and accepted the physical restrictions and changes in their life (Chiaranai et al., 2018).

This section has argued that adjusting to life with a chronic illness is challenging and is often related to perceptions of control, fear, and frustration about a loss of 'normal life'. In the next section will explore research on psychosocial adjustment in more detail.

## 2.2.1 Psychosocial adjustment to diabetes

Persons with diabetes have a 60% higher risk of severe psychological distress than people without diabetes; a large part of this increase is linked to increasing degrees of impairment with diabetes, especially when measurement error is considered. Physical incapacity is significantly linked to mental distress (Elmira et al., 2018). For example, people with type 1 diabetes expressed that living with diabetes was described as a psychological burden, with those on insulin or diagnosed with diabetes had a negative influence on half of all family members (Jones et al., 2016).

Depression and diabetic stress are two common mental health problems among type 2 people with diabetes (Owens-Gary et al., 2019). Pouwer et al. (2020) conducted a systematic review of 25 years of psychosocial research on our understanding of the relationships between depression and diabetes and found 20 studies that matched their criteria (the case-control studies). The findings show that people with type 1 diabetes and type 2 diabetes have higher rates of depression (three times in type 1 diabetes and nearly twice in type 2 diabetes) than people without diabetes, which has a negative impact on quality of life and is linked to less effective self-management. Previous studies have shown that some depressive symptoms, such as fatigue, poor sleep, or changing eating habits, can also be signs of poor glycaemic control. Some symptoms of depression, a higher risk of diabetes problems, as evidenced by the data, patients with diabetes and depression are at a higher risk of developing microvascular and macrovascular problems, as well as cognitive impairment and mortality. Furthermore, those with diabetes are more likely to commit suicide than people without the disease. Depression has long been linked to poor diabetic self-management (i.e., higher BMI and waist circumference; less physical activity), poor glycaemic control outcomes (Ajuwon & Love, 2020; Darla et al., 2014), and a negative impact on their health and overall quality of life (Penckofer et al., 2007). In people with diabetes, depression and self-management have a negative association. This suggests that the lower the level of self-management, the higher the amount of depression in patients with diabetes, and vice versa. Difficulty adhering to dietary guidelines, smoking, forgetting prescriptions, and diabetes discomfort were all linked to an increased risk of depression (Nanayakkara et al., 2018). Individuals who have glycaemic control have a better degree of perceived integration of diabetes and depression care (Laiteerapong et al., 2021).

Diabetes distress is a negative impact on emotion linked to diabetes management that has the potential to impact diabetes self-care and control (Hu et al., 2020), and has a negative impact on one's quality of life (Vigen et al., 2018). Individuals with higher levels of stress are less satisfied with their quality of life than those with lower levels of stress (Yang et al., 2019).

Shorey and Ng (2020) discovered that initial reports of unpleasant emotional experiences and disease perceptions were mixed in with progressive acceptance of their position and beneficial coping mechanisms in their systematic reviews, which looked at 55 research papers published between 1991 and 2018. All children and adolescents with noncommunicable diseases wanted to enjoy a normal life, but physical limitations sometimes resulted in social marginalization and self-imposed limitations. Despite the help they received from family, friends, and healthcare professionals, they struggled with disease management, the need for autonomy, and the fear of reporting their conditions. Diabetes distress was associated with higher HbA1c and poor adherence to a treatment plan (Wong et al., 2017). Kamody et al., (2018) found that acceptance and diabetes stress, as well as adherence behaviors, may be important targets for individual psychosocial therapies aiming at increasing type 1 diabetes adaption in children. In adult outpatients with type 2 diabetes, Diabetic distress is likely to be a substantial psychological driver of glycaemic outcomes, even in the setting of individually tailored diabetic therapy (Theodoropoulou et al., 2020).

Changes in behaviour, including eating habits and exercise, are critical for people with diabetes to follow. As a result, individuals may feel guilty when they eat sweet foods or do not exercise. For older adults with diabetes, forgetfulness is a concern because they have trouble remembering things and remembering things, such as health professional instructions or meals. This type of lived experience with diabetes puts them under a lot of stress (Hernandez et al., 2020).

Anxiety is also report as a common issue in people living with diabetes (Galarraga & Llahana, 2018). This is often undiagnosed and untreated which may result in, "confusing with the common symptoms of anxiety and hypoglycaemia and the misidentification of anxiety disorder as poor adjustment to diabetes" (Rubin & Peyrot, 2001, p.462). Individuals who have poorer lifestyle management and poorer glycaemic control have greater depression and anxiety than people who better behavioural management (Hsieh et al., 2020; Darla et al., 2014).

Fear is a factor that can distort and represent anxiety disorder. People living with diabetes reported that they fear hypoglycaemia, complications, and the effects of diabetes on daily life which are the common fear found in people who living with it (Due-Christensen et al., 2019; Driscoll et al., 2016). After a diagnosis, health practitioners frequently failed to attend to participants' emotional needs, and the language employed frequently evoked negative emotions such as anxiety or a sense of failure (Due-Christensen et al., 2019). Fear is linked to a lower quality of life, particularly in people with other complications such as diabetic foot ulcers, who have a significant fear of amputation, which causes physical pain, emotional distress, and a lower quality of life (Vileikyte et al., 2020).

Improvements in psychological variables are feasible, if social support can be enhanced (Wu et al., 2013). According to the findings, social support and coping have an inverse connection, meaning that an increase in social support is linked to a reduction in emotional distress. At the three- month follow- up, participants in the diabetes support group had improved glycaemic control and less depression symptoms (Ellis et al., 2019). Diabetic patients benefit from social support in managing with their diabetes and improving medication adherence

(Ramkisson et al., 2017). Higher levels of social support function and better quality of support were found to be substantially associated with reduced risk of prevalence of diabetes and improved psychological outcomes in people with type 2 diabetes (Al-Dwaikat et al., 2020). The aspects of social support and empowerment should be addressed when developing interventions to increase self-care behaviours and glycaemic control in patients with type 2 diabetes (Arda Sürücü et al., 2018).

Research shows that adjustment to 'a new normal' as a person with chronic illness can be socially, psychologically, and emotionally difficult and challenging. It also involves the challenge of learning new practical skills, making behavioural changes and taking on the responsibility of self-management. This will be explored in more detail in the next section.

#### 2.3 Self-management of diabetes

Self-management is widely regarded as an important aspect of treatment for patients with diabetes and other chronic diseases (Trappenburg et al., 2013). It is an intervention that enables individuals with long-term conditions to make behavioural changes and effectively manage their health conditions on their own (Donald et al., 2018), and it can determine whether someone with chronic illness has a good or better life (Stenberg & Furness, 2017). Consequently, the good self-manager is defined as a patient who has transformed from a passive recipient of treatment to an empowered partner in their own health management by taking on increasing personal responsibility and so accepts responsibility for their health; is knowledgeable and uses that knowledge to control risks; and is active in using information to make informed decisions about their health and social well-being (Ellis et al., 2017).

There is evidence that self-management improves the health outcomes of people with chronic illnesses. Jonkman et al. (2016) used a systematic review and meta-regression analysis to look for components of self-management interventions that improve health-related quality of life in chronically ill patients. These interventions were defined as those that aim to provide patients with the skills to actively participate and take responsibility in the management of their chronic condition in order for them to function suitably through at least knowledge acquisition and a combination of at least two of the following: stimulation of independent sign/symptom monitoring, medication management, problem-solving and decision-making skills for medical treatment management, and change management. They looked at 47 studies from January 1985 to June 2013 in people with chronic heart failure (CHF), chronic obstructive pulmonary disease (COPD), and obstructive pulmonary disease (OPD), or type 2 diabetes. The study's objectives are to measure the diversity of self-management intervention components and determine which ones are linked to improved health-related quality of life. The findings revealed that self-management interventions improve health-related quality of life in patients with type 2 diabetes at 6 and 12 months, as well as teaching problem-solving abilities. Individuals with CHF focused on medication management or self-monitoring of symptoms, people with COPD addressed medication management and action plans, and those with type 2 diabetes emphasized goal-setting skills and lifestyle improvements through exercise or nutrition. Furthermore, the authors advised evaluating self-management therapy at the patient level rather than at the aggregate study level.

In the patient level study, Dwarswaard et al. (2016) examined self-management support from the perspective of people with a chronic condition, identifying 37 studies of 992 people with rheumatic diseases, a variant of cancer or chronic kidney disease from Australia, Canada, Europe and the United States in November 2013. They found that there are three types of support that individuals with chronic conditions need: Instrumental, psychological, and relational assistance are the three forms of care that people with chronic illnesses require. Information and instructional knowledge regarding diagnosis, symptoms, and treatment alternatives, internalization of professional knowledge, and changing daily living are all examples of instrumental support. Psychosocial support focuses on recognizing the emotional components of a chronic illness, as well as boosting self- esteem and empowerment. Relational support is at the heart of persons with long-term illnesses' support needs, and it inspires all other forms of help. Partnership, sympathy, dynamics in self- management support, disease stage, and individual-related characteristics including age and ethnic group are all part of it. Professionals, family and friends, and fellow patients are also sources of support that individuals would want to receive.

Prior research has shown that individuals with chronic conditions found it difficult to selfmanage due to a perceived lack of or limited help from healthcare practitioners, they felt they required increased assistance from healthcare professionals to achieve their selfmanagement goals. In the early stage of a long-term condition like kidney disease, Costantini et al. (2008) discovered that people with kidney illness wanted more support and guidance from healthcare providers to help them understand the implications of the diagnosis and the need for ongoing treatment. As well, during the self-management routines, individuals with long-term illness said that healthcare providers discussed self-management with them too late or not at all, and that they felt unsupported when they experienced the effects of pain, such as short appointment times and extensive waiting lists at the primary care level (Gordon et al. 2017). In addition, people with chronic illnesses reported primarily access barriers in their ability to reach services, which were related to illness- related disabilities ( limited mobility, chronic pain, fatigue, frailty) and limitations in the availability and accommodation of health services to address patient preferences (unavailability of after-hours services, lack of alternative modes of service delivery) (Song et al., 2019).

In young people with long-term conditions, they felt isolated which can impact their disease management and they require ongoing help and trusting interactions with health experts to develop sufficient knowledge and abilities to manage their disease and relationships (Rasmussen et al., 2018). While many older persons with various chronic diseases need more information on their medical issues from professionals in less technical language (McGilton et al., 2018). Even though the quality of care for people with long-term illnesses is improving, over half of patient care still fails to meet quality standards (Harris & Zwar, 2007). In this context, patients may seek alternative sources of knowledge such as online health communities where there are people who have experience of self-management who are willing to offer support from that perspective.

Gallant (2003) conducted a study of 29 papers and found that social support had a positive relationship with chronic disease self- management. Community groups, mentoring,

befriending, self-help groups, online communities, and support groups are all examples of peer assistance. The agreement to share experiences is the reason for each group's meeting (Challis, 2016). One of the venues for which there is evidence that it can create a space for people with chronic disease to tell their stories and get support is an online community, which I explore further in section 2.6.

### 2.3.1 Challenges of self-management for people living with diabetes

The World Health Organization (WHO) defines adherence as the degree to which a person's behaviour such as taking medication, following a diet, or making lifestyle changes / matches to agreed-upon advice from a health care professional (World Health Organization [WHO], 2003) and adherence it is a daily challenge for self-management of diabetes (Whittemore et al., 2019; Kyokunzire & Matovu, 2018). The issues of self-management for people with diabetes differ depending on where they are in the disease's course (Gardsten et al., 2018). People who have recently been diagnosed with diabetes face the challenge of learning to accept the diagnosis and motivating themselves to make lifestyle changes, whereas those who have had diabetes for a longer period may face complications and more serious treatments. Furthermore, people with diabetes face the regular challenge of determining why their blood glucose levels fluctuate at any moment. According to a report issued by the American Diabetes Association (ADA) in 2018, obesity, eating habits, and physical activity are among lifestyle factors that can contribute to type 2 diabetes prevention and control (Wing et al., 1995). As a result, diabetes care would involve finding a balance between social surroundings and medical restrictions (Knyahnytska et al., 2018).

Barriers to diabetes self-management include a lack of resources, barriers to lifestyle alteration, a lack of family support/competing demands, and mental health difficulties (Whittemore et al., 2019). Devan et al. (2018) synthesized the enablers and barriers of incorporating self-management strategies for people in everyday life from inception to July 2016 and discovered that the barriers to self-management included difficulty maintaining motivation, anxiety, and depression, as well as unsupportive relationships with clinicians, family, and friends. All these factors may affect successful diabetic self-management (Whittemore et al., 2019).

On a regular basis, self-managers must acquire and mobilize abilities in the areas of food selection and consumption. In Thailand, there is evidence that people with diabetes misunderstand some dietary concepts, especially those surrounding carbohydrates e.g., they perceive rice as being a bad carbohydrate source, while fruit is a good one. Patients have misconceptions surrounding portion control and accurate food estimation and lower sugar varieties of food types (Prutanopajai et al., 2018). Food culture in Nepal has been recognized as a barrier to successful diet management, with high-carbohydrate meals, restricted food options, and food preparation methods being identified as barriers (Sapkota et al., 2017). Changing established habits to eat healthy or exercise are also reported as difficult. Unhealthy 'street' food, frequent 'carnivals' with many opportunities to eat poorly, and cultural preference for atole (corn flour-based beverage), pan dulce (sweet bread), and tortillas also were expressed as barriers to healthy eating (Whittemore et al., 2019).

Cultural influences have an impact on diabetes diet adherence, which is the cause of blood glucose fluctuations (Gardsten et al., 2018). For example, In Mexico, lowering customary food servings feels like renouncing culture, while eating away from the shared family plate produces emotions of social isolation (Magny-Normilus et al., 2020). For young people with type 1 diabetes, simple habits like eating out with friends, drinking responsibly, and engaging in physical activity present unique hurdles and the members of the general public often scrutinized and criticized their health practices or lifestyle choices (Mullan et al., 2020). The significance of the Thai cultural context regarding barriers to effective self-management will be explored in this thesis.

In the transition process, people with diabetes have the potential to improve their quality of life and build resilience, even though it can be challenging (Kralik et al., 2006). Individuals have the potential to manage their transition by employing strategic thinking and planning with self-negotiation strategies to minimize risks; managing diabetes using prior experiences; connecting with others with diabetes; actively seeing information to patch knowledge gaps; and putting diabetes into perspective (Rasmussen et al., 2011). Additionally, resilience was found to be substantially correlated with glycated haemoglobin, diabetes distress, and self-care behaviour, supporting the validity of the study in people with type 1 diabetes (Xu et al., 2020).

Boredom can also be a challenge as a result of persons with long-term conditions being monitored and maintained by case managers, support workers, and peer support workers (Milbourn et al., 2015). Furthermore, relationships with healthcare providers were strained because of the actual experience. They also experienced remorse, dread, loneliness, and amnesia (Hernandez et al., 2020), and they require assistance from healthcare providers, as well as family and friends (Willemse et al., 2018).

### 2.4 Caring for people with long-term conditions

As discussed in chapter one, family members or friends may act as carers to overcome challenges related to new daily routines and mobility issues (also see Faronbi et al., 2019) and assist persons with diabetes in better self-management. After someone has been diagnosed with a chronic illness, especially family members, an informal carer may be vital for providing practical and emotional support. Bellato et al. (2016) described the family environment as a host of care that provides an action care for them to take care of their love throughout their lives.

Prior studies show that majority of family carers are female and with 80 percent being the patients' spouses or children (Alves et al., 2020; Peacock et al., 2020; Greenwood et al., 2019; Brown, 2010). In Asia caring is viewed as a child's job to their parents. Adult children in Turkey, for example, take on the obligation of caring for elderly parents with Alzheimer's disease *and* it is considered a morally unacceptable *not to* (Ar & Karanci, 2019).

Carers must also learn adjust to their new responsibilities, and there are several challenges that include first acknowledging their circumstances then fear and worry related to the illness; life changes and restrictions; burden due to caregiving; uncertainty about illness management; helping patients to cope with the illness; love and affection towards the patient

(Catchpole & Garip, 2021; Petruzzo et al., 2017). The most common barriers for carers of persons with chronic illness is supporting people to make lifestyle changes (Topcu et al., 2020; Petruzzo et al., 2017), especially diet (Chesla et al., 2019).

Carers also may be puzzled by the training they receive regarding lifestyle changes, such as regulating their children's diets, while their children refused to cooperate with the diabetic diet, which was in direct contrast to their expectations, and they could not resist their wishes (Khandan et.al, 2018). Conversely, according to one study, spouse carers adapted their social lives to their spouse's health since they did not want to leave their partner alone for long periods of time. Seeking help and relying on one's own talents to manage one's life. Because the participants were dealing with both physical and psychological difficulties because of their spouse's illness, they turned to themselves and others for support and encouragement. Finding formal and informal help for the current situation, as well as using one's own resources to handle daily life, are all part of the experience of living with a spouse's illness (Eriksson et al., 2019).

Furthermore, people with chronic diseases, such as diabetes, would prefer that their carers engage in healthy activities with them rather than setting them out as individuals who require healthy habits (Mayberry et al., 2016). Additionally, carers provide empathy for those living with this difficult chronic condition, as evidenced by long-term patients' responses to illness downturns, progression symptoms, or the chronic emotional impact of living with a progressive disease over time (Chesla et al., 2019).

Carers may become frustrated during their care routines as a result of their uncertainty about chronic illness management and the difficulty of learning the amount of information they are expected to learn about the symptoms (Ferreira et al., 2020; Oser et al., 2020; Topcu et al., 2020).

Emotional burden has occurred to the carers during their caregiving. They experience fear and worry related to the illness (Petruzzo et al., 2017) and they report more mentally unwell days than someone who are not carers (Secinti et al., 2021). Clemmensen et al. (2020) conducted a scoping review that yielded 2,748 articles after removing duplicates, as well as 122 articles mapping dementia carers' support needs. They discovered that carers required emotional support to help with feelings like guilt and stigma, as well as to reduce stress from caregiving and knowledge. There is evidence that the unpredictable course of a disease alters the carer's experience and increases the difficulties they face. Carers' information demands are not always met satisfactorily. Carers' quality of life can decrease as a result of their loss of control, despite their ability to incorporate unpredictability into their everyday lives (Barnes & Whittingham, 2020). Some of the key quality of life issues that are relevant to carers of cancer patients with cachexia were the impact on daily living, some carers' attempts to take charge, the need for healthcare experts' input, conflict with the patient, and negative feelings (Wheelwright et al., 2016). The authors believe that addressing the consequences of caring for a patient with cancer cachexia on carers could improve both carers and patients' quality of life.

Negative experiences of informal carers may have an impact on the people for whom they care (Matthews et al., 2020). They demand medical care due to their physical and emotional tiredness, which they believe is inadequate (Simeone et al., 2018). Sharing similar experiences with other carers, on the other hand, may help them feel less isolated and alone since they will know there are other carers out there who have gone through similar things (Bellato et al., 2016; Pelentsov et al., 2016). An online community is one possibility where carers could share experiences and seek support, and in Chapter 7 this thesis explores the use of the Pantip online community by carers of people with diabetes.

### 2.5 Using the internet for health information

The number of people who utilize the internet has considerably increased both globally and in Thailand. As of January 2021, the world's population would be 7.83 billion in 2020, with 4.66 billion Internet users, or 59.5 percent of the overall population, up 316 million or 7.3 percent, and 4.2 billion individuals participating on social media (Kemp, 2021). The number of internet users globally reached 4.9 billion, which indicates that about two thirds of the world's population is currently online as of 2021 (Statista, 2023). In Thailand, there were a population of 69.88 million people with the internet users account for 48.59 million people, or 69.5 percent of the total, increasing 3.4 million people or 7.4% from 2020 (Pptvhd36, 2021). Thai internet usage has increased from over 6 hours per day in 2016-2018 to 10 hours per day in 2018-2019 and 11 hours per day in 2020 (Electronic Transactions Development Agency, 2020). Furthermore, the Covid-19 pandemic has unavoidably resulted in an increase in the usage of digital technologies as a result of social distancing norms and nationwide lockdowns (De et al., 2020).

The most common devices for accessing the internet are mobile phones or smartphones (Forlani, 2019). Web 2.0 technology has supported the evolution of many forms of electronic communication, allowing people to participate, collaborate, and share data more easily (Coulson, 2018). It is important to stress that individuals can contribute and produce new information in addition to consuming and receiving it (Darwish & Lakhtaria, 2011). By publishing and replying to messages at any time, users can communicate with one other synchronously (at the same time) or asynchronously (at different times). Asynchronous interaction platforms, such as online discussion boards, allow users to participate without having to be online at the same moment (Gruzd, 2017; Finfgeld, 2000), even if they live far apart (Äkkinen, 2005). Computer and internet experience enhances the possibility of utilizing the internet for health-related information (Nangsangna & Da-Costa Vroom, 2019).

The internet has profoundly changed the way that people are experiencing illness (Ziebland et al., 2014). Social media websites enable patients and family members to communicate with others, search for health information, and produce and share their own material on the internet as the number of health-related information websites has grown and Web 2.0 technology has advanced (Xu et al., 2017; Heilferty, 2009;). People search for health-related information online because it is convenient, covers all health topics, and receive opinions from peers. Even though online searches provide additional information and a cross-check for patients (Diaz et al., 2002). Many people who look for health-related information online

find the internet more helpful than the health professionals when they need emotional support, a quick remedy, and practical advice for an everyday health issue (Fox, 2011).

The Internet's function as a source of health information has grown, along with an increase in interest in online health services (Bujnowska-Fedak et al., 2019). Referring to internet users, the most common searches are for pharmacies, medical symptoms, and pain. According to Bach & Wenz (2020), individuals searching the internet are looking for information about pharmacies, symptoms of medical illnesses, and pain, and they are interested in information about living a healthy lifestyle, alternative medicine, mental health, and women's health. In Chapter 6 I will explore discussions about Thai alternative medicine for diabetes on Pantip.

The majority of internet users seeking medical information online are women, have a high level of education, were employed, had higher incomes, lived in the cities, and were younger in age, according to the findings of an empirical study of internet users seeking medical information online (Bujnowska-Fedak et al., 2019; Weaver, 2016; Diaz et al., 2002). However, M. & Piguet (2013) found that users searching for long-term conditions were older than 50 years old. Furthermore, those who have had a negative experience with healthcare systems have been observed to seek health-related information online (De Rosis & Barsanti, 2016). Likewise, people with low self-rated health and high levels of reported psychological distress turn to the Internet for health-related information to help them cope with their worries and suffering (Oh & Song, 2017).

According to the findings, 76.9% of participants utilized the Internet for health-related objectives, with 72.6 percent of active users and 27.4 percent of passive users distinguishing themselves (Bujnowska-Fedak et al., 2019). In the United States, 80 percent of internet users look for health-related information on the internet (Weaver, 2016). In the United Kingdom, the majority of people who used the internet to look up health-related information did so for five reasons: to look up symptoms/diagnoses (73 percent), to read up on how to manage a condition/illness (63 percent), to get information to improve health (39 percent), to research potential medicines/treatments/etc. (39 percent), and to look up risk associated with a condition/illness (38 percent) (Statista research department 2015). In Thailand, the top three health subjects searched among elderly were healthy lifestyle (6.40 percent), sickness treatment (6.30 percent), and medication (Tipkanjanaraykha et al., 2017).

In Thailand, older women aged 60 and up residing in Bangkok and its environs utilized the internet for 1-2 hours a day, a few times a week, and their primary health concern was diabetes, for which they sought medical advice. They said they were happy with the internet and that they used it to deal with their current situation. The elderly, it was discovered, prefer to look for general disease and symptom information (Rattanawarang, 2015).

There is evidence that the number of people accessing clinical information via diabetes online website such as MyDiabetesMyWay has increased (Cunningham et al., 2019). This could be because current health-care services and education programs are not really meeting patients' needs adequately, whereas a digital health intervention could address the unmet need described by the patients, which include an emphasis on emotional and role management,

being available 24/7, providing patients with up-to-date evidence-based guidance, and providing access to peer-generated and peer-reviewed content (Pal et al., 2018).

The next section focuses on online health-related communities which support social interaction and sharing of experiences amongst those living with, supporting and/ or managing a chronic health condition.

#### 2.6 Online health communities

Social media such as online news groups, websites and blogs are key resources for on-going management of health and wellbeing conditions due to individuals turning to online network resources (Fox & Jones, 2009) including YouTube, Facebook, MySpace, Twitter, and Second Life that are famous sources especially for teenagers and young adults to search for health information.

Online communities or virtual communities (Gruzd, 2018) are defined as, "social aggregations that emerge from the Net when enough people carry on public discussions long enough, with sufficient human feeling" (Rheingold, 1993, p. 5). The first online community was The Well (established in 1985) and Usenet newsgroups founded in 1979 (Ridings & Gefen, 2006). The names of online communities are based on the activity and the target group which they serve or the technology that supports them (Preece & Maloney-Krichmar, 2006).

There are two main groups of people who take part in online communities: lurkers and posters. Lurkers or silent groups refer to people who do not want to share or post online. They play a passive role by only reading messages and comprise the majority group of people in online communities (Sun et al., 2014; Tagarelli & Interdonato, 2013; Edelmann, 2012; Nonneeke & Preeee, 2000). Posters or active participants are individuals who often participate and contribute most of the content (Williams et al., 2012; Preece et al., 2004; Okleshen & Grossbart, 1998) and they are a key component to any successful online community (Malinen, 2015). Some authors make a distinction between lurkers and posters, and that successful communities need a minimum level of posters, and some authors even suggest that posters may feel they get more benefits (Lai & Chen, 2014; Sun et al., 2014; Setoyama et al., 2011; Ridings et al., 2006). Even though posters and lurkers have different attitudes to the online communities, both have the same reason to go online – they both want more information about the community topic and support (Nonnecke et al., 2004).

Online health communities are the subset of online communities (Johnston et al., 2013) which provide a platform for patients, their families, and friends to interact with individuals who are living with a diagnosis of various diseases (Xu et al., 2017). Patients consider the internet to be a major source of health information, with topics discussed ranging from diagnosis, medical treatment, decision-making, specific disease, medical problems, diet, nutrition and vitamins, exercise, prescription, alternative treatments, health insurance, depression, anxiety, stress, to a particular doctor or hospital (Morris, et al., 2016; Weaver, 2016; Diaz et al., 2002). Online health communities allow users to share medical knowledge through a variety of venues, including message boards, discussion forums, and social media sites (Bender et al., 2011). Some of these online interactions may help people to cope with their

long- term illness conditions and their adjustment to the disease (Wicks et al., 2010). Individuals discuss their personal experiences with illness in ordinary life may raise collective awareness of illness-specific concerns (Kingod et al., 2017).

Online communities are crucial for clinical outcomes and self-management behaviours, according to existing data (Bernardi & Wu, 2017; Foster, 2016; Johnston et al., 2013; Van der Eijk et al., 2013; Hartzler & Pratt, 2011). Those who are more engaged in the diabetes online community have better glycaemic levels than those who are less engaged. In addition, diabetes online community members have a high level of health-related quality of life and diabetes self-care (Litchman et al., 2018b). As a result, the number of people with diabetes visited annual outpatients were decreased which made a significant contribution to helping patients and their healthcare providers better manage this chronic illness (Wei et al., 2018).

Online health communities are perceived by users as a valuable source of health information since they allow others with similar medical issues to share their experiences but the trustworthiness of advice or information from online communities is one topic that people are concerned about. Important personal information is frequently revealed, the quality of information offered by others fluctuates, and the consequences of acting on wrong advice can be severe as a result of community members identifying themselves only by a pseudonym (Fan et al., 2014; Fan et al., 2010). Information offered in regulated online communities is likely to be more reliable than that supplied in online forums where no one supervises the entries (The University of Sheffield, 2019). In a study by Kyriacou & Sherratt (2019) 77.1% of online health community members thought online health information was of excellent quality, however 59.4% were ignorant of website certification techniques. 36.6 percent of online health information seekers reported favourable behavioural changes as a result of obtaining online health information (Kyriacou & Sherratt, 2019). Similarly, a study by Cole et al. (2016) found that forum users trust the health information in the forums. The researchers surveyed users from Reddit, Mumsnet, and Patient with the goal of improving understanding of the quality and quality characteristics of information found in online discussion forum. However, several studies have found that people, particularly the elderly, trust health information from health experts more than information from the internet (Kwon et al., 2015).

Because an online health community is a gathering place for people who have a connection to the same health condition to share their thoughts and ideas, it can provide a useful data stream or target audience for businesses and scientists (for example, PatientsLikeMe data in clinical studies and new product development). As a result, people who use social media need to make an educated judgment on how much personal information to publish, and what their personal return on sharing this information will be (Jane Sarasohn-Kahn et al., 2008). Pharmaceutical companies are increasingly advertising their products through social media as the popularity of online health communities grows (DeAndrea & Vendemia, 2016). Low cost, quick transaction self-management through a large community, and user participation are all advantages of social media marketing, whereas blind authorship, absence of source reference, and the presentation of opinion as truth are all disadvantages (Vance & Howe, 2009). Organizations are constantly looking for better ways to reach a broader audience for their product or services. As a result, we are surrounded by latent advertising messages whose content is not advertising but rather "recommendation, creating profiles, groups, and fan pages for products and services, and initiating conversations with emotive topics" (Glichrist, 2019). In Chapter 6 I examine the way that latent or explicit adverts for complementary and alternative medicine products and services are placed on Pantip.com. In the next section we review research that explores why people with chronic health conditions and their carers use online communities and their perceived benefits before considering research that examines how online communities support self-management and might help improve the experience of living with chronic illness.

#### 2.7 Why do self-managers and carers use online health communities?

Common motives cited for joining health online forums are to exchange information and for social support (e.g., Nambisan, 2011; Ridings et al., 2006) from peers who are living with the same medical condition (Bernardi, 2016). Patients with inflammatory bowel illness according to Coulson (2013), use online support groups to meet people who have comparable experiences. Peers share their experiences with similar concerns and make it easier to share information about topics that are considered humiliating or have a social stigma (Zigron & Bronstein, 2019). Individuals seeking health information may obtain social and emotional support as a result of peer-to-peer connections (Zhao & Zhang, 2017). Peer support in the form of an online forum has been shown to provide several benefits to their users, particularly those experiencing major health difficulties or missing social support and acceptance in their offline lives (Rains & Wright, 2015). People can use online fora to connect with others who are dealing with similar issues, as well as to seek emotional support and mutual understanding that they may not be able to get from their offline social circle (Fan et al., 2010). Individuals with medical concerns have found that online health forums have become a significant source of social support (Wang, Zhao, & Street, 2017). Patients in the uncommon chronic disease online community use the forum to meet peers, share knowledge, experience, emotional support, and other resources (Haik et al., 2019).

An online discussion board may also allow users to ask other members questions on how to self-treat (Brown & Altice, 2014). Finding information, feeling supported, developing relationships with others, experiencing health services, relating to stories, visualizing disease, and altering behaviour are all part of the online peer-based patient experience (Ziebland & Wyke, 2012). Furthermore, according to Willis and Royne (2017), peers exchange healthrelated information through online health communities, and as a result, online health communities provide as a type of informal self-management that provide possibilities for health behaviour change messages to educate and persuade people about how to manage chronic diseases. By utilizing authoritative domain expertise in the medical profession, online health communities meet the information demands of people living with chronic conditions (Chen et al., 2020). People with chronic disorders, such as fibromyalgia, used Instagram to share information about how they manage their symptoms by uploading photos of themselves or images found on the internet. The posts included captions describing their feelings, symptoms, pain management, and the difficulty in gaining access to health-care systems. Instagram encourages people to talk about their disease and to share their day-today management experiences with others (Berard & Smith, 2019).

Self-managers can spend as much time as they need communicating with other members in online communities, but health experts cannot have extended talks, and they may learn more about their disease by using forums (Panesar, 2016). Patients can make their daily routine decisions with the aid of real-time technology and be able to share knowledge gathered from their online communities with their healthcare team, as well as seek help and make additional choices (King et al., 2012). People can find and connect with others with similar ailments and in comparable situations (Corter et al., 2019; Wellman & Gulia, 1999).

In a study investigating carers supporting family members with Alzheimers it was found that due to the strain of caring for others, family carers may ignore their own healthcare needs, which led to poor health outcomes and decreased quality of life. An online forum gave family carers a place to ask for help as they tried to learn more about managing their care recipients' Alzheimer's disease and related dementias as well as how to manage their own lives as carers (Du et al., 2020). Egan et al found that an increasing number of UK carers are becoming aware of the advantages of adopting digital technologies to assist in caregiving (EganClark et al.; 2022).

In a systematic review that included 40 studies among 2,325 publications, internet-based interventions aimed at assisting family carers of dementia patients were examined. The findings indicate that web- based interventions may enhance the wellbeing of family caregivers, including impacts on depression, anxiety, and stress. Online counselling was very helpful. Online knowledge exchange proved to be most beneficial when it was tailored for the user and used in combination with additional multi-component interventions. Most participants acknowledged how stress was eased by the peer support provided in online communities. Carers valued quick and simple access to individualized practical advice, emotional support, and a decrease in burden and pressure preferred online connection with a professional (Hopwood et al., 2018).

### 2.8 How do online health communities support self-management?

Research suggests that people go to online communities for advice, opinions, or information from other forum participants (Yang et al. 2011). The participants share information regarding a problem-solving technique in which some members can make major adjustments in their lifestyle and social network (Zhou et al., 2011), exchange disease experiences, and learn how others have dealt with similar situations. In the context of chronic illness, online peer-to-peer groups provide a secure space for everyday self-care, with various sorts of assistance being offered and received (Marsh et al., 2020; Oser et al., 2020; White et al., 2018). A huge majority of online members believe that social support is the most beneficial aspect of online networks (Elnaggar et al., 2020). Informational, emotional, instrumental, and appraisal support are the most prevalent types of social assistance. Individuals feel less alone, more understood, and supported as a result of these supports (Oser et al., 2020). Many people mentioned how this aided them in their daily lives and described various ways in which they felt they had directly benefited (Coulson, 2013), such as symptom interpretation, illness management, and interactions with health care professionals (Coulson, 2005), as well as new treatment options (Armstrong & Koteyko, 2011; Coulson, 2005).

Patients opt to participate in online forums to connect with others who, they believe, understand their situation (Coulson, 2013). Empathy can also be triggered by people sharing personal experiences or self-reporting. Coulson (2014) investigated the role of alcohol-related forums in the United Kingdom and discovered that participants illustrate their personal story with alcohol, and forum members give supportive messages and encourage the topic poster by replying with their experiences and condition in response messages. Members of online communities share similar experiences in this way, and these exchanges appear to exhibit empathy and understanding. Huh et al., (2014) conducted research on online social support and video blogs for health. They discovered that the unique video medium enabled viewers to get intense and enriched personal and contextual disclosure, resulting in substantial community-building activities and social support among vloggers and commentators, both informationally and emotionally.

Patient empowerment is important for patient-centred care (Chiauzzi et al., 2016). Individuals can exchange information, share their knowledge, and experiences in online health fora, resulting in increased patient empowerment (Aardoom et al., 2014). Existing research shows that people who participate in online health communities benefit from them because the members' interactions contribute to the forum's overall knowledge and help them gain knowledge, feel more socially supported, and feel empowered to learn from one another. Individuals obtain direct benefits of informational and social support when they participate in online health groups, as previously described. These resources assist people in shaping community members' perceptions of empowerment (Johnston et al., 2013). The empowering processes reported by members of the group included: *c*onnecting with others who understand; access to information and advice; interaction with healthcare professionals; treatment- related decision making; improved adjustment and management (Holbrey & Coulson, 2013).

Members may visit online communities out of curiosity or affirmation for activities already undertaken. Most people find it difficult to evaluate information, so the community may play a role in double-checking sources or talk to others about online health information (OHI). OHI appears to have a more limited impact on specific types of health behaviours, such as dietary or physical activity improvements, and only serves as a supplement to more serious health issues. (Diviani et al., 2019).

Social support can assist patients with chronic diseases adjust and live with their illness and disability by empowering them in self-management. Individuals said that they received support from family, close and intimate friends, peer morale, and certainty and satisfaction with the participants' workplace organization as sources of support (Valizadeh et al., 2014).

#### 2.8.1 Research on online diabetes communities

After being diagnosed with diabetes in Thailand, people receive health information from health care experts to teach self-management principles as discussed in Chapter 1. However, they may need more active and continuing day-to-day help and support than is provided by health education formats, healthcare settings and organizations (Oser et al., 2020; Lichtman

et al., 2018; Cooper & Kar, 2014). As a result, people with diabetes may seek online communities to help them manage their diabetes and other comorbidities.

The majority of studies on diabetes online communities focus on peer support for diabetic self-care and how people with diabetes utilize them to manage their illness (Elnaggar et al., 2020; Litchman et al., 2019). Diabetes fora also provide participants with a sense of belonging and may help to promote adherence by promoting recognition and acceptance of the disease (Fernandes et al., 2018). Peers can provide long-term support and successful management for persons with diabetes by executing the core tasks of daily management help that they can discover on the diabetes forum.

Individuals who engage with diabetes online communities seek information related to their health conditions to help with self-management of health difficulties, for feelings of informational and social support, and for having a community with whom to share (Lewis et al., 2018). They saw diabetes online community as a way to learn knowledge, improve selfcare, and exchange emotional support with others for diabetes control (Litchman, Rothwell, & Edelman, 2018). The diabetes topics that are shared in the forums are various such as glucose values, diet and recipes through storytelling, and problem-solving strategies which some members can change their lifestyle and network (Zhou et al., 2014). The evidence showed that individuals living with diabetes trust the information from patients more than that given by health care providers (Zhou et al., 2014). The advice regarding lifestyle changes and diabetes management, which they get from online communities rather than health care professionals, is the information that forum participants are more likely to follow (Elnaggar et al., 2020). Furthermore, those who use diabetic online forums have a positive relationship with diabetic self-care because they use them to problem-solve with their peers. Sharing diabetes-related experiences in internet networks is a very typical occurrence (Litchman et al., 2019).

For emotional support, individuals with diabetes who use the internet to manage their condition share their stories on a forum, which provides additional psychosocial benefits (Litchman et al., 2019). It also includes healthy food advice to combat the disease, as well as personal stories of people with diabetes who have overcome their ailment and emotional support remarks (Verma, et al., 2019). People with a high emotional approach score are less engaged in the forum and receive less emotional assistance. Both groups, however, have improved their well-being over time (Batenburg & Das, 2014), gained information, and received decision support in the forum (Bernardi & Wu, 2017).

Elnaggar et al., (2020) examined patient's use of social media for diabetes self-Care in a systematic review of studies from 2008-2019 and found that individuals with diabetes use social media to report their HbA1c. and from reporting this glucose in blood values, it is associated with lower HbA1c. Therefore, online interventions can help people living with diabetes improve their HbA1c values and their condition (Celik et al., 2020; Parks et al., 2020)

As discussed above, individuals with diabetes may turn to online communities to feel more empowered. Empowerment is linked to a better quality of life, especially for those who participate in diabetes online forums frequently (Litchman et al., 2019). Individuals gain

empowerment through online networks, which gives them the confidence to make selfmanagement decisions such as caring for themselves, asking for help, and conquering obstacles. Diabetes online communities allow people to share their experiences and receive technical assistance, as well as inspire self-advocacy and patient empowerment, all of which help people with chronic illnesses and improve their health-related quality of life (Gavrila et al., 2019; Gabarron et al., 2018; Litchman et al., 2018).

Furthermore, when members of the diabetes online community utilize someone else's experience as a standard for their own management while that person is still a member of the online community and wants to help others. When individuals can provide or receive information from others when they get lost or from those people who have been in the forum as a role model of good diabetes control, they are empowered (Litchman et al., 2018). Participants who use the forum's guidance, information, and support are better able to position themselves as active participants in their own health care and to communicate with health-care professionals more effectively (Brady et al., 2017).

For Thailand, there is relatively little research in diabetes online groups, but the literature review revealed one study that looked at how elderly persons with diabetes utilize social media and their health literacy by gathering questionnaire data from 400 patients in Bangkok. The patients use health social media to avoid sickness, promote health, and treat medical conditions, according to the findings. When elderly people with diabetes understand how to prevent the condition, they are less concerned. There is a recommendation that diabetes information on the internet is still scarce, thus diabetes care centers should give diabetes information on their websites to help people living with diabetes in Thailand double-check the information they get on the internet (Thepsud & Korcharoen, 2018).

Because Thailand is rapidly aging, most studies on health online communities focus on the elderly, particularly in the field of health literacy. All older citizens in Thailand, according to prior surveys, use the internet or social media. People who use it search for drug information, thus there is a recommendation to encourage seniors to use the internet for health information more (Yaree, 2019; Yuenyong & Sineeporn, 2019; Thepsud & Korcharoen, 2018).

Prior studies have found a link between diabetes self-management behaviours in online health forums and improved health status. However, little is known regarding the association's applicability in Thailand.

### 2.9 Summary, research aims and objectives

In this chapter, I discussed the challenges of adjusting to life with diabetes for self-managers and for carers, who must adapt to a variety of limitations in everyday activities, diet, and lifestyle, including routine monitoring and living with worry about symptoms and control of blood sugar levels. Self-management involves medical management, behaviour management, and emotional management and self-managers are encouraged to accept responsibility for their health, control risks; and make active informed decisions utilizing health education information. In practice, adjustment to diabetes and self-management presents many dayto-day practical, psychosocial, and emotional challenges. An online health community has the potential to support adjustment and self-management through peer support in the form of empathy, exchange of experiences, information and advice based in experience, empowerment, and encouragement. Diabetic forums also give users a sense of belonging and understanding, and they may aid in adherence by fostering illness recognition and acceptance.

Nonetheless, limited research on this topic has been conducted in Thailand.

This program of research aims to examine the ways in which people use the online community Pantip to exchange their knowledge and experience as part of the self-management of diabetes and as carers, as part of an overall strategy of managing diabetes, and to explore the cultural context for diabetes self-management in Thailand. The main objectives are:

- 1. To explore how Pantip.com supports the self-management and control of diabetes on Pantip.com by analysing the interactions on the forum and the topics of discussion that members bring to the online community.
- 2. To explore how Pantip.com supports family members and carers of people living with diabetes by analysing the interactions on the forum and the topics of discussion that members bring to the online community.
- 3. To consider the significance of Thai culture in discussions about living with diabetes on Pantip.com, including consideration of the popularity of complementary and alternative medicine.
- 4. To explore members' accounts of the experience of adjusting to and living with diabetes or caring for someone living with diabetes in Thailand including the reasons for visiting Pantip.com

In the following chapter, the methodology will be illustrated, including research design, and ethical considerations, case selection, threads and posts collection and analysis, interview process and analysis.

## **Chapter 3: Methodology**

#### **3.1 Introduction**

The first chapter provided an overview of diabetes mellitus (diabetes) in global and Thai health care and cultural context and noted that living with diabetes requires a self-management approach and may benefit from peer support and support from carers and family members. However, most people living with diabetes are unable to control their condition.

In Chapter two, I looked at the lived experiences of people with chronic illnesses, particularly diabetes, to better understand what it is like to live with and adjust to long-term ailments. I examined practical and psychosocial challenges of self-management and considered carers' perspectives and experiences. Research on online communities was reviewed to consider what we know about why self-managers and carers might use online communities and how online communities support those living with diabetes. The programme of research in this thesis is comprised of two main strands. It aims to explore how the online diabetes community at Pantip.com supports daily self-management by examining interaction in message threads and topics of discussion on the site. It also aims to explore experiences of living with diabetes, including why they use online communities, by interviewing self-managers and carers who use Pantip.com. The focus of the enquiry is on social processes in interaction and lived experience and the research therefore takes a qualitative approach.

This chapter sets out how the research was conducted. I start by introducing netnography as a methodological framework then describe Pantip.com, the online community which is the focus of this research. Methods of data collection and approaches to analysis for both studies are described. Ethical considerations relating to internet research and researching with people living with diabetes and challenges, such as translation from Thai to English for the purposes of analysis and reporting, are also discussed.

#### 3.2 Qualitative research

Qualitative research is employed to explore experience, process and meaning making (Daher et al., 2017; Creswell, 2009). Its goal is to investigate, explain, and comprehend social phenomena by examining the context in which they occur, as well as the experiences, interactions, and communication of individuals or groups (Kvale, 2007; Denzin & Lincoln, 2005). In quantitative research, questions may focus on e.g., categorising characteristics, quantifying outcomes or benefits, user satisfaction, and may employ closed-end survey formats (Shim & Jo, 2020; Nimrod, 2010). In qualitative research, the questions focus on the why and how of human interactions and experience. For example, what kinds of information Chinese family members of cancer patients seek in an online health community and why they visit the online community (Ma et al., 2021).

The qualitative research method has been employed in a significant quantity of study on online health forums. This strategy is similar to earlier patient-centered studies in online diabetes communities. Their objectives would be to investigate how online social interaction

may influence patients' experiences of diabetic management in order to better understand patient health management (Zhou et al., 2014), to examine the texts posted by members of the social networking site in order to discern the community's values (Arduser, 2010), and to better understand the positive social effects of diabetes (Basinger et al., 2020; Zhou et al., 2014).

There are examples of quantitative research in online health forums. Bagnasco et al. (2014), for example, investigated at the personal characteristics that determine the success of type 2 diabetes self-management education. They looked at age, gender, marital status, social-cultural characteristics, educational level, socioeconomic status, and ethnicity.

## 3.3 Netnography

Netnography is, "the approach of ethnography applied to the study of online cultures and communities" (Kozinets, 2010, p. 12). Both ethnography and netnography are naturalistic and unobtrusive approaches so attractive to those interested in studying social practices in their everyday context (Kozinets, 2010). Netnography was first developed in marketing research by Kozinets and others, but has been used to explore online communities who discuss other issues and topics such as health. Tenderich et al. (2019) used netnography to investigate the online activities of people living with diabetes by collecting posts on social media sites such as Facebook, Twitter, and Reddit with the goal of providing patients with important practical tips and tricks related to diabetes self-care and decision-making information from peers. Gün & Şenol (2019) gathered parents' submissions to online community platforms to investigate how parents of children with cancer seek information through these platforms.

Kozinets recommends the following forms of data for netnographic studies (Kozinets, 2010; Kozinets, 2006), all of which were collected during this programme of research:

• Field notes obtained through the researcher's direct observation of the community and its members. This can help determine who uses the site, who generates and responds to the threads and to get a broad understanding of the questions posed and topics discussed.

• Archival data collected for textual analysis e.g., pre-existing messages and online interaction threads, posts, comments, pictures, etc. from the community. Online researchers can potentially gather a vast amount of data without making their presence visible to culture members (Kozinets, 2010; Beaulieu, 2004).

• Elicited data collected through interviewing or chatting with the members of the community. Doing interviews can help researchers put the online community into a wider context of daily use and understand more about when and why people go to the site and their experience as users.

A netnographic study involves identification of a suitable online site (or sites), gaining access including to the community and/or permission to download data from the site, data collection, observations of the community and its members, copying of texts from communication sites, contextualising communication and analysis and interpretation of social interaction and other data to understand more about the culture, practices and functions of

the online community (Caliandro, 2018; Langer & Beckman, 2005; Kozinets, 2002). It also involves careful consideration of whether to research the community from a position of being an active member or observer (lurker). Although I am a registered member of Pantip, I do not post or respond to posts on the Pantip diabetes forum. This can be an advantage in decreasing the impact of the researcher's presence (Kozinets, 2002). However, my identity as an outsider was significant to members of Pantip and had an impact on my ability to recruit interviewees from Pantip for the interview study. Some of the online community members were reluctant to engage with someone they perceived as an outsider, which required careful negotiation to recruit interviewees to participate in this study.

### 3.4 Introduction to the Pantip.com diabetes community

#### 3.4.1 Selecting Pantip

I began looking for online communities by conducting a Google search utilizing a variety of search phrases (e.g., diabetes, forum, and online in Thai language), including social media. As a result, I found some Facebook pages, such as the Diabetes Association of Thailand's page, which offers expertise and information to people with diabetes. Unfortunately, there is no exchange of information. Most participants click like, and the comments only say, 'thank you'. I found that Pantip is Thailand's only active online diabetes community offering those living with diabetes the opportunity to, "get information, advice, and support from peers" (Centola & Van de Rijt, 2015, p.19). It is well regarded for its peer support function (Lewinski & Fisher, 2016; Gilbert et al., 2012) and patients and carers actively seek assistance from other members of the community. Pantip meets Kozinets (2002, p.65) five criteria for a viable online community from a research perspective (1) a focused segment, topic, or group relevant to the research question (2) high "traffic" of posts (3) discrete message posters (4) detailed or descriptive, rich data; and (5) between-member exchanges. Pantip has a dedicated place for posting diabetes-related discussions and has a high traffic of posts. According to the digital usage data in Thailand 2020, Pantip is Thailand's largest online community, and it ranks in the top five most popular websites in Thailand, alongside Google.com, Facebook.com, YouTube.com and Google (Electronic Transactions Development Agency, 2016-2020). Pantip platform gives members a place to post, discuss, read, and exchange textual and visual material. In October 2020 there were 6 million members of Pantip (accessed 22 October 2020), but it is difficult to know how many people use the diabetes forum.

Pantip is a Thai language discussion website and active forum, open to the public for reading and accessing data but to post on the forum individuals must register to be a member (see more detail in section 3.4.3). It was founded on 7 October 1996 by Mr.Wanchat Padungrat, an electronics engineer. The name of Pantip means 1,000 tips. The initial purpose of its establishment was to produce an information technology (IT) E-Magazine, but the feedback from the reader was that they were interested in the public forum more than the content of the E-Magazine. From this point on, the purpose of Pantip changed to becoming a forum and the topics expanded from being restricted to IT to a huge number of others: 38 topics such as politics, religious, sport, cooking, movies, travelling etc. and 15,000 tags such as Thai football, K-pop, coffee shop, monk, living abroad, politicians etc (as of 31<sup>st</sup> January 2021). The set of

tags in Pantip is fixed, in contrast to Twitter, where anyone can create new hashtags and attach them to any post. Each topic has its own room and there is a homepage which shows all the topics.

Pantip also provides other features, including BlogGang (personal diary), Pantip Market (online marketplace), PanTown (online society), PantipStore (online store), MagGang (free blogging platform), and ipicazz (digital art academy). However, the main purpose of the site is to provide web boards for the members. The main income of Pantip is from selling advertising space on the main page and sub-forums.

### 3.4.2 Registering to use Pantip

Although individuals can access (as a lurker) to Pantip, since 2003 it has required a National ID Card number to register for a membership. To complete the registration, all members must have an email address and scan their National ID Card and fax it to Pantip to verify their identity. At first, this system received feedback about the difficulty to register and some people do not want to disclose their ID number. However, the membership has grown, and the members feel like the content has improved and they seem quite satisfied.

In 2008, Pantip added other channels to registration. Therefore, there are 3 options to apply: (1) register by using National ID Card Number; (2) register by SMS (mobile register); and (3) register by email address or Facebook log in or Google Plus log in. These three types of memberships have different permissions. Only members who register by ID Card can post threads and reply to posts in every topic, upload photos, edit their username, and the smile face icon will appear after their username. The second type of membership can post topics but no more than four posts a day, reply to unlimited threads, can upload photos, and have mobile phone icon after their username. For the third type of member, they get permission to post one thread a day and only in a question type topic, they are not allowed to upload photos and change username, and no icon will be shown after their username.

### 3.4.3 Posting to a topic thread on Pantip

Pantip members who would like to post a topic into the forum have to follow these steps. Firstly, they must log in to https://pantip.com/. Secondly, click on the icon "post topic" then the member will go to the page of http://pantip.com/forum/new\_topic. Thirdly, select the type of topic which Pantip categorizes into six types. The first type is a question thread in which a poster asks a question or problem, or they need some help from members in the forum and this kind of post will have a question mark next to it. The second type is conversation thread, in which a poster would like to share or discuss something with other members. This kind of post will have a smiling face sign. The third type is a poll thread where the individual would like to survey some issue, indicated by a graph. The fourth type is reviewing thread where people share their experiences with goods or services. This kind of thread will have a sign of stars (the number of stars indicating the satisfaction of the reviewer). The fifth type is news thread where members would like to share some interesting news that might be useful for others and its symbol is of newspapers. The last type of thread is the commercial topic, where members on Pantip can sell anything new or second hand and

the sign of this topic is a trolley. However, people do not seem to openly declare a commercial thread, e.g., when selling complementary and alternative medicine (CAM), as we can see in Chapter 7, where people are selling CAM-like hidden advertising in the conversations.



Figure 4: The layout of the six types of the post page (Pantip.com, 2023)

Next, the members can start to write their topic sentence, which is limited to 120 characters, then they can write a detail in the next column, which has a 10,000-character limit. In this section, members can add photos (maximum 20 photos but not over 720 mb), clip, slide, document, map, and Pantip Toy (emotion icon). The member can adjust the writing style and page layout. After that, they can select to tag in a relevant group with their topic and not over five hash tags. Lastly, the members can preview to see their topic and detail before they post into the forum. If they think that it is completely as they want, they click to post the topic and then it is finished.



Figure 5: The layout of the post topic page (Pantip.com, 2023)



**Figure 6:** Interface of an initial post of a typical thread which there is no different in all types of question on Pantip.com. (The poster stated that his grandma has been diagnosed with diabetes and that her blood glucose level is 300 mg/dL. What foods should she eat, and how can this be treated? (Pantip.com, 2023)

Except for commercial topics, all posts appear on Pantip's main page, and they will appear in chronological order by time and date. The reader has the option of viewing the posts by topic or by gallery on homepage. When readers click on a topic that interests them, a new page will appear that contains all the information on that issue. On this page, the data will be organized by topic and comments. If the posters want to respond to any of the comments, they can do so in a sub-comment. If the poster wishes to respond to comment 1, for example, his or her response will appear as comment 1-1.

Pantip will show a topic that the reader might find interesting at the bottom of each page, as well as a link to a page that shares a tag from that topic. In addition, there are three alternatives on the main page of Pantip: Pantip Now, Pantip Pick, and Pantip Trend. Pantip Now displays the most interesting topic that the forum participants are reading at the moment. The Pantip Pick is a topic that the Pantip team thinks members will find interesting or useful. Pantip Trend is the most popular topic among participants in the last 24 hours.

#### 3.4.4 Moderation

Pantip is run by a private company, and there are moderators to manage the threads and posts on the forum. There are two types of moderation on Pantip. One is the duty of the Pantip moderator team who take responsibility to remove offending posts from the forum such as Popular Image Board, and the other is the duty of the members on Pantip, where, if they find some topic to be offensive to the forum, they can click the "trash icon" (see Figure 5) to report it to the moderator team and get it deleted. Threads and posts that Pantip remove from the forum include the following: messages which are critical of the king and the royal family are absolutely prohibited, foul language or sexually explicit content, insults or posts that may cause a person to be hated, posts that are solely intended to cause quarrels or chaos, negative attacks on religion or the teachings of any religion, use of pseudonyms that may resemble somebody else's real name with the intention of misleading others, messages that might cause conflicts among different educational institutions, and posts containing personal data of others, including e-mail addresses or telephone numbers. All posts and threads that follow these guidelines will be retained and not deleted, though the original poster may request to delete it. Moreover, the members can share their original posts or their favourite threads via Facebook, Twitter, and Google Plus, for which Pantip provides sharing icons.

However, some threads and posts may try to present and review goods without any real experience of them (sell goods) in the forum. The moderator team of Pantip will patrol and if they find out that these messages are from the same computer, and there is an active intent to push their threads as a popular topic, they will assume that it is a ruse, and they will post a message into those threads to announce a warning that these threads and posts are from the same computer, which are related to other posts, and it could be a shill topic. The members can also moderate here by clicking the "trash icon" to report to the webmaster.

### 3.5 Ethical considerations in researching an online community

The Association of Internet Researchers Ethical Guidelines highlight a range of ethical issues for internet researchers to consider, which include tensions over whether a community or website is a public or a private space, authorship in contrast to research subjects. whether a researcher has informed consent to research the site, whether it is possible to anonymise posts and posters, researching from a covert position (as a lurker), and data quality. According to the Association of Internet Researchers Ethical Guidelines (Markham & Buchanan, 2012) and the terms of service (TOS) of Pantip, the site is not considered to be a private and personal network, as users are aware that its content can be read by anyone (Herring, 1996,) and users do not require an invitation, registration, or approval to read and share (except posting users need to register on Pantip.com). Data from Pantip can be shared to third party sites such as social networks (e.g., Facebook, Twitter, and Google), including advertisements. Pantip is also often in the news, which means the stories sharing on Pantip is not private. As discussed above, it is highly regulated space and measures are taken to protect site users and prohibit unacceptable messages. Since Pantip is fully in the public domain (Kozinets, 2010), researchers do not need explicit permission to collect threads from the site and there is no need to obtain a signed consent form from individual posters, as has also been demonstrated by previous studies on this website (Kongcharoen, 2015; Bodhibukkana, 2013). I opted to collect data from the website covertly, but it could be argued that identifying yourself on the forum which can make the environment changed and informing others about your research is an ethical approach to take, even if permission isn't required to download discussion threads. However, the participants know who they can contact if they have questions or any problems during the research project.

However, it has been argued that being observed has the potential to influence the behaviour of the person being observed (Olsen et al., 2004). The goal of qualitative research is to comprehend the social reality of individuals, communities, and cultures by studying objects in their natural setting (Aspers & Corte, 2019). So, to diminish the influence of the researcher's presence and minimize the harm, the researcher should limit his or her disclosure (Garland, 2009; Kozinets, 2002). Furthermore, obtaining consent from all individuals monitored is impossible (Spicker, 2011). Even though I did not reveal my presence in this phase of the study, I did reveal myself to the online community (Pantip) to recruit interviewees in the next phase.

Prior to starting the research and as part of the work in preparation for the ethics approval application, I checked for relevant forum policies and whether there were any Pantip officials who I should contact to obtain permission from or agreement with the forum owner or moderators. I sent a message to ask for permission to collect data to the Pantip team, but no one replied. Then I sent a message to someone who collected data from Pantip for research (I found it from Google search), and she confirmed it was allowed to collect data without asking for permission from the Pantip administrator team.

To protect the anonymity of participants, any potentially identifying information about participants has been removed. Pseudonyms were used to present the results in this dissertation. Pantip is not password protected, therefore any quoted material from the site is paraphrased or has words altered and anonymised to ensure that nobody can search for it online and identify the original posters (Ess, 2007). In this study, the pseudonyms generated resemble the participant's name chosen for the Pantip community. In the forum, the names of users are in various languages including Thai and English. I retained similar username choices, when selecting pseudonyms e.g., if the username was a flower name, tree name or number, I selected a different flower or tree name to replicate Pantip's actual environment. In addition, the researcher translated the English names into Thai and the Thai names into English. It was to ensure that, as previously mentioned, no one could look it up online and find the original posters.

#### 3.6 Netnography phase 1: observing the diabetes forum at Pantip.com

The first phase of the netnography involved a period of familiarisation with Pantip.com, spending time visiting the Pantip diabetes online community to gain an initial understanding of e.g., how to join the community, community norms, rules and moderation, how the board was used, how to post to the site (as discussed in section 3.4.3), who uses it, the types of posts people make and frequency of posting. Observations also provide a way to explore the emotional tone of the site and time spent on various activities (Schmuck, 1997).

During the research, I took fieldnotes which I logged every day during my three months of observation. I observed who participated in the forum and what topics were discussed by the forum participants. I noted that the forum users included carers, people living with diabetes and health care experts. It became apparent that carers were active users on the diabetes site.

"Lumpini", or health topics is one of the fora on Pantip, these allow the participants to read, post, share, and exchange information/opinions about health. In Lumpini, at the time of study, there were 17 main hash tags and 56 different sub-hashtags. "Diabetes" is a sub-hashtag in the main tag of "physical health". If there are posts that are related to health, posters can use the hashtag of "Lumpini" or be more specific and also tag to a disease (with the maximum 5 hash tags per post). If the poster does not add any tag, the post will appear in the forum in the miscellaneous topic page. Every new post appears on the main page as well as the diabetes sub-forum, shown in sequence as per date and time.

By selecting the heart-shaped plus icon to get to Lumpini's main page, you can enter the Lumpini sub-forum. The topics that other users have recommended are the top two things on the first page, followed by the Pantip 'trending', which shows that this kind of topic has grown in popularity over the past 24 hours (see Figure 7). Pantip Pick refers to the topics that Pantip moderators have highlighted based on their interests. The most recent member-uploaded threads are displayed last.

There are numerous health-related topics on Lumpini's home page. If you only want to search for diabetes, you must click on the physical health sub-tag that is displayed on the middle page's right side. You can click follow, and it will be simpler to get there if you want to follow the diabetic sub-forum or other topics that interest you.

On the diabetes forum, you will see the Pantip trend first then followed by the latest posts. You can scroll down to see the topic headline and some of the details including the name of the topic poster, the date of posting, and the number of people who interact in that thread.



Figure 7: The diabetes forum's home page on Pantip displays information about Pantip Trending (Pantip.com, 2023)



**Figure 8:** The most recent member-uploaded threads are displayed on the diabetic forum's home page (Pantip.com, 2023)

From my observations of Pantip, the questions and discussions varied reflecting the problems and issues the posters are facing with diabetes; the most recent questions are displayed at the top. There are different thread lengths, ranging from 1 to 50 message replies. The community sometimes respond to questions that are commonly asked by directing posters to older posts that are relevant to their situation. Most forum postings receive responses from other users within a day but a reply to a message can be posted sometimes after months or years since threads remain there without being deleted from the forum. Daily new subject posts in the forum range from one to five, and most posts were tagged as questions, as shown in Table 2.

Observing the Pantip forum allowed me to understand the forum norms and rules (Giles, 2017) including disagreements and how they were resolved in practice. For example, I observed disagreement between a doctor and a poster who asserted that drinking a certain herbal beverage may lower blood sugar levels (see more information in Chapter 6 Section 6.4). "Dr. Orange," sought to challenge and double-check the topic poster's comprehension of diabetic medicine, while another poster also asserts that the research (about the herbal beverage) is insufficiently supported. Other community members join in the debate and attempt to mediate between the two sides. The issue was resolved because the other participants agreed with the doctor. Dr. Orange is widely known in the community, and her profile confirms this. Perhaps for this reason, people around her pay attention to what she has to say. It is significant that Dr. Phone is also a medical professional, and this is displayed on his profile, and made clear in his posts. Doctors are among the people who actively comment on the quality or accuracy of advice and information offered on the site. They post to explain what is wrong with ideas or information suggested by other posters, for example, posts with advertisements or questions about herbal remedies may receive cautionary messages about the dangers of promoting complementary or alternative approaches to selfmanagement, unless a patient first consults a doctor. Medical expertise is therefore respected and deferred to by many of the community members when an interest in complementary or alternative approaches is raised. Additionally, if someone shares a successful tale of control such as a food blogger who shares her story of effectively managing diabetes—the community members refer to her as an expert on Pantip. Users of the diabetes forum frequently indicate that anyone who asks questions, even after obtaining an answer, should consult healthcare professionals for personalized support and treatment options because this does not replace expert medical advice.

The Pantip diabetes forum uses informal but polite language and communication styles. The majority of self-managers begin by introducing themselves and describing how they came to have diabetes before going on to ask for information or advice. Discussions are sympathetic and supportive in what is understood as a shared fight against diabetes. The forum has a warm vibe.

There are some active, high-profile members who consistently respond to questions. Their names are seen frequently, including those of doctors and those who have successfully controlled their diabetes, and I became accustomed to seeing them and identified them as a

regular user e.g., 'Yorkshire' and 'NMKEN'. Active members include people with diabetes, carers, and health professionals. The content of the messages can show who the posters are and their role or status in relation to diabetes. For example, "my father has diabetes...", so it can be understood that the poster is a son or daughter and likely in the carer role or, "I do diet control, but why are my blood glucose levels still high?" We can immediately understand that this person is living with diabetes. Health professionals are recognisable due to the use of 'Dr' as a title and/or indicate their profession in their profiles, which anyone can see. Health professionals who are regularly active in the forum are 'Dr. Orange' and 'Dr. Phone'.

Some interviewees noted the presence and contribution of medical professionals to the discussion threads on Pantip:

I have been here a while. In the forum, we are aware of who is constantly present. We are aware of the people we can rely on, like Dr. Orange, who consistently provides us with good information about diabetes. (Interview with Kaew, female)

## 3.7 Data collection in phase 2: sampling discussion threads from Pantip

The data collected in the second phase was archival data i.e., pre-existing messages, posts, comments, pictures, etc. tagged to "diabetes" on the Pantip forum. Catterall and Maclaran note that there is an abundance of data online therefore, "the researcher may have to restrict the period covered by the analysis or decide to only follow certain conversational threads or specific themes" (2001, p.231). I decided how much data to collect, I considered mean sample sizes in previous studies of similar phenomena using similar methods. For example, the study of messages posted to alcohol-related online discussion forums in the United Kingdom by Coulson (2014) selected sample of 125 conversational threads, and yielding 758 messages in total.

I opted to collect topic threads and their individual posts on Pantip's diabetes forum, http://pantip.com/tag/โรกเบาหวาน, during a period of 6 months, from September 2014 - February 2015. The selection of a time frame to harvest the data and decided which parts of the site I would take data from based on my initial observations of how people interact with the site.

All data was included even though someone post it after this time. In total, I harvested 177 threads and 992 individual posts including images that were uploaded to the threads. The whole threads and their reply posts were picked and transferred into text on Microsoft Office 365 and saved to the Hallam Q drive. The numbers of each type of thread in each month of the study period are shown in Table 2.

Thread Type	Sep	Oct	Nov	Dec	Jan	Feb	Total
	2014	2014	2014	2014	2015	2015	
Question	26	26	31	25	23	20	151
Conversation	5	3	2	5	8	2	25
Poll		-	1	-	-	-	1
News		-	-	-	-	-	
Review		-	-	-	-	-	
Total	31	29	34	30	31	22	177

 Table 2: The number and type of threads collected during the study period

### 3.8 Preparing the data for analysis

The text from threads and their individual posts including pictures and emoji were kept. The usernames or avatars, dates and times were also kept (Holtz et al., 2012).

There were two types of interview data: one was gathered via video call and the other was acquired using Pantip's messenger. Using the Transcribe Tool, all audio data were verbatim transcribed. When the transcription was finished, I double-checked it by reading it while listening to the interview's files, correcting any spelling or other problems, and anonymizing the transcript so that the participant could not be recognized by anything mentioned, such as names, places, or events (Sutton & Austin, 2015). Pseudonyms were used to hide the participant's identities. Following that, all interview text data was produced and stored in electronic and paper versions. The transcriptions will be kept for least 10 years, but the audio recordings were destroyed after the transcription. All the interview data were imported into a Microsoft Word Office only after removing any personally identifying information.

### 3.8.1 Translation and back translation

The data for this study was gathered in Thai from Thai sources, with the results provided in English. The process of translation entails changing something written or spoken into another language (Wehmeier et al., 2005). This process is where "the meaning and expression in one language (source) is tuned with the meaning of another (target) whether the medium is spoken, written or signed" (Crystal, 1991 p. 346). Another concern with translation is translating the quotations of the participants. When the researcher translates it, the participants' voices alter, and providing individuals voices is critical in qualitative research (Denzin & Lincoln, 2000). Language is used to express meaning, on the other hand, language and presenting the findings in another may have a direct impact on the validity of the research due to the translation process, which is dependent on the researcher's decisions (Birbili, 2000).

The translation process in this study was adapted from Brislin's (1970) model:

1. Determination of the relevance or context

According to Twinn (1997), translators are critical to the translation process and are knowledgeable with both cultures. As a result, I am the translator in this study, and I am fluent in both Thai and English, as well as having understood the subject of study. The translation was not a verbatim reproduction of all data, but rather an interpretation of the outcome from Thai to English for reporting purposes. Van Nes et al. (2010, p.1) recommended that the researcher stay in the original language as long as possible during the translation process. As a result, I chose to translate the study's findings from Thai to English.

2. Forward-translation of the research instruments

I reviewed the transcript in Thai and made notes and annotations for future reference. During the translation process, I used Lexitron's online dictionary (https://lexitron.nectec.or.th/), which was created by National Electronics and Computer Technology Centre: NECTEC of Thailand.

During the translation, I found the difficulty to translate some Thai words and/or phrases that were not recognised by the Lexitron program. As Twinn (1997) indicated that one of the difficulties of translation is when an equivalent for the source language is not found in the target language. Halai (2007) suggested to used quotes when the source words or phrases either do not have a direct equivalent or are difficult to translate or interpret. For example, the phrase of "people living with diabetes", in English means "being diagnosed with diabetes, or knowing someone who is diagnosed with the condition" (Diabetes UK, nd). However, Thai people will not draw the same meaning from this phrase, which simply refers to someone who is diagnosed with diabetes. In the Thai context, we therefore use the terms diabetes patient or diabetic people.

After the translator entered the word/s into the translation log, I conferred with my British supervisors and reviewed the interpretation with a Thai friend who was a Ph.D student in the UK.

3. Backward-translation

Back translation is a technique for ensuring that an accurate version of a document is agreed upon. It is the process of translating from the target language back to the source language, such as from English to Thai, and determining the equivalence between the source and target versions (Brislin, 1970; Chapman et al., 1979, as cited in Chen & Boore, 2010). Back translators should be proficient in both the original and target languages, as well as familiar with the subject matter of the source materials (Bracken & Barona, 1991). Back translation was used in this investigation with some words/phrases that were not recognized by the Lexitron algorithm, as previously mentioned. The back-translation was done by a PhD friend of me who is fluent in both Thai and English and had no prior knowledge of the original materials. I checked the meaning and correctness of both versions (forward and back translations). If any disagreements arose, I worked out a solution with my supervising team and a PhD buddy.

After that, I had a completed draft. The main point of contention was regarding the actual names of Thai foods, herbs, or specific symptoms. For instance, the data indicated lists of vegetables suitable for people with diabetes, but when translated into English, they primarily displayed scientific terms, so I had to jointly decide what to translate to. One of the vegetables on the example list that I translated is the cultivated banana, which was first found to be Pisang Awak banana. Another example is a word that sounds like several Thai phrases but has a distinct meaning in English e.g., 'numb', which in Thai pronunciation translates to 'tea' in English. In the end, I have to select a word that could still convey the context's true meaning.

4. Final stage

I went over the entire procedure again to ensure that the interpretations were consistent. There was no difference in the themes and meaning generated between the English and Thai transcripts, indicating that the translation process is reliable and genuine (Brislin, 1970).

# **3.9 Data collection in phase 3: qualitative interviews with users of the Pantip diabetes forum**

The third phase was to investigate Pantip members' experiences of diagnosis and living with diabetes in Thailand, carers' experiences and members' perceptions of the role and significance of Pantip in supporting self-management and supporting others with diabetes. Qualitative research interviews were employed to explore in depth participants experiences and to comprehend their world as they perceive it (Tenny et al., 2020; Austin & Sutton, 2014; Patton, 2002) using questions to encourage individuals to express their perspectives, opinions and emotions (Kallio et al., 2016). Previous research on online health communities has also employed a semi-structured interview to explore the experience of people living with diabetes (Brady, Segar, & Sanders, 2017; Fergie, Hunt, & Hilton, 2016;Goetz et al., 2012).

In research that investigates people's experiences, a variety of data collection techniques can be used, including focus groups, and interviews. They are both qualitative data collection techniques that elicit experiences by – in the case of interviews - asking them questions or – in the case of focus groups – generating discussion amongst a small group of participants. They can be used in conjunction with observations and are helpful for acquiring information regarding participant views, user preferences, or understanding of a procedure, task, or issue (Cassano-Piché, 2015). However, each method has advantages and disadvantages. An interview is an excellent way to provide the researcher with the understanding of participants' experiences, how they describe those experiences, and the meaning they make of those experiences (Rubin & Rubin, 2012), e.g., an understanding of why a forum member might visit Pantip and how it fits into their daily management of diabetes or care for others. It enables a more thorough investigation of a subject or problem from the perspective of the particular interviewee. They also give the interviewer the chance to delve into research topics and topics raised by the interviewee in a conversation format. This level of involvement allows space to consider nuances, individual experiences, and distinctive viewpoints. In online community research, the interview is a common technique for gathering data, in addition to observation and analysis of threads on the forum. For instance, Hirschfeld et al., (2019) study of peer support through a diabetes social media community used semi-structured qualitative interviews with carers and patients who are involved in continuous glucose monitoring in the Cloud Facebook group to examine how the online community affected peer support. Another example is the research of Pikkemaat et al. (2019) which uses interview techniques in the investigation of "I have got diabetes!" - Interviews of patients newly diagnosed with type 2 diabetes to explore the thoughts, experiences and reactions of newly diagnosed patients with diabetes to this diagnosis and to the risk of developing complications.

Focus groups are also widely used to examine experiences (Krueger & Casey, 2014). A focus group is essentially a group interview, typically done in person. One advantage of focus groups is that discussion can develop between group members with minimal intervention from the researcher, who acts as moderator and uses techniques to generate conversation between participants, including questions and/or group tasks. This can generate a range of perspectives or experiences at the same time and participants have the opportunity to compare and contrast their experiences in the group. However, one disadvantage is that some members could dominate the conversation. Also, focus groups may be less suitable when discussing sensitive or personal topics such as experiences with diagnosis or self-management of diabetes or caring for others. Interviews allow for a greater degree of control and trust in the process on the part of the interviewee and may lead to more in-depth reflection and disclosure.

Surveys are useful for asking many respondents a set of fixed questions. They can be given out in person, online, on paper, or in other ways. Although open-ended questions are also permitted, surveys frequently incorporate closed-ended questions with predetermined response alternatives (Newcomer & Triplett, 2015). Surveys produce quantifiable data, which makes it simpler to evaluate and spot trends, patterns, and connections. For instance, Liang and Fan (2020) explored social support and user characteristics in online diabetes communities: an in-depth survey of a large-scale Chinese population using a questionnaire survey. Researchers examined the characteristics of participants in online diabetic communities as well as the factors impacting the provision and acceptance of social support among people with diabetes who belonged to these communities. They found that scores of social supports between males and females varied depending on the patients' ages and educational levels. However, the pre-determined responses used in surveys do not allow for the exploration of meaning and experience as it is expressed by the participant, or for new topics to be raised by them.

The objective of this study is to examine how people with diabetes and their carers use Pantip.com as part of their self-management approach. Interviews were selected because they can shed light on people's perspectives and be valuable in understanding individual's experiences with diabetes, including the role of Pantip.com. As a result, the interviewer can have a deeper understanding of how each person's experiences are unique.

#### 3.9.1 Recruiting interviewees and sample

During phase 1, I took note of who posted and who replied to messages and found out that there were 4 types of people who participated in diabetes forum on Pantip: (1) carers (the majority group of users), (2) individuals living with diabetes, (3) health care professionals, and (4) unknowns. I tried to recruit a health care professional, but he refused to participate. I

therefore decided to attempt to recruit interview participants from the two biggest categories of Pantip users: carers and diabetes self-managers. The criteria of recruitment for the interviewees were:

- individuals aged 20 years or older
- member of Pantip
- pre-diagnosis or diagnosed with diabetes OR
- caring for someone with diabetes (this could be as a family member or friend)

The age criterion was set as Thai people becoming sui juris on the completion 20 years of age (Rungsin et al., 2011), furthermore, the majority group of people who visiting health forum on Pantip age between 25-44 years old. The criteria were also based on the purpose of the current research (Schwandt, 2007), and targeted those who "have had experiences relating to the phenomenon to be researched" (Kruger & Stones, 1988, p.150) i.e., purposive sampling. Therefore, the researcher attempted to recruit both people living with diabetes and carers to be the sample in the interview session. There are no specific requirements for the number of interviewees to be recruited for a qualitative research study (Creswell, 2009). Guest et al. (2006) recommended 12 interviews to reach data saturation. In this phase, I recruited 15 volunteers, which is similar to average numbers used in previous studies (Liu et al., 2021; Robertson et al., 2017; Huh & Pratt, 2014; Zhou et al., 2014; Armstrong et al., 2012; Newman et al., 2011).

Following approval from the Research Ethics Coordinator of Sheffield Hallam University, I disclosed myself as a member in the Pantip forum to ask for the volunteer and to post the recruitment announcement in the community. Two days after the first recruitment announcement was posted on the forum (see Appendix F), I received critical feedback from one member about my approach to forum members. They said that the detail in the announcement used very formal language, that most forum members did not want to volunteer themselves because I were asking them to sign the participant consent form, my history on Pantip was lacking, despite showing full name, there was a lack of transparency over the goal of the study, language, what is the result, and they also asked why they could not interview here in Pantip's messenger. In response to this feedback, I produced a new announcement (see Appendix G) with more informal language and added Pantip's messenger as way to conduct the interview, which the first plan did not include.

There was still nobody interested in participating in the study. I decided to send a message to the member who gave the feedback and found that the language used in the announcement was still too formal and the wording must be altered to ask for help more than only saying "could you help me please". I sent it to a colleague in Thailand so that she double-checks the phrasing before I issued another new announcement. I then messaged it using Pantip's chat to the person who provided feedback. Then I posted the new recruitment post again on the forum which now allowed the participants the choice to interview via video call or, for participants who feel uncomfortable with a video call, they could choose to conduct it via

Pantip's messenger. Four days later, the first participant contacted me via Pantip's messenger, and he chose to interview by video call on Skype. Other interviewees followed but I still needed more participants. Another recruitment announcement was posted again after another month to ask for more volunteers.

In total, 15 individuals responded to the recruitment advert using the Pantip via private messages function on the forum and then the participation information sheet and the participation consent form were sent to all participants. The information sheet (see Appendix A and B) explained the aims of the research project, the description of what they must do, the amount of time that they will spend, a statement which addresses confidentiality and security of information, a statement that participation in the research is completely voluntary and they are at liberty to withdraw at any time without prejudice or negative consequences, a statement about any potential risks, harms and benefits to participants, and the contact details of me in case the participants have any questions. The interviewees returned the consent forms by taking a photo and word file depending on their convenience. A copy of the consent form and information sheet was retained by the research participant. Signed consent forms were stored securely by me.

In some cases, I was sensitive to the possibility that participants may feel distressed, anxious, and embarrassment while answering the questions in the interview. In such cases I planned to take a break, switch off the audio record, and try to engage in enjoyable activities, to come out of the research environment (Donalek, 2005). In addition, I was aware about the fact that the participants may need some help to provide contact details for supporting services, such as a counselling centre (Corbin & Morse, 2003).

The participants and I communicated in detail via Pantip's messenger, answering some questions raised by interviewees such as why I have to interview them, acquiring the signed consent form, and the decision of individuals' selection to conduct the interview by video call or Pantip's messenger. Each participant was contacted to make an appointment date and time to do an interview and got a reminder from the researcher one day before.

In summary, the total participants were 15 people, consisting of 11 people living with diabetes, 3 carers, and 1 health professional. For people living with diabetes, 5 conducted a video call and 6 people interviewed by Pantip's messenger. For carers, 1 individual conducted a video call and 2 participants interviewed by Pantip's messenger. And the health professional chose to interview via Pantip's messenger.

# **3.9.2** Developing the interview questions and conducting the interviews

A semi-structured interview approach was used in this part of the study. The interview guide (see Appendix E) was structured into two main themes: theme one contained questions to explore the background about pre-diagnosis, diagnosis and adjusting to life with diabetes and theme two contained questions to explore the experience of using online communities and why and how they engaged with Pantip. If the participants lived with diabetes, they were asked to describe their diabetes experiences and the role that Pantip may play in the diabetes management. If the interviewees were carers for a person living with diabetes, they were
asked to explain their experiences of taking care of people living with diabetes and the role that Pantip may play in this, such as seeking online information or support.

The interview schedule went through a process of refinement (four times developed), so that the questions asked would elicit participants accounts of, and their reflections on, the topics of interest to the inquiry. Both versions of the interview consisted of two levels of questions: main themes and follow-up questions which encouraged the participants to speak more about their experience. After consulted with the supervisors' team, the questions were developed four times to cover the purpose and the research questions. I checked all questions to make sure that they will not be leading to answer and removed ambiguities. The interview guide was then pilot tested by trying out the questions with a PhD friend to check the wordings and questions made sense; and reflected on whether they were likely to generate conversations to help address the research questions of this study.

It was necessary for the interviews to be conducted remotely, as the participants were in Thailand and in other countries whilst I was in the UK. I therefore explored potential methods for remote interviewing, including Skype. The pilot interview was conducted with a friend living with diabetes and one carer to practice and assess the advantages and disadvantages of video calls. I created both a digital sound file and digital video file for the pilot interviews. The results of this test were impressive. The interviewees were very active, and they felt comfortable. They chose the time and place by themselves, and it was convenient for them. The quality of the audio and video was excellent.

From this pilot interview, I made several decisions about how to conduct the main interviews. It emerged that the interviewees who help me in the pilot session did not want to get the interview questions before the interview starts. Both preferred being given the questions during the interview. In addition, both participants also expressed concerns regarding their appearance on the video, as they asked the interviewer if they looked good which like the study of Hay-Gibson (2009) which stated that "the possibility that participants may feel embarrassed or nervous to be on camera" (Hay-Gibson, 2009, p. 43). Since the analysis of the study does not involve analysing any visual content, the video call was used for the interview process and only the audio was recorded.

The video call interviews were conducted from 7 February 2017 to 9 June 2017. The length of time spent in the video call interview was between 35-60 minutes and in the Pantip's messenger interview was between 1 day and 2 months and 9 days. The duration of the interview conducted via the forum's messenger took longer because some participants did not come to the forum every day and the time difference between UK and Thailand is +6 hours. In addition, one participant lives in New Zealand (+12 hours) therefore it took longer to find a suitable time to interview.

#### 3.10 Data analysis methods and process

A thematic analysis is employed as the research methodology for this study because the goals of the investigation are to explore the meanings and experiences of individuals who use the online community Pantip to exchange knowledge and experiences as part of their overall diabetes management strategy and to explore the cultural context for diabetes selfmanagement in Thailand. Thematic analysis is a suitable technique for understanding experiences, beliefs, or behaviours across a data set (Kiger & Varpio, 2020).

A different method, such as ground theory, which focuses on generating theories from the data, develops a theory grounded in the data and seeks to discover new concepts and relationships (Fagiolini, 2011). Furthermore, content analysis, which focuses on communication patterns in a repeatable and systematic way, frequently focuses on counting and classifying certain words (Bryman et al., 2011). These considerations make theme analysis appropriate.

The data in this study was analysed using inductive thematic analysis, following Braun and Clarke's six-step procedure (Braun & Clarke, 2006). The data was coded openly to best fit the meaning communicated by the participants but at the same time guided by the research questions. The analysis of the threads will be discussed first, followed by the interview data.

# 3.10.1 Data analysis: Pantip diabetes online community threads

#### Step 1: Familiarising myself with the dataset

This stage involves reading and rereading each thread to become very familiar with the whole data set and comprehend all the details and investigate what was going on across the threads. While reading the discussions, I took notes as well. Words relating to diabetes self-management were highlighted and underlined. Some pages with fascinating narratives or experiences were printed out for additional interpretation due to the length of each thread.

In addition, to keep data under control, I took a systematic approach taking notes as I went along about my initial thoughts and by writing in a six-column paper document. I established a protocol that included noting: 1. Threads' date, month, and year, 2. Topics discussed 3. Who started the conversation (diabetics, carers, health experts, etc.) and who responded? (People living with diabetes, carers, health professionals, etc.) 5. The type of self-management activity and 6. Diabetes status (whether they mention it is managed or uncontrolled).

#### Step 2: generating initial codes

Preliminary codes are data characteristics that appear to be interesting and significant in relation to the phenomenon (Boyatzis, 1998). "Codes are the building blocks of analysis," Braun and Clarke (2006) noted. "If your analysis is a brick-built house with a tile roof, your themes are the walls and roof, and your codes are the individual bricks and tiles" (p.6). The process of coding is therefore undertaken to produce succinct, shorthand descriptive or interpretive labels for pieces of data that may be of relevance to the research questions (Byrne, 2022). For example, the code 'diet control' might refer to a post where individuals ask about or explain a problem with eating or food such as when a member enquires about the kind of food that produced their high blood glucose level. They were diagnosed with diabetes and were seeking help from the community to control blood glucose levels through dietary changes and what foods to avoid. This relates to the first research objective outlined at the

end of Chapter two, to explore how Pantip.com supports the self-management and control of diabetes.

I play an active role in interpreting the codes and themes and in considering meaning and meaningfulness that is more than surface level. A good example of this is data coded under 'diet control' in this post: "the doctor said that desserts and soft drinks are poisons then we should not eat it. Oh doctor...it is a sweet poison, I sometimes think that dead is dead 555++ (555 denotes laughing in informal Thai writing, and it is pronounced ha ha ha in English). In interpreting this, the dark humour of 'sweet poison' would be noted in suggesting a theme that individuals with diabetes can demonstrate they know what they must or should do to control diet e.g., avoid sweet food and drink, but may want to share with the community how extremely difficult it is to do.

The table below shows a few examples of the process in generating initial codes from the Pantip community threads. The type of poster is noted, and the data items are the meaningful fragments from the original post. For the most part, data was tagged to a single code, but some are tagged to more than one, as shown in Table 3 below where one data unit is coded as seeking both advice and emotional support. Pantip members frequently seek emotional support in addition to advice or information.

Examples of the development from meaning units to codes		
Meaning unit quotes (data items)	Condensed meaning unit	Code
I have diagnosed with diabetes around 1 year, blood glucose level was 228 mg/dl., blood pressure was 185/110 mm Hg., cholesterol was 324 mg/dl	Self-manager: I have diabetes, and this is my health situation	Health Reporting/ Self-presenting
Now, blood glucose level is 90-110 mg/dl. (HbA1c:6%), blood pressure is 127/71 mm Hg., Cholesterol is 146 mg/dl. Treatment: I take medicines (Metformin 500 mg two tablets morning-evening, Amlo 1 tablet)	Self-manager: Blood glucose level is as normal person/My medication.	Health reporting/in control of diabetes
I control my diet, do exercise (cycling, weightlifting)	Self-manager: Diet control and exercise	Lifestyle management

Examples of the development from meaning units to codes		
Meaning unit quotes (data items)	Condensed meaning unit	Code
<ul> <li>I ate sticky rice, deep fried pork and pink noodle soup which I ate only vegetable and tofuI had questions:</li> <li>What caused the blood glu- cose level to increase? Per- sonally, I thought it was from sticky rice or because I ate late because normally, I never eat after 6 pm (but on this day, I finished work late around 8.30 pm).</li> </ul>	Self-manager: Review of diet in relation to blood glucose increase	Seeking advice - dietary management
<ul> <li>Whole wheat bread by FarmHouse with a green bag, I eat one piece a day. Does it increase blood glu- cose level? I sometimes want to eat crispy snacks then I bake the whole wheat bread to make it crunchy and eat it as a snack in the afternoon.</li> <li>What to do with an elderly patient</li> </ul>	Carer: Advice about how to	Seeking advice –
who does not want to see the doctor?	get self-manager to engage with doctor	managing self- manager
My father-in-law has diabetes. He fallsand has wound. After 2 days, this wound becomes a canker and eczematous.	Carer: How to deal with very difficult acute or crisis situations	Seeking advice – managing self- manager (crisis)
But he does not want to see the doctor. He buys medicine without a prescription, does not clean the wound, is very stubborn, never listens to us.	Carer – frustration - how to deal with self-manager who doesn't follow medical advice or practice self-care	Seeking advice – managing self- manager Seeking emotional support
I would like to know if Thai traditional medicine practitioners treat diabetes. If yes, I would like	Carer: Seeking information and advice about CAM (S-M not listening to clinicians)	The appeal of CAM

Examples of the development from meaning units to codes		
Meaning unit quotes (data items)	Condensed meaning unit	Code
him to go there perhaps he will listen to TTM doctorI don't know what to do so I come here to find more information from someone who knows about TTM practitioners, thank you.		
Sweetener instead of sugar? Asking anyone who knows whether using sweetener instead of sugar will have a problem with diabetes or not. I see that it is in the candy, chewing gum, coffee then I have doubt. Can people living with diabetes eat it? Thank you!	Self-manager: diet management (safe foods)	Advice about substitutes

**Table 3:** Examples of the development from meaning units to codes inthe online community data

#### Step 3: generating themes

A theme represents some level of structured response or meaning within the data set and captures something important about the data in relation to the research question (Braun & Clarke, 2006). The aim is for the pattern of codes and data items to communicate something meaningful that helps answer the research questions (Braun & Clarke, 2013). The themes are generated by actively interpreting the coded data, considering how similar and overlapped the codes are, noting where codes are clustered together into similar themes and the relationships between them. At the end of this stage, I should be able to produce a thematic map or table that collates codes and data items relative to their respective themes (Braun & Clarke, 2012).

Step 4 involves reviewing the generated themes, checking, and developing them to make sure they are relevant to the codes and data examples as well as the study's objectives. Braun and Clarke (2012, p. 65) proposed a series of key questions that the researcher should address when reviewing potential themes. They are: Is this a theme (it could be just a code)? If it is a theme, what is the quality of this theme (does it tell me something useful about the data set and my research question)? What are the boundaries of this theme (what does it include and exclude)? Are there enough (meaningful) data to support this theme (is the theme thin or thick)? Are the data too diverse and wide ranging (does the theme lack coherence)?

The themes, subthemes and related codes are set out in table 4 below. The codes and clusters of codes indicate the topics that people discuss on the forum and what they are seeking from the online community:

Pantip data: map of themes, subthemes and codes				
Theme	Adjusting to Life with diabetes (Chapter 4)	Living with diabetes (Chapter 5)	TTM & self- management (Chapter 6)	The role of Pantip in supporting carers (Chapter 7)
Subtheme	Pre-diagnosis and diagnosis	Experience of self-management	Appeal of CAM	Place of induction into the caring role
Coded data cluster	<ul> <li>Diagnosis stories</li> <li>Joining Pantip for peer support</li> <li>Seeking advice about symptoms</li> <li>Seeking advice about test and results</li> </ul>	-Self- management and daily life - Control and wanting to be normal - Sharing success stories - Sharing confessions and lapses	<ul> <li>Don't understand medical advice</li> <li>Don't like medical advice or treatment</li> </ul>	-How to become a carer -Looking for information on how to care for people with diabetes
Subtheme	Adjustment to diagnosis	Community support for diet control	TTM as complementary or alternative	Caring for well- being in the context of self- management
Coded data cluster	<ul> <li>sharing difficult emotions (denial)</li> <li>Acceptance stories</li> </ul>	<ul> <li>-Thai food</li> <li>Advice about substitutes</li> <li>Advice about safe foods and portion control</li> <li>Problem solving for raised glucose levels</li> </ul>	<ul> <li>Pros of TTM for SM of diabetes</li> <li>Dangers of TTM for self- management of diabetes</li> <li>accessing TTM/resources for TTM</li> </ul>	-Day-to-day care activities -Care in complex situations -Trying to interpret symptoms

Pantip data: map of themes, subthemes and codes				
			<ul> <li>balancing TTM with medically sanctioned approaches to self-management</li> <li>Disclosing use of TTM</li> </ul>	
Subtheme		Community support for lifestyle	Promoting CAM on Pantip	Community support for the job of caring
Coded data cluster		<ul> <li>Blood glucose testing</li> <li>Managing exercise and diabetes</li> </ul>	<ul> <li>Product or service placement (including as 'advice')</li> <li>Community dealing with traders</li> </ul>	-Over restriction - Managing self- manager's eating habits
				Community support for managing self- managers
				supporting with the challenging daily care tasks
				Dealing with crisis and seeking professional help
				supporting in the difficulty of day-to-day care activities

**Table 4:** Map of themes, subthemes, and codes in the Pantip data

#### Step 5: defining and naming themes

Defining themes requires analysis of the underlying data items and identifying which data items to use as extracts when writing up the results of the analysis. The chosen extracts should provide vivid a compelling reference point for the arguments being made within a respective theme. The data extracts in the following chapters were subject to analysis, to both illustrate the types of things participants said and, importantly, to interpret how the Pantip community supports self-managers and carers living with diabetes. Each extract was interpreted in relation to its theme, as well as the broader context of the research questions and literature to create an analytic narrative that informs the reader what is interesting about the extracts and why.

Step 6 is producing the report, in this case writing up the thematic analysis into the chapters that follow, alongside the findings from the interviews. Integrating analysis of threads and interview data when writing the report. Chapters 4-7 present the analysis of the online community threads and the interview material in relation to each of the themes.

#### 3.10.2 Data analysis: interviews with online community users

The interview data analysis technique was broadly the same as described above for the online threads, once again following Braun and Clarke's guidelines for thematic analysis (2006). To begin, I went through all interview transcripts numerous times to become familiar with the data, gain a grasp of the participants' experiences, and obtain a sense of the entire dataset. Then I examined individual interviews and made notes for the initial codes and potential themes on each transcript. This was inductive but also informed by the research objectives set out at the end of Chapter 2, particularly objective 4 - to explore members' accounts of their experience of adjusting to and living with diabetes or caring for someone living with diabetes in Thailand and the reasons for visiting Pantip.com. The coding was also informed by knowledge of the themes already generated from the analysis of the Pantip diabetes online community threads. The interview material was in used to develop a deeper understanding of adjustment to diabetes, from the perspective of self-managers and carers, their motivations for visiting Pantip.com and their experiences there. Table 5 below shows some examples of how the interview data was coded and mapped onto the themes developed in Table 4 (thematic analysis of threads).

Interview data item	Subtheme/Code	Theme
Self-managers		
The first time I knew I had diabetes I felt relieved because I knew what	Pre-Diagnosis & Diagnosis/Diagnosis	Adjusting to Life with Diabetes
it is	experience (relief)	
The difficult thing is about eating, I know what kind of food will affect my blood glucose level, but I	Self-management & Daily Life/Sharing confessions and lapses (lack of self-	Living with Diabetes

Interview data item	Subtheme/Code	Theme
cannot control my feeling, I want to eat it.	control around prohibited foods)	
Carers		
I use Google and Pantip to look for	Pantip as a place of	The role of Pantip in
food-related information for my	induction into the caring	Supporting Carers
grandma, who has diabetes.	role/Information seeking	
The biggest difficulty is diabetes	Community Support for	The role of Pantip in
food. It is very difficult to cook for	Caring/Managing eating	Supporting Carers
my mum because she is addicted	nabits	
to the previous taste.		

**Table 5:** Examples of interview data mapped onto codes and themes from Table 4(threads analysis)

#### 3.11 Summary

This research employed a qualitative approach and netnography methodology and gathered data from the online community Pantip.com and in interviews with users of the site. The thread and post data were collected over a six-month period, from September 2014 to February 2015. There were 177 threads and 992 unique posts in all and interviews with 15 people including self-managers and carers. Both datasets were analysed using a thematic analysis approach based on Braun and Clarke's methodology (2006).

The thematic analysis is presented in Chapters 4, 5, 6, and 7. In Chapter 4 and 5, you will learn how and why people use Pantip before and after getting a diagnosis and the role of Pantip in the forum users' day-to-day diabetes self-management will be explored. In Chapter 6, discussions on Pantip about the use of Thai complementary and alternative medicine for glycaemic control, as it relates to everyday self-management, will be explored. The experiences of carers who use Pantip, particularly adult children caring for parents, will be detailed in Chapter 7. The Thai context for self-management of diabetes will be considered across all the chapters, include challenges posed by diet, lifestyle and Thai food cultures for people living with diabetes.

# Chapter 4: Adjusting to Life with Diabetes and the Role of Pantip

# 4.1 Introduction

The purpose of this chapter is to explore how and why people use Pantip before and during the early stages of diagnosis with diabetes. The first part of the chapter examines journeys towards diabetes diagnosis and the reasons people turn to Pantip for support, including to seek peers, ask questions about symptoms or getting tests and to share and ask for help understanding a new diagnosis. The second part of the chapter examines how people go to Pantip to get help with coming to terms with a diagnosis including to share difficult emotional reactions and get help with acceptance and adjustment. The chapter concludes with a discussion of the role of Pantip in supporting people from the early stages of experiencing symptoms, to adjusting to life with diabetes.

# 4.2. The journey toward diagnosis and the role of Pantip

In the interviews, people were asked to talk about signs and symptoms before being diagnosed with diabetes. Some said there were no signs but were diagnosed with it after a routine medical checkup, others noticed minor symptoms over a period, whilst others experienced more sudden and severe symptoms and acute hospital admission or contracted diabetes as a complication from another health condition.

These interview extracts show how for some, diabetes can be invisible for a time, with no obvious symptoms and that a diagnosis can be sudden, surprising, and shocking. This can prompt a search for information online, such as at Pantip.

*My annual health check from work revealed that I have diabetes. (Interview with Ant, male)* 

I work as a nurse assistant and draw blood for patients. Then I have a good time checking myself... I assumed that I was simply obese and that everything would return to normal. The end outcome is... I've got diabetes. (Interview with Kiwi, female)

These findings are supported by the analysis of threads in the Pantip forum, where several posters state how they discover diabetes through a routine medical check-up, as in this message post which describes how a diagnosis was revealed through a routine general medical check-up at work:

A general medical check-up was held at my workplace, and I went through it as normal. I drew samples and had to fast overnight in order to check it in the morning. The nurse drew blood and then handed it over to the blood glucose testing machine (this is the first year that I saw it). When I asked for the result, she said that it was 198 mg/dL. (Message posted by Charm, 9 October 2014)

In contrast, some interviewees described how they suspected something was wrong before a diagnosis because they noticed signs or symptoms over a period of time such as being very

thirsty, unexplained weight loss, ants being attracted to their pee, impaired vision, frequent urination at night, or combinations of these:

I'm extremely thirsty, and I'm losing weight for no apparent reason (Interview with Yorkshire, male).

I noticed ants swarming my pee (Interview with Popeye, male).

These sorts of symptoms can prompt action, such as getting a blood test and a diagnosis may follow, with subsequent search for information online:

I pee a lot and am afraid of getting sick as a result of it. Following that, I do a blood test, which confirms that I am diabetic (Message posted by Tiger, 4 November 2014)

Other interviewees indicated that they discovered they had diabetes after being diagnosed with other illnesses, and as a complication of that illness, for example:

I have been diagnosed with polycystic ovary syndrome which the doctor told me at the start that this symptom has a high risk to have diabetes. After 5 years, I have living with diabetes (Interview with Apple, female).

Or more suddenly and following an acute hospital admission. As one person put it:

There was a Spirit Festival on Sunday with plenty of food. I ate a lot more than usual, especially prawns, and then I had stomach pains, nausea, and vomited at night. [...] The doctor advised me to admit to the hospital to have my symptoms investigated... The doctor also took blood samples to examine... The nurse informed me that my blood glucose level was 239 mg/dl, which is considered high. The doctor also wants to check my Hb A1C (Hemoglobin A1c) to make sure I have diabetes... The doctor came to see me and informed me that I had been diagnosed with diabetes, with a blood glucose level of 254 mg/dL and a Hb A1C of 11.2 %. (Interview with Sugar, female)

As we can see, the journey towards diagnosis varies, but Pantip plays an important role at this stage as a source of information to find out more about what living with diabetes might mean and as a place to connect with and share feelings with other people who may be in a similar position:

Which mothers are diabetic during their pregnancy? ... The doctor informed me that I had diabetes the day I received my blood results. I had a lot of anxiety (Message posted by Lila, 24 December 2014)

... I went to Pantip to see others who have the same conditions as me. I did not know about diabetes. I believe no-one can say about diabetes except a diabetes person. (Interview with Parn, male)

People who have recently been diagnosed with diabetes are eager to learn more about their disease and connect with others who have gone through similar situations.

# 4.3 Seeking peers on Pantip's diabetes forum

To find out why individuals come to Pantip, the interviewees were asked about how often they use the internet and when they joined Pantip. Most of them use the internet every day and search for topics of interest to them. The reasons for joining the Pantip diabetes forum included that individuals were already using Pantip before they were diagnosed, so they knew Pantip as a social space and a place where members might find information about diabetes. As stated by Sayan:

Society is Pantip. Here's a lot of people. All information can be found here (Interview with Sayan, male)

Another respondent said he was looking for the online community for diabetes topics, and found that most of them are foreign forums, only one is in and relevant to Thailand, which is Pantip. As he stated:

I've been looking for a forum for diabetes, but they're all foreign forums. In Pantip, I found it (Interview with Parn, male)

As evidenced by their use of the same words to describe the newcomers, the forum members clearly welcome the newly diagnosed. These words imply that both parties are on the same side of the issue and that they will be able to rally together. As the following example indicates:

Does anyone have diabetes since young age? (Message posted by Opal, 4 November 2014).

Yes, I have it when I was 17 years old... (Reply posted by Vivi, 4 November 2014).

I have diagnosed with diabetes when I was 28 years old... (Reply posted by Si, 4 November 2014)

One of the reasons people come to Pantip is because they are actively searching for others in a similar situation with similar symptoms. For example, a pregnant diabetic woman posted to Pantip to share her stress and fear that her infants would be harmed because of her diabetes. She seeks those who have had similar experiences so she might get help with learning how to deal with the problem and help manage the stress and confusion of gestational diabetes. As a member posted:

Does anyone have diabetes while pregnant? I would like to know that when you deliver your baby, do you have any problems? Or does your baby stay healthy? ... The doctor told me that I have diabetes... The doctor makes an appointment with me again on 12 January 2015. I am very stressed and scared. I am afraid that my baby will not be strong. Does anyone have experience of this? Please give me some suggestions, what should I do while I am waiting to see the doctor? I am so stressed (Message posted by Pui, 24 December 2014)

Six mothers replied to share their experiences and offer advice, this is one example:

I had it. I found that I had diabetes in the third month of my pregnancy. The doctor advised me to do diet control for a month. I followed everything including eating less rice and flour, eating more vegetables, eating low sugar fruits, but it was not effective. My blood glucose level was still high. The doctor injected insulin and adjusted the medicine in the proper dose. I injected insulin four times a day. I delivered my baby by Cesarean section with the weight 2,700 grams. Healthy and everything in good condition. Please feel free to ask me anything, especially about diet control. (Reply posted by Off, 24 December 2014)

On Pantip, there is a sizable community of pregnant women who aid and support one another. Pantip is perceived as a source of valuable and trustworthy information because it is based on peer experience. This can help members predict and prepare for what might happen to them, including likely outcomes as above, where off explains that following a diagnosis of gestational diabetes she tried lifestyle changes before moving onto an insulin regime and delivering a healthy baby. Accessing a range of relevant experiences in one place is helpful and may be reassuring or helpful in making decisions and taking action, including what to ask at medical appointments. As one participant shares:

The poster of the topic learns what to do and meets others who have had similar experiences. She also responds to the feedback. As she feeds back:

Thank you for a very useful suggestion. Now, I have started to control my diet because I have to meet the doctor and check it again... If I cannot control it, I will be admitted to the hospital. It seems very difficult, but I will do my best for my baby. (Reply posted by Pui, the topic poster, 24 December 2014)

Peers are important for persons living with diabetes because they help people with comparable chronic diseases receive and provide social support, which is linked to mutual understanding, identity sharing, giving of relevant guidance and information, and mutual action, as discussed in section 1.10.2.

People joining the diabetes forum on Pantip often introduce themselves by describing their status in the diagnosis journey, for example by describing symptoms and/or stating their experiences with tests and results. This included disclosing quite personal health related information such as HbA1c and cholesterol, as well as an individual's blood glucose level, blood pressure, and age. People acted in this manner because they knew others who had shared their experiences would be present:

I made drawing blood, and in the morning, I had to fast to check it. The nurse drew blood and put it into the glucose testing machine... She said it was 198 mg/dL, I looked at her and asked for the results... I am 39 years old, 171-cm high, weight 102.8 kg. I started feeling worried. Try to find the symptoms from Google...About my symptoms I often pee, dizziness, and hand numbness etc. (Message posted by Boo, 9 October 2014)

I was diagnosed with diabetes; my blood glucose level was 228 mg/dl, my blood pressure was 185/110 mm Hg, and my cholesterol level was 324 mg/dl. Currently, my blood glucose level is 90-110 mg/dl (HbA1c:6%), my blood pressure is 127/71 mm Hg, and my cholesterol level is 146 mg/dl. (Message posted by Cat, 3 September 2014)

These examples show that test results – at diagnosis and now - are highly significant when posting messages on Pantip, standing in for the identity of the message poster. Members can understand and recognize the situation of the posters if they introduce themselves with a pattern of blood glucose level results. Other figures, such as cholesterol and blood pressure, are also provided.

# 4.4 Seeking information about tests on Pantip

Individuals who believe they may have diabetes or are in the early stages of diabetes come to Pantip to learn more about their symptoms and also to seek information on how to prepare for a diabetes checkup. For example, fasting is an important consideration while getting ready for a diabetes check-up. Individuals want to make sure that they prepare properly and choose to seek help and information from the Pantip community on what to do. This could be in addition to or possibly instead of medical advice, posters may prefer to ask the community possibly because they trust the advice more, or might feel reluctant to ask or go back to the medial practice for clarification:

I want to see a doctor to determine whether or not I have diabetes. I'm not sure when I should start fasting. (Message posted by Ball, 3 September 2014).

Members responded with detailed information and instructions, and in Neo's post, adding additional and helpful information about the fasting time required for the lipid test:

Six to eight hours fast. Start at 12 a.m., then draw blood in the morning... If your fasting blood sugar (FBS) is less than or equal to 126, you don't have diabetes. (Reply posted by Balm, 3 September 2014)

Some say it takes 6-8 hours, while others say it takes 8-12 hours. Fasting for eight hours is fine if you only check your blood glucose level. If you fast for 10-12 hours, you can also get your lipid profile checked. (Reply posted by Neo, 3 September 2014)

Thai people are entitled to a free diabetes checkup under the country's public health insurance (for more information, see section 1.7, but the cost of the checkup is left to the discretion of the doctors, who must analyze their symptoms. Members may ask the community for information about the different costs of a public versus private hospital for tests. The community were able to respond by providing helpful information, based on their experience or community-held knowledge. In this way Pantip acts as a useful resource for making decisions about where to get tests:

The blood glucose level, HbA1C cost 200 Bath per item but at the private hospital, the price is 500 Baths per item. (Reply posted by Sasa, 3 September 2014)

The results from the interviews revealed that people come to Pantip because the doctor does not explain anything to them. As one explained:

Due to polycystic ovarian condition, I was diagnosed with a specific type of diabetes. After the doctor informed me that I had been diagnosed with it, she gave me no guidance on how to handle it. The doctor informs me that I don't need to lose weight because I'm already slim, and she simply prescribes medications for me. (Interview with Apple, female).

The basic facts regarding diabetes and advice on how to do diabetes self-management should be described by a health professional for newly diagnosed diabetics for the first time. Because they do not comprehend, they seek out someone with whom they can always communicate and be available, such as ICT services (Gardsten et al., 2018). As a result of her seeking guidance, she begins with Google and then moves on to Pantip, where the participants receive the solution and meet others who share her symptoms. Consequently, the doctor believes that everything is under control and nothing to be concerned about, which is a stark contrast to the patient's initial reaction to being diagnosed with diabetes.

# 4.5 Asking the Pantip community for advice about symptoms or results

Online communities provide an opportunity for people who may be going through the same thing to communicate with one another. For example, those experiencing symptoms they think might be related to diabetes can post to ask others what they think, instead of or in addition to going to see the doctor. Here is the opening post in a thread where Thana describes her current condition, age and diet and explicitly asks the community if they think she might have symptoms of diabetes:

Is this a diabetes symptom? Now I'm exhausted, sleep a lot, and fall asleep whenever I have free time. I usually sleep late, but right now I'm feeling drowsy around 8-9 p.m. I drink a lot of water and use the restroom frequently, but I don't get up in the middle of the night to use the restroom. I don't normally eat sweet foods, but I do consume a lot of carbohydrate foods like rice. Is it conceivable for me to develop diabetes now that I am 20 years old? (Message posted by Thana, 5 September 2014).

Thana's post is followed by a sequence of posts in the same thread, where members of the community respond to her question by making additional inquiries about the symptoms, the poster's weight, height, BMI, and family history of diabetes, thus conducting a thorough investigation:

Is there anyone in your family who has diabetes? How is your weight, height, and BMI? From your data, I cannot tell you that you have diabetes or not...you have to check your blood glucose level. (Reply posted by Kae, 5 September 2014) The symptoms that you have listed are not specific to diabetes. And if you have diabetes at the first stage, it may be invisible. If you have any questions, please go see the doctor and check the glucose in your blood. It does not take long time. It is better not to worry. (Reply posted by Yui, 5 September 2014)

You have to check the glucose in your blood. Perhaps, these symptoms might be from your lack of sleep and not enough rest. Going to the toilet very often can be from drinking too much water. Diabetes can be found in any ages. To make sure that you have it, go to see the doctor. (Reply posted by Pond, 5 September 2014)

These forum members suggest that the symptoms are not specific to diabetes and offer sympathetic counsel that it is better to know rather than worry. All three members agree that the topic poster should see a doctor and have their blood glucose levels checked, emphasizing that this is really the only way to diagnose diabetes. The community does not claim to have the ability to indicate a diagnosis, instead they play an important role in reassuring and supporting the poster to seek a definitive answer.

In some circumstances, a person who has a blood test result may seek help from the community to understand what it means. In this message the original poster outlines the facts of a seemingly inconclusive blood test result and asks the community if this means he has a diagnosis of diabetes:

Is it possible that I have diabetes? Glucose = 85 mg/dL, HbA1C = 6.48 percent, eAG = 139. I fasted for ten hours. Why is my blood glucose level normal? ... HbA1C is used to diagnose diabetes; normal is less than 5.7 percent, diabetes is 6.5 percent or more, and prediabetes is 5.7 to 6.4 percent, according to Google. Do I have to round up or down my HbA1C if it's 6.48 percent? I frequently have headaches, dizziness, weakness, neuritis pain (burning pain), and numbness in my hands and feet... Diabetes runs in my family. P.S. For over a year, I've been taking Prednisolone 5 mg 5 TB each day. Is this a probable reason for high blood sugar levels? Thank you so much for everything. (Message posted by Himalaya, 28 October 2014)

The topic poster is confused as to how to interpret the numbers and asks for assistance. One of the Pantip members advises him in the same thread that:

Based on my experience with people who have diabetes, it's very likely that you have it... The average sugar level is 6.48 percent of HbA1C. We should have less than 6% in most cases. It's possible that the low glucose (normal is 110 mg/dL) is due to you not eating sweets before doing a blood test. That is why the doctor will perform an HbA1c test. I'm not familiar with the medication you've been prescribed. Please look at the other people's opinions. (Reply posted by Intra, 28 October 2014)

Intra helps to explain the test results by suggesting a reason for the low glucose level and interpreting the significance of the HbA1c result, with a reading of 6.5 percent or more indicating that a person has diabetes (World Health Organization, 2011). This forum participant offered an opinion about how to interpret the results but was careful to indicate the limits of their expertise regarding the specific medication mentioned in the post and

therefore seek and consider other opinions on the significance of that to the test results. The original poster thanked the person who answered.

Here is a similar example, this time of an individual going to hospital for a test but not being able to get an interpretation of the results from the doctor. His aunt obtained the results, but they did not know what they meant. He therefore went to Pantip to post his blood test results and ask for someone in the forum to help him understand the result. As he states in the original post:

My aunt is taking me to the hospital today for a blood test. I have to wait an hour for the results after I draw blood. Then I decided to go to the temple and wait for the results of the blood test in the late afternoon. When I returned to the hospital, the doctor had already gone home. My aunt got the blood test results for me, but she has no idea what that means; all she can say is that it's normal. Because I have a sugar tooth, the goal of my blood test is to monitor for diabetes. Thank you for all your feedback. (Message posted by Robert, 24 February 2015).

The topic poster has come to Pantip because he knows this is a forum where he may find people who have had experience with diabetes and who should be familiar with blood glucose levels, his profile shows that he follows and is a member of the diabetes forum on Pantip. A health online community like Pantip has the advantage of being accessible at any time, it isn't like working in a hospital with set hours. As a result, people with diabetes who have questions or problems can come to Pantip and get answers without having to worry or wait. As we can see, the following is how the community responded to his question:

Some results are a bit high, but it's nothing to worry about. (Reply posted by Dior, 24 February 2015)

I agree with Dior. Following each outcome, the doctor writes the letters "L" and "H." "L" stands for low, and "H" for high. It indicates that it is normal if these two letters are absent. (Reply posted by Dr.Orange, 25 February 2015)

# 4.6 Adjusting to a diabetes diagnosis: sharing difficult reactions

Individuals who are living with diabetes want emotional assistance in addition to other forms of help such as informational or peer support. The topic poster in the example thread asks for peer support while also describing her feelings about his circumstance. As this participant states:

Is there anyone who has had diabetes since they were a child? I'm 24 years old and in poor health... The doctor informed me that I had been diagnosed with diabetes, and when I asked what I should do, he advised me to adjust my eating habits, stop eating sweet and fatty foods, and return in three months for another blood test. The doctor has yet to prescribe me any medication... I'm quite tense. I'd like to question anyone with diabetes if it's feasible to get rid of it. "How should I proceed?". (Message posted by Sririta, 4 November 2014)

Yes, I was diagnosed with it when I was 17 years old. I am now 26 years old and no longer need medication because my blood glucose levels are normal. Diabetes is incurable and can recur at any time if not managed properly. Regularly exercise, consume healthy foods, and most importantly, do not stress, accept, and ready to deal with it. Diabetes is not as frightening as we had imagined. I can eat cake and go about my business. Fighting. (Reply posted by Malee, 4 November 2014).

Thank you so much for your suggestion. (Reply posted by Sririta, topic poster, 4 November 2014).

Diabetes has been a part of my life since I was 28 years old. I was quite stressed at the moment because I am a person who enjoys eating. When I have diabetes, I have to be careful about what I eat and avoid some of my favorite foods. Every month, the doctor gives me medicine. When I did any real research on diabetes, I discovered that it is far scarier than I had anticipated. Then I take care of myself by eating brown rice rather than white rice, focusing on vegetables, and wishing to spend more time with my child. (Reply posted by Cat, 6 December 2014).

Keep fighting. (Reply posted by Sririta, topic poster, 4 November 2014)

We can see from the comment posts that the topic poster encounters persons who have diabetes at an early age. Both confirm what they have done to keep their blood glucose levels under control, just as the topic poster's doctor had informed her. She also asks for emotional support, which she receives, and she reciprocates by offering assistance to those who respond to her message.

In several of the threads, posters went to Pantip to share their emotional responses to finding out they had a diagnosis of diabetes. Some disclosed difficult emotions such as worry, feeling discouraged or anger:

I checked the glucose in my blood and got a result of 112 mg/dL. Is it dangerous? I don't want to have diabetes. Now I am upset and worry too much. (Message posted by Greentea, 16 December 2014).

These types of emotional response were also described by some of the interviewees, as here from Kiwi who remembers feeling scared because of being so young:

I feel scared because I am still young. (Interview with Kiwi, female)

In some situations, individuals share their stories and express the lack of emotional support from medical professionals when learning of their diagnosis. As one participant posts:

The doctor looked at the result and told me that "I have been diagnosed with diabetes". I was dejected. The doctor told me not worry... why I should not worry, I asked him do I have to take medicine. He laughed and told me to try to do diet control and advise me what I should eat or should not eat... (Message posted by Ken, 9 October 2014)

This contrasts with the community response to Ken's post offering empathy and support by sharing their experiences of how they made sense of a similar situation and started to adjust. In the message below for example, Alpaca notes that diagnosis can be thought of as a 'starting

point' and an opportunity for a positive lifestyle modification. He describes the process of adjustment as difficult at the start but getting easier, like a 'wound healing slowly':

I am supporting you. I thought that it is a starting point to change yourself. Except for the heredity factor, lifestyle is also another factor that have causes diabetes.

In addition, if you have diabetes, you will get a consequence of the wound healed slowly. (Reply posted by Alpaca, 9 October 2014)

Other responses share the sense of shock, but emphasise the importance of taking action, and importantly the promise of continued support and advice:

Change your habits and do some exercise... I didn't believe it when I was told I had diabetes at first... I am on your side. We can discuss it if you have any questions. (Reply posted by Doremon, 16 December 2014)

Some of the interviewees reflected that diagnosis was for them a relief, as it helped explain symptoms they had been experiencing:

The first time I knew I had diabetes. I felt relieved because I knew what it was [...]-Previously, my weight lost without trying and I was very thirsty. I am so relieved to know what happened to me. (Interview with Yorkshire, male)

Similarly, this participant communicates to Pantip that she is grateful for the fact that she checked her blood glucose level and discovered she has diabetes. She claims that it motivated her to take excellent care of herself. She disclosed that she discovered she has diabetes at an annual medical check-up, and that she is now able to take care of herself by modifying her lifestyle, exercising, and controlling her diet. She also compares her blood glucose levels before and after she was diagnosed with diabetes for one month. As she explains:

Thankful for taking the time to check my blood that day. I started taking care of myself seriously about a month ago, after my annual medical checkup revealed that I have diabetes. Stop procrastinating on exercising, diet control, switching from white to brown rice, reducing portion sizes, stopping coffee, quitting international food, avoiding crispy snacks, not eating late at night, and let's see how it goes. Despite the fact that my blood glucose level is still above normal, I shall do my best. (Message posted by Two, 11 December 2014)

Pantip is therefore a place where people go to share difficult emotions as they adjust to life with diabetes, and the data shows that diabetes status posts receive emotional support, encouragement, practical advice, or combinations of these things. One form that this takes is the idea that diagnosis can be a positive turning point and a trigger for action to make changes to achieve a healthier lifestyle. This in turn can help people cope with the difficult emotions associated with diagnosis, turning a negative scary event into an opportunity for improvement.

# 4.7 "Keep fighting": online community encouragement

As discussed in the previous section, people's reactions to learning they have been diagnosed with diabetes for the first time were a mix of negative emotions and some relief. When community members share these feelings in the Pantip forum, the word "fighting" appeared frequently. In Thai culture, "fighting" entails encouraging people to carry on, as well as providing emotional support. Participants use this word, and they also use the phrase "keep fighting" or "fighting fighting" with the same meaning to describe their own attitude or to encourage others to adopt the same resilience and ability to cope post-diagnosis. For example, the post topic "I don't want to have diabetes" and one of the replies mentions:

Keep fighting! I think, I also have diabetes... I am supporting you; you can do it, I can do it. (Reply posted by Zea, 9 October 2014)

Beach also replies to express encouragement and solidarity, saying that they have joined, "the same club":

*I encourage the thread poster too. We joined the same club. (Reply posted by Beach, 9 October 2014)* 

When Pinky posts that she does not know what to do following a diabetes diagnosis, and with a question about whether it is curable, a community member replies with straightforward practical advice that diabetes is manageable and that the poster should adopt a "Fighting" attitude, that is, to not let this defeat the poster:

I am 24 years old... I am very stressful. I would like to ask anyone who has diabetes, is it possible to cure it? What should I do? (Message posted by Pinky, 4 November 2014)

The reply post from one of the members states:

Diabetes is incurable and can return at any time if it is not managed properly. Regularly exercise, consume healthy foods, and avoid stress by accepting it and preparing to cope with it. Diabetes is not as frightening as we had imagined. I can eat cake and go about my business. Fighting! (Reply posted by Cola, 4 November 2014)

As discussed in Chapter 2, psychological well-being is linked to social support and is related to health outcomes. In this section we see that the online community plays an important role in providing peer support to people newly diagnosed with diabetes who may be scared or stressed about the way this will change their lives. One form this takes is expressing solidarity and encouraging the poster to "fight", to not let the new diagnosis defeat them and to quickly come to terms with the practical steps they can take to actively manage the condition. Peer support such as mentoring can be available in online communities such as Pantip.

# 4.8 Learning to live with diabetes: stories of acceptance on Pantip

Acceptance was a common theme in discussions about learning to live with diabetes on Pantip. Newly diagnosed diabetics go through five stages in their transition to diabetes: denial, anger, bargaining, sadness, and acceptance. (https://www.medtronicdiabetes.com/

loop-blog/5-stages-of-diabetes-acceptance/). This stage is critical; if people with diabetes can accept their diabetes quickly, they will be able to maintain and better cope with their diabetes, avoiding or delaying the development of other complications. Members of Pantip share their own experiences of accepting the diagnosis and encourage others to get through this stage.

As we saw in the previous section, after being diagnosed with diabetes, many people with diabetes are scared. They are afraid of what this means for their health, their lifestyle and of the future and may be confused about what is causing their diabetes. They must come to terms with and realize that diabetes is a chronic illness that cannot be cured. They will have to live with it for the rest of their lives. This interviewee describes the process of acceptance as 'becoming friends with it':

I have to accept that I have diabetes. It is incurable; I will have to live with it until I die. I'm going to have to become friends with it. (Interview with NMKEN, female)

Acceptance is about accepting diabetes as a part of one's life and learning to live with it.

NMKEN says she makes a list of what is in her life plan, and then makes a decision in relation to diabetes for each narrative. She intends to have a child but accepts she must postpone this plan until she is able to control her sickness. She is a food blogger and has decided that she will continue to blog but with a more limited selection of foods.

Lewis, a forum user, describes how after a period of denial, acceptance that he needed to act. came about a year after diagnosis and was triggered by feeling fatigued and being unhappy with taking medication. He says that that throughout his first year with diabetes, he did not follow the doctor's advice. As he explains:

I had a medical check-up in 2009 and discovered that I had type 2 diabetes. The doctor assured me at the time that if I lost weight to under 200 pounds, the condition would go away. I haven't changed anything yet. But I was sick of taking medicines. Every three months, I've been taking medication. My disease is making me fatigued until October 2010. I've started eating more nutritious foods... I eat a lot more vegetables now. I work out 150 to 180 minutes every week... My weight has dropped dramatically... My blood glucose level was lower than it should have been... I quit taking my medication... My weight fluctuated between 130 and 70 kilograms. My lifestyle has changed, but I continue to look after myself. Once a week, I check my blood glucose level, and I have a medical check-up once a year. For dietary changes, if you would like to lose weight very quickly, don't eat rice. I eat oats with yogurt, a white egg, blueberries, blackberries, raspberries, and protein shakes (1 cup) for breakfast. I eat a hefty breakfast. I get carbohydrates from vegetables and fruits, but I also receive fiber and vitamins. Late in the morning, I eat an apple, an almond, a walnut, and a pistachio. For lunch, I mainly eat meat mixed with garlic and pepper or baked salmon, and I sometimes eat chicken breast. Before and after dinner, around 2 hours later, I eat an apple. For dinner, I eat cooked vegetables, and then later, for a while, I eat raw vegetables. (Message posted by Lewis, 31 January 2015)

Lewis describes how he finally accepted the doctor's advice to lose weight and eat more healthily and notes that this was so successful he had to stop taking the medication as his blood glucose level was found to be too low. The story he presents is of being forced to accept his diagnosis but in doing so, of reaching a stable and manageable situation where he is looking after himself and continuing to monitor his blood glucose. Individuals who share their acceptance stories on Pantip want to aid others who are looking for guidance and encouragement from their peers. The forum members will be able to learn from others' experiences as they share their stories with the goal of supporting the transition to diabetes. This can encourage acceptance and provide emotional support by presenting stories in which the poster is decisive and in control, which leads to a positive outcome.

#### 4.9 Discussion

The aim of this chapter was to investigate people's early experiences with diabetes, why they engage with Pantip, and what functions Pantip can play for people from pre-diagnosis to adjusting to life with diabetes, in the early stages.

I saw that people go to Pantip to seek information and advice about possible symptoms and for help to interpret test results. This is consistent with other findings that people utilize the internet to search for health-related information (Nangsangna & Da-Costa Vroom, 2019). This may be before they have consulted a medical professional, and in the examples here, to share a worry that they might have symptoms of diabetes and to look for help with self-diagnosis. The forum plays an important role in offering encouragement and reassurance that it is better to know what is going on for sure rather than speculate, and to seek a test.

The interview data also underlined that members joined Pantip to connect with peers who are going through or have been through the same experience as them, as also described by Xu et al. (2017). Members seek peer support instead of or in addition to medical services - who may not have the time or explain things very well - or family and friends – who they may not be ready yet to discuss their concerns or problems with, or who may themselves be in the process of adjusting. This finding is consistent with Hernandez et al. (2020) and Kneck et al.'s (2011) who also showed that healthcare professionals may generally pay more attention to dose and glucose level (HbA1c) than to patients' queries, challenges with adjustment, or emotional experiences.

People's initial feelings and reactions to a diabetes diagnosis may be initially difficult including denial or ignoring advice, which may affect their capacity to regulate their disease and other consequences (Gardsten et al.,2018). I saw that Pantip plays an important role in providing peer support to people newly diagnosed with diabetes who may be scared or stressed about the way this will change their lives. They share worries, fears and confusion and receive empathy, emotional support, and encouragement from members to remain hopeful and believe in the possibility of coping and regaining control. I saw for example how the experienced Pantip members argue that diagnosis can be a positive turning point and a trigger for action to make changes to achieve a healthier lifestyle. They express solidarity, reassurance, and welcome new posters to the Pantip community – expressing that they are all in it together and must 'keep fighting' to not let diabetes defeat them.

Members also share their positive stories of accepting the need to change and learning how to manage their diabetes, which may be of help to others as they adjust. Hearing other personal stories of chronic illness experience can be helpful in coping with difficulties, obstacles, expressing needs, and findings resources to overcome barriers and improve quality of life (Cheng et al., 2019; Brown, 2018; Ho et al., 2016; Wu et al., 2016; Stanhope & Henwood, 2014).

Adjusting to Life with Diabetes	Key points of analysis (development of themes)
Pre-diagnosis	Pantip is a place that people go for support and advice pre-diagnosis and share worries about possible symptoms. The forum counsels against self-diagnosis and encourages posters to engage with medical services.
Adjustment to diabetes diagnosis	New members seek peer support on Pantip to find answers to queries, support with adjustment to diagnosis and emotional encouragement, rather than consult with medical services.
	Experienced Pantip members support adjustment by helping to see diagnosis as a positive turning point. They express solidarity, reassurance, and welcome new posters to the Pantip community – expressing that they are all in it together and encouraging them to 'keep fighting' and not let diabetes defeat them.
	Members also share their positive stories of adjustment to diabetes, of accepting the need to change and learning how to manage their diabetes, to help others adjust.

4.10 Summary of key themes and points of analysis

# **Chapter 5: Living with Diabetes and the Role of Pantip**

# in Self-Management

# **5.1 Introduction**

In Chapter 4, I explored how people use Pantip in the early stages of their diabetes journey and make the adjustment to being a person with diabetes. The purpose of this chapter is to examine the role that Pantip plays in assisting site users with the daily self-management of their diabetes. The analysis is informed by interview accounts and explores interactions on the Pantip diabetes forum.

Diabetes self-management is an important technique for persons with diabetes to control their blood glucose levels and delay the onset of other issues, as indicated in Chapter 1. Diabetes self-management activities include diet control, exercise, self-monitoring of blood glucose, and diabetes drugs. People with diabetes receive initial advice from doctors on lifestyle management and monitoring but are then expected to take responsibility for these activities most of the time.

I will examine how Pantip supports diabetes self- management practices including selfmanagement: being in control, self-management and diet control, self-management and lifestyle: community advice about exercise, community advice about monitoring blood glucose and medication, community support for 'unexplained' blood glucose levels, and sharing experiences of self-Management.

# 5.2 Self-management: being in control

During the interviews, the question "what kind of things do you need to do in selfmanagement?" was asked. Monitoring and 'control' are central to the experience of diabetes self-management: monitoring their blood daily to control blood sugar levels and being in control by identifying and taking responsibility for necessary lifestyle and diet changes. The following is what the participants had to say:

The doctor told me to control glucose in blood, if I can control it, the triglyceride level will decrease. The doctor gave me Metfodormin 500 mg to take 1 tablet in the morning and evening and gave me blood glucose testers to check every 2 hours after a meal. I also met with a nutritionist to understand more about the things that I am allowed to consume and those that I am not allowed to eat. (Interview with Newyork, female)

I see the doctor on a regular schedule. Whenever I go to the doctor, he gives me medicine and tells me to control my diet and exercise. I am attempting to follow the physician's advice, and take my prescription on a regular basis, avoid drinking alcohol, and diet control. (Interview with Blackeyes, male)

Being in control can therefore involve restrictions or taking on new behaviours, some of which may be particularly challenging in the context of Thai culture. There are therefore many threads in Pantip where people ask the community about how to be in control, including how to do diet control, how to do exercise and how to do self-monitoring of blood glucose and diabetes drugs, or other questions that the participants have found during their daily diabetes self-management. Effective self-management is often described on the site as the route to "living as a normal person", positioned as the reward for monitoring and control:

As this member says:

Diet control, decrease consumption of sweets and do exercise regularly to <u>control</u> the blood glucose level between 70-130 mg/dL and maintain the level of HbA1C less than 7.5%. Follow only these instructions, you can live as a <u>normal person</u>. (Message posted by Tom, 13 February 2015)

However, as we will see, monitoring and control activities are in themselves challenging and given the disease will still be with them, the identities of 'normal' and 'self-manager' need to co-exist and can sometimes be in conflict. In the next section I examine how the Traditional Thai diet presents challenges for restricting sugar and carbohydrates in the diet, how effective self-management can disrupt ideas of a normal Thai diet and how diet control is supported by the Pantip community.

# 5.3 Self-management and diet control

# 5.3.1 The challenge of Thai food and culture in dietary management

Individuals receive advice from health professionals to stop consuming sugar and to decrease the portions of starches. This advice may not seem difficult but in practice, diet control is one of the main challenges and problems for people living with diabetes that is presented to the community on Pantip. It seems that Thai food is a challenge for people living with diabetes due to the need to reduce sugar in their meals, for which they may have a personal preference or are used to as part of dietary and cultural habits. As one of the interviewees describes:

# I like to eat white rice. It is flour and it will change to sugar later. (Interview with Yorkshire, male)

There is a lot of hidden sugar within Thai cuisine, which is based on the five basic flavours: bitter, salt, sour, hot, and sweet. Even savoury spicy dishes contain a significant amount of sugar, which means that it is not straightforward to eliminate it from a diet (Winn, 2010). Furthermore, Thailand has a lot of tropical fruits that contain natural high levels of sugar like mango, durian, rambutan, etc. There are plenty of them around throughout the year and individuals can eat them anytime but especially after main dishes.

In Thailand, main dishes have white rice or sticky rice in some regions, which is grown widely across the country and inexpensively. Since they both contain more sugar than brown rice, people with diabetes are advised to avoid consuming it. However, the taste of brown rice is not good as white rice, and the price is higher. Since Thai people eat rice every day, it is very difficult for them to change their dietary habits (Sowattanangoon et al., 2009).

This interviewee describes how she continued to eat and drink traditional Thai dishes such as Thong Yord and Oishi which are very high in sugar content after her initial diagnosis. It was not until she had her medication increased that she started to realise she had to cut down on these foods and drinks: In the first month after I was diagnosed with diabetes, I ate Thong Yord (egg yolk fudge balls cooked in syrup) five pieces every morning and evening... Then I went to the doctor who discovered that my FBS level was 300 mg/dl. The doctor increased the dose of medicine before meal by one tablet. But this month, I've cut down on my sweet's consumption, stopped drinking soft drinks, and Oishi (cold Matcha Tea). I still drink some beverages on occasion, but not more than four cups each month (and adding only a little sugar). (Interview with Tree, female)

One of the interviewees compares Thai food with Chinese food:

I have diagnosed with diabetes for 10 years... During these 2-3 years, I have been in China, and I noticed that my blood glucose level is decreased from 120-130 mg/dL to 80-90 mg/dL and my weigh lost from 93 kilograms to 78 kilograms without diet control and trying to lose weight... Chinese food is not sweet and added sugar like Thai food. It tastes only salty and greasy. I eat like Chinese people, and it is benefit me. (Interview with Andy, male)

Thai culture of eating out at dessert cafes can also make it difficult to reduce dietary sugar. As one interviewee explained:

The difficult thing for me is to stop eating sweets. I am still young (25 years old). After work, in the evening, my friends and I often go to dessert cafes. Since I have been diagnosed with diabetes, I have to stop hanging out with them. My happiness has gone. (Interview with Apple, female)

This interviewee is upset because she knows she has to restrict suage as part of her diabetic self-management, but this creates a challenge as it means she is also restricting her social life and interaction with friends, that previously involved going out to dessert restaurants.

#### 5.3.2 Advice on diet substitutes and meal planning

Dietary and nutrition control is therefore one of the most difficult aspects of diabetes selfmanagement, and there are many questions concerning food on Pantip. For example, individuals who want to reduce consumption of sugar go to the community to seek alternatives that are sweet and enjoyable but do not affect their blood glucose levels so much and for advice on glucose content. This member asks about sweetener as a substitute for sugar:

Sweetener instead of sugar? Asking anyone who knows whether using sweetener instead of sugar will have a problem with diabetes or not. I see that it is in the candy, chewing gum, coffee then I have doubt. Can people living with diabetes eat it? Thank you! (Message posted by Victoria, 18 November 2014)

Yes, you can eat it but not too much. It is not good in the long term, and it is not a substitute for sugar. (Reply posted by MaiLex, 18 November 2014)

Use Stevia. (Reply posted by LexPaad, 18 November 2014)

The first reply agrees that artificial sweetener can be used, but only in little amounts, but the second reply suggests that Stevia (a natural sugar alternative) is preferable. The topic of sweetener in beverages is also discussed. As one of the participants asks:

Can I drink Coke Zero or Pepsi Zero to control my glucose level if I want a soft drink? Is this the best approach to handle it for diabetics? (Message posted by Joanne, 12 November 2014)

According to the responses, he should be able to consume it. As stated by the participants:

I think you can drink it, but some sweeteners are dangerous. You have to be careful with your selections. (Reply posted by TenGame, 12 November 2014)

It helps in the reduction of sweet cravings. My husband has diabetes, and whenever he sees someone drinking a soft drink, he wants to have one himself. I hand him a Coke Zero and tell him to drink it. He's been drinking soda water or lime and soda with no sugar or Schweppes lately. When he is fatigued and the weather is hot, he drinks it to refresh himself. When he consumes spicy cuisine, he craves a carbonated beverage. He consumes it, but he significantly reduces the amount he consumes. (Reply posted by Jira, 12 November 2014)

The topic poster receives advice that Coke or Pepsi Zero is probably okay in the first reply but also caution that some sweetener is dangerous. This advice is a little ambiguous then, leaving the poster to decide which sweeteners may be problematic. The second reply is also interesting in that it is not a clear yes or no, rather she says that Coke or Pepsi Zero can be helpful when managing sweet cravings. Jija says that, rather than cutting soda out totally, her husband substitutes for Coke Zero or reduces the amount he consumes. This strategy of consuming 'near enough' substitutes or modifying rather than eliminating consumption of food and drink is offered as a way to eat and drink things they enjoy and not feel too deprived, retaining a sense of normality. The advice itself then is either slightly ambiguous or is open to interpretation in practice, so there is still risk and responsibility involved for the original poster e.g., it would be easy to start out intending to only drink a little, but drink too much. However, the community is playing an important emotional support role in acknowledging and empathising with the poster that realistically there may be foods and drinks that selfmanagers are attached to which are extremely difficult to eliminate, and that reasonable substitutes or moderation can be a way forward, but in practice not a substitute for selfmonitoring. The presence of carers and family members offering (and looking for) support on Pantip is also in evidence here, which we return to in Chapter 7.

Some posts on Pantip are from self-proclaimed experts with knowledge about nutrition and based on their status as an experienced self-manager. For example, based on advice from a nutritionist and her own experience, NMKEN posted an article about how to eat for people living with diabetes. She goes over how many food categories there are, what kind of foods are in each group, portions and portion control or the potential negative consequences of eating too much and food exchanges. The diet information she offers is clear, with images, step-by-step and easy to follow. She advises individuals with diabetes on what foods to avoid and what foods to eat. In summary, she advises people with diabetes should eat brown starch, brown rice, low-energy vegetables (Chinese cabbage, green cabbage, tomato, zucchini, and morning glory), small amounts of fresh fruit, low-fat milk, non-flavoured milk, no added sugar, or stevia, use less oil in cooking, and eat meat as much as possible if they do not have high cholesterol.

NMKEN also illustrates examples of daily meals e.g.,

Breakfast: 2 slices whole-wheat bread, 2 fried eggs, and 1 apple. Or 2 slices whole-wheat bread spread with smashed liver, salad vegetables, and ½ teaspoon honey herbs tea.

Lunch: 3 ladles brown rice (1 ladle = 1 portion), stir-fried Thai milkweed flowers with egg, fried pork, and fresh vegetables. Vegetables should come first, followed by rice.

Dinner: Tofu steak, fresh vegetables, and Japanese Balsamic Salad Dressing.



Breakfast

Lunch

Dinner

Figure 9: Example meals for one day for people who do diet control

We can see that NMKEN claims to be a diabetes food expert, she also publishes a snapshot of herself bouncing on the beach to support the success of her methods. Her apparent understanding of diabetes foods, combined with excellent writing, makes her posts highly appealing.

The Pantip members appreciate the poster's advice since it offers a detailed step by step plan of how to plan meals and eat healthily. It helps understanding of what and how much to eat, providing clear instruction on how to measure portion sizes and thus put into action the basic clinical recommendation to monitor food and exercise. Members express gratitude for sharing food portion sizes and food substitute information, stating that they were previously unaware of this type of practical information. As one of the members explains:

Thank you, NMKEN, for sharing this valuable diet control information. I was diagnosed with diabetes last month... My heart was in my mouth. Now, instead of taking medicine, the doctor advises me to monitor my food and exercise. I'm trying to lose weight, but I've never heard of such a good portion before. I've cut out carbohydrates and sugar, but I still eat a lot of fruit. Fortunately, I came upon NMKEN's thread, which clarifies what I need to do. In December, the doctor scheduled a meeting with me; maybe, the results will be as wonderful as NMKEN... I'm supporting you, NMKEN, and I appreciate you letting me know that sweet females like us can enjoy eating. (Reply posted by Sara, 2 November 2014)

For people living with diabetes, portion size is an important component of food planning. This is a further example where NMKEN offers advice to Pantip members about portion sizes and corrects a view that it's possible to eat unrestricted amounts of noodles:

NMKEN: This is not the case. Glass noodles are made from Mong bean flour, and 2 ladles equals 1 portion. You should not take more than 3 portions in a single meal, so only 6 ladles should be used. We must count the portions; for example, if you eat rice

with glass noodle clear soup, you must reduce the rice portion. (Reply posted by NMKEN, the topic poster, 5 November 2014)

PLOY: I appreciate it. (Reply posted by PLOY, 5 November 2014).

We can observe that PLOY has had diabetes for more than ten years, but she lacks the necessary information to control and monitor her diet. The community can therefore play an important role in offering easily accessible, detailed practical advice to support the daily task of monitoring and controlling glucose intake, particularly when clinical or formal health education has been forgotten or was not clear or helpful. Several members leave comments to express gratitude for the information provided in NMKEN's posts, e.g.

*Thank you very much for your story sharing. It is very useful. (Reply posted by Sophie, 11 January 2015)* 

# 5.4 Self-management and lifestyle: community advice about exercise

Exercise is something that people with diabetes need to do, and Pantip members will have been told that they must do it as part of self-management by health specialists. The Pantip community provides a useful place to check out what types of exercise other people are doing or would recommend and for participants who exercise to seek information on how to plan for exercise given their diabetes profile, and/or how to build up the amount it is possible to exercise. As this member asks at the start of a question thread:

Is there anyone who knows how to work out properly for diabetics? I generally go for a run in the morning, but I quickly tire out. And now I am getting the impression that my body isn't in great shape. I've only been walking for a few rounds, and I am already tired. Please assist me in getting adequate exercise. My body will crumble if I do not exercise. Thank you for disturbing all my friends here to provide me with some suggestions. (Message posted by Mark, 26 December 2014)

There are 16 reply posts answering and giving suggestions. Most of the answers (5 responders) suggest cycling as the best exercise for diabetics and the other suggestions include jumping 100 times 3 sets every day and doing dumbbell for another 15 minutes, flexing both arms strapped by a rubber band, running, and weightlifting. The other comments are about the concerns for doing exercise for people with diabetes, including not doing heavy exercise because the body will need a lot of energy and it leads to high glucose in blood, being careful to avoid injuries from exercise because if diabetics have a wound, it will take long time to heal, and the view that diet control is more important than exercise. As one participant replies:

Cycling is less exhausting than running and can be done for longer periods of time. While cycling, you can also travel at the same time. Many diabetics ride bikes, and I believe that is the finest kind of exercise for diabetics. (Reply posted by Sunshine, 26 December 2014)

This poster asks the community for advice about how to extend his cycling to 100 km in the same day:

Diabetes with long-distance cycling (touring). I have been living with diabetes for around 1 year, blood glucose level was 228 mg/dl., blood pressure was 185/110 mm Hg., cholesterol was 324 mg/dl. Now, blood glucose level is 90-110 mg/dl. (HbA1c:6%), blood pressure is 127/71 mm Hg., Cholesterol is 146 mg/dl. Treatment: I take medicines (Metformin 500 mg. two tablets morning-evening, Amlo 1 tablet), I control my diet, do exercise (cycling, weightlifting). I would like to know how to bike a long distance around 300-500 km across the province which I will bike 100+ km/day. Ps. Normally I bike every day approximately 25-30 km on the weekdays and 70-100 km at the weekend. (Message posted by Joe, 3 September 2014)

One reply gives him a suggestion that, because there is a chance of hypoglycaemia from the medicine he has taken, he should have a buddy to call in case of an emergency. As the individual replies:

I think it's a little worrying because MFM medicine has a small chance to make you hypoglycemic. Your blood pressure and cholesterol are good, and you regularly do exercise, then your heart and blood vessels are pretty fit. I only recommend that you have a buddy who can be available to call on an emergency number, to make you feel safe. Moreover, about diet controlling, avoid drinking mineral water which contains sugar because it will make your blood glucose level swing, try to avoid it, eat food that contains low sugar index should be better. (Reply posted by BBQ, 3 September 2014)

The suggested response will assist the poster in properly preparing for the strenuous workout. The poster of the topic adds advice about drinking too much mineral water with sugar and sticking to foods with small amounts of sugar.

Yorkshire often replies to posts in the forum with the slogan "*Exercise beats diabetes*". He says that, in the first three years, he could not control diabetes and had high blood glucose levels above 200 mg/dL. He has been exercising regularly for 6 years already at the gym, doing it 4-5 days a week and spending 1–1.30 hours per session together with diet control. For now, he has blood glucose level  $\leq$ 130 mg/dL, which is satisfactory for people with diabetes. In his interview he says that:

Pantip gives me knowledge and encourages me to do exercise which is the essential thing for diabetics to control the blood glucose level. (Interview with Yorkshire, male).

Kiwi, an assistant nurse only started to exercise about 7 years after diagnosis. She was obese, but after taking regular exercise, she lost 17 kg, going from 87 kg to 70 kg in 4 months. She also does diet control. She says that she really loves to spend her time at the gym every day. In her interview she explained how she likes to post on Pantip to give encouragement to other people to lose weight and do exercise as she has had success in it, and she uses Pantip very often and always visits it every hour. She likes to answer others' posts, based on her own experience, to help other members to control their disease.

#### 5.5 Community advice about monitoring blood glucose and medication

Monitoring blood glucose is an important and regular task for self-managers. One of the interviewees, Kiwi, discussed this and explained how to use a blood glucose monitor to check blood glucose levels. She monitors her fasting blood sugar level every morning before and after breakfast. Common questions asked on Pantip were about the practicalities of blood

glucose self-monitoring. This includes how to operate a blood glucose monitor, which brand to purchase, how much blood to use, or whether this is a must-have device for diabetics. As this participant asked:

*Please help me choose a blood glucose monitor. (Message posted by Tracy, 12 October 2014)* 

The participant gets an answer with a recommendation. As one member replies:

I have also bought it and I chose this one http://www.biomed.in.th/review-acc-chekglucose-monitor/. (Reply posted by Patrick, 12 October 2014)

This individual asks how much blood to use:

How much blood to use with ACCU-Check Active? (Message posted by Megan, 13 January 2015)

The reply posts give her information about the amount of blood and how to apply to the test strip:

You have to put it in the full strip. For me, if it is not full, it will just show an error. (Reply posted by Onion, 13 January 2015)

A health professional posting in Pantip comments:

*If it too little but not so little that the machine does not work, the result will be lower than it should be (Reply posted by Doctor Bee, 13 January 2015)* 

NMKEN also posts about how to use a blood glucose monitor. The main purpose of her sharing is the difficulty of her first using the blood glucose monitor and to let the community know it took her time to become familiar with it. She makes a video clip of how to do it and attaches that video clip to her thread. This offers encouragement to members who may be struggling with the idea of testing their blood glucose and practical instruction for those who need it about how and how often to test their blood:

People living with diabetes should do their blood tests but there is no need to do it every day. But in the beginning, we should do it every day to find out how to eat and the portions of eating properly. (Message posted by NMKEN, 2 November 2014)

This post prompts a discussion about the best times to test and how frequently blood glucose should be tested, and why. This member, who is a carer, says:

Doing blood drawing in the morning is too lax. My father has been diagnosed with diabetes; I do blood drawing for him two hours after every meal. Then I will know what he sneaks to eat or if he eats too much flour or sugar. If his blood glucose is more than 140mg/dL, for the next meal he should not eat flour. If he can do this, in the next morning, his blood glucose level will be less than 100mg/dL which is equal to normal people, the Hb 1Ac will also decrease then the doctor will stop ordering any medicine and you will turn to only diet control. Ps. At the moment, I do not check it like that with him, so I do not know if he sneaks to eat any dessert or not. If I draw his blood and find out that his glucose in blood increases to 200 mg/dL, he will get plenty of blame. (Reply posted by Water, 2 November 2014)

I will explore the use of Pantip by family members and carers of self-managers more in Chapter 7. Here, Water shares her preference to test her father's blood sugar after every meal so she can detect if he has eaten forbidden food and adjust what he consumes on a meal-by-meal basis. NMKEN replies that a doctor told her that it is not necessary to check it every day. Too much blood drawing and being overly strict about eating will cause stress:

The doctor told me that I do not need to do a blood test every day. Too much blood drawing and too much strictness in diet control is too stressful. I can say that at the first moment of my blood glucose control, I screamed consciously, crazy cried because the glucose in blood is too low and put me in a bad mood. So let him eat some of it, but control something that he should not really eat like a durian, too sweet dessert, soft drinks. Making a life is a life. Too Stressful, if it blows up, it will be very difficult. Allowed to not do anything, cannot eat anything, I sometimes do not know why I am alive. Do not be too tight, do not too lack, find the balance and then he will be happy and strong as you want him to be. (Message posted by NMKEN, 2 November 2014)

Opinions differ on what is 'adequate' control and Pantip provides a place for self-managers to discuss the reality and practical challenges of self-management for them - such as how frequently to test, monitor and adjust diet to maintain control. The community in turn is a resource to help reflect on and consider the relative merits of 'strict' or 'lax' approaches.

The Pantip community is also used as a source of advice and information about drugs and dosage. When it comes to diabetic medications, many of the participants are interested in the efficacy of different medications, reducing medication, or stopping taking it altogether – as a sign that they can control their blood glucose levels through diet and exercise, and/or because they believed that taking too much medicine may harm their kidneys. This is a topic we will return to in the next chapter which examines the way that Pantip is used as a source of information about the potential benefits of Thai Traditional Medicine.

One poster enquired about which of the two drugs, Galvus or Metformin, is better for controlling blood glucose levels. She had attended both a government hospital and a private hospital, where she was covered by the Universal Coverage Scheme but had to pay a fee and pay for her own drugs. Metformin was prescribed by the government hospital doctor, while Galvus is prescribed by the private hospital doctor. As a result, she was curious about the best medicine. A doctor responded to her question by saying:

Controlling blood glucose levels can be done in a variety of ways. Although taking medicine is one of these treatments, I do not believe that diabetics can regulate their blood glucose in only one method... Stronger medicine will undoubtedly be more effective, but it will also have a disadvantage if you do not utilize it properly. It also makes you un-willing to try other methods, such as diet restriction. Finally, you must increase the drug's dosage. The least effective drug is gentle on our bodies. Other methods of mental and dietary control may be tried. Maybe you get a bonus if you quit taking medicine, but you still have to keep track of other things. It's entirely up to you which one you like. (Reply posted by Viva, 14 November 2015)

The advice once again stresses the importance of active self-management and keeping track of things, including diet control, regardless of which drug is prescribed and taken. The

question is redefined as about which drug is gentler on the body and the 'bonus' of one day not having to take medication if there is success in diet control.

Some self-managers fully cut rice and flour from their diet, but this poster isn't sure if this is the best way to go about it. He's concerned that restricting all grains and flours might be bad for him, but also is trying to weigh that up against the benefits of not taking medication. He goes to the forum to check what other people have to say. As he explains it:

I'm 62 years old and have had diabetes for about 20 years. I've always taken medication, and now I don't consume rice and only eat meats and veggies. I've had diabetes for a long time and take medication, but I never follow a diet plan. My blood glucose level rose to 260 mg/dL on occasion, so I limited my intake by avoiding grains and flours. As a result, I lost 6 kg and my blood glucose level dropped to 128 mg/dL. I'm still on medication. I would like to know whether I will get sick if I do not eat rice and noodles, and if so, whether I'll be able to avoid taking medicine. (Message posted by Gorge, 6 October 2014)

According to the information I have read about diabetes, you should consume rice three times a day to keep your blood glucose levels stable. (Reply posted by WYZ, 6 October 2014)

I am not a doctor. This is my opinion about diabetes, and you have to consider it by yourself. Rice, flour, or noodles if you do not eat them without any fatigue symptoms or hunger, it will be good for people living with diabetes. If you do not eat flours, then you can try not taking medicine. If the blood glucose level decreases, you can reduce taking it. In addition, do not forget vitamin supplements and follow up with the doctor periodically to prevent complications from diabetes. (Reply posted by Kiko, 6 October 2014)

Pantip is an active resource that members turn to for help with problem solving when trying to figure out the impact of varying elements of diet and medication on glucose level. The responses in these reply posts offer slightly different perspectives. The first reply claims expertise based on information he has read and recommends a straightforward regime of eating rice three times a day to keep blood glucose levels stable. The second reply emphasises the importance of self-monitoring individual experience when cutting out rice and flours, suggesting if that doesn't cause fatigue it could be of benefit and mean medication could be reduced. In contrast to the first post, Kiko says they are not a doctor, and this is only their opinion. We can see how visitors to Pantip are able to pick and choose an explanation or advice that they prefer. One reply authoritatively supports a return to eating rice in a consistent daily quantity– which may be less effort that the action entailed in the second reply which emphasises active self-management, trial and error and monitoring outcomes.

# 5.6 Community support for 'unexplained' blood glucose levels

In some cases, people living with diabetes may not understand why their blood glucose level has increased. Individuals come to Pantip to share the details of what they have eaten in a particular day or typical meals and/or their exercise levels and ask the community for advice to help them work out the possible cause of a rise in blood glucose levels they can't explain. In this post, Momon asks if it might be what she's eaten or when she ate and asks a specific question about snacking on bread:

I ate sticky rice, deep fried pork and pink noodle soup which I ate only vegetable and tofu...I had questions:

- 1. What caused the blood glucose level to increase? Personally, I thought it was from sticky rice or because I ate late because normally, I never eat after 6 pm (but on this day, I finished work late around 8.30 pm).
- 2. Whole wheat bread by FarmHouse with a green bag, I eat one piece a day. Does it increase blood glucose level? I sometimes want to eat crispy snacks then I bake the whole wheat bread to make it crunchy and eat it as a snack in the afternoon. (Message posted by Momon, 9 December 2014)

The replies from the members suggest that sticky rice is the cause of it, while another member says that all her dishes contain sugar. The poster answers to say thank you to all comments and says she will avoid eating sticky rice. Here is the interaction between the topic poster and the members who replied to her post:

Sticky rice should be the cause because many of the north people have diabetes. The doctor said that sticky rice contains sugar more than normal rice. One piece of bread is too little, and it is whole-wheat bread. I do not think it was from it... (Reply to post by Nattapong, 9 December 2014)

*Thank you so much...I will avoid sticky rice... (Reply posted by the topic poster, 9 December 2014)* 

Sticky rice for sure! (Reply posted by Paseao, 9 December 2014)

*Thank you. I will avoid eating it. (Reply posted by the topic poster, 9 December 2014)* 

This member, who has type 1 diabetes, posts to ask for help with understanding why - if he monitors his blood sugar, exercises, and avoids sugar-his blood glucose level remains elevated:

I'm always keeping an eye on my blood sugar levels. I gave up sugar and began exercising practically every day. [...] My FBS is 110-130 mg.dL after an 8-hour fast. It is higher before lunch and dinner. And after meals, it can reach 200 mg/dL, with peaks of 300-400 mg/dL. I'm not sure what's causing it... What causes my blood glucose levels to rise even though I don't consume any sweets and exercise (running)? (Message posted by Oscar, 13 February 2015)

The Pantip members (a total of 13 persons) responded to him to help explain why his blood glucose level remained high. One reply is from a medical professional who offers a comprehensive explanation:

Type 1 diabetes is characterized by a shortage of insulin. That's why you don't have blood glucose-lowering hormones... In healthy persons, the body uses glycogen, triglycerides, free fatty acids, and glucose as energy sources, balancing insulin secretion to avoid hyperglycemia... As a result, the body consumes the correct amount of sugar... People who have type 1 diabetes mellitus should be aware of the following information... The body does not get enough insulin if it is not addressed properly. A lot of adrenalin is excreted during exercise. Ketoacidosis is the result of a high blood sugar level. Conversely, if there is too much insulin in the body, hypoglycemia can occur... Recommendations for type 1 diabetes patients who want to exercise.

- Do not exercise if your blood glucose level is higher than 250 mg/dL in the morning.

- If your blood glucose level is less than 100 mg/dL, eat sugar.

- Check your blood glucose levels before and after you workout.

- Have sugar on hand in case of hypoglycemia when exercising.

- Prevent hypoglycemia by adjusting insulin and meal intake. (Reply posted by Dr.Phone, 13 February 2015).

This respondent appears to be a health practitioner, as his Pantip history shows that he only posts and replies to health-related topics. Health professionals reveal their status as doctors on their profiles, as described in Chapter 3 (section 3.6). They are recognized by other community members since they are active users.

#### 5.7 Sharing experiences of self-management

Pantip has a section dedicated to sharing successful stories, and its users are particularly interested in it. The sharing person recounts their diabetic self-management journey from the beginning to the outcome of living successfully with diabetes and keeping it under control, a goal that Pantip members strive for. Individuals also share their self-management struggles with the community in the hope that other members will offer advice or point them in the right direction to address their difficulties. We will look at each in turn and consider why people might come to Pantip to share experiences of being in control and successful self-management or their struggles with self-management.

#### 5.7.1 Being in control – success stories on Pantip

This is an example of an individual who reports that they are successfully controlling their condition. Members often share news of an improvement in blood glucose levels with the community in a similar format to below i.e., reporting the starting blood glucose figure, the level now and the actions they have taken to bring about the improvement. This post also mentions the requirement and intention to maintain those changes:

[I] began with a blood glucose level of 254 mg/dL. It has dropped to roughly 120-130 mg/dL after a month. This result has made me very happy. However, I take medication in conjunction with a healthy diet...Recently, I met with a doctor and had blood drawn at the hospital, with the result that my blood glucose level had dropped to 124 mg/dL and my A1C had dropped to 7.5 percent. The doctor was pleased with the outcome but advised me to continue with my diet restrictions. (Message posted by NMKEN, 2 November 2014)

The post receives favourable comments and praise from the forum's members with 20 reply postings. Here is an example of a reply to post:

I would like to have my mum hear your story... She has been diagnosed with diabetes many years already; I will tell her to do the right way to diabetes management. (Reply posted by Love, 2 November 2014)

Here is another example of with similar elements to the story:

In 4 months, I can reverse my hyperlipidemia and diabetes...My lifestyle has changed after I was diagnosed with diabetes. Change my dietary habits, give up smoking, get to bed earlier, and stop going out late at night. I switched from white to brown rice, consumed more veggies and lean meat, and decreased my intake of rice ... My prior blood glucose level was 310 mg/Dl; now it is 110 mb/Dl ... I ran to the doctor in excitement. I continue to be very rigorous about my diet, choosing what I eat and avoiding desserts and greasy foods.... I regularly monitor my glucose levels and always see the doctor. Now that I've lost 20 kg, my cholesterol and blood sugar levels are within normal bounds...I'm overjoyed. However, I continue to maintain my nutrition regimen... (Message posted by Adder, 27 February 2015).

The community members appreciate hearing stories of successful self-management, as it encourages them that being in control is possible and worthwhile and inspires them to persevere with diet control and exercise, which many find challenging. As this reply post says:

I appreciate you providing this good story. I have type I diabetes. It's really challenging to control one's lifestyle. My diabetes was only recently discovered. Both diet control and exercise make me feel discouraged. After reading your tale today, I am inspired to continue fighting. For you, thumbs up. I'm going to try to do it like you. (Reply posted by Pimry, 4 March 2015)

#### 5.7.2 Feeling out of control – sharing struggles on Pantip

All the interviewees talked about their struggle with restricting sweet dishes and eating fewer starches. Some of them said that they desired or were used to sweet flavours and so it was very difficult to change their eating habits and lifestyle, even if they knew they were eating prohibited foods. For example:

The difficult thing is about eating, I know what kind of food will affect my blood glucose level, but I cannot control my feelings, I want to eat it. (Interview with Number, male)

Previously, I ate dessert all day but since I have been diagnosed with diabetes, I eat it only once a day. I know that I shouldn't eat it, but I sometimes forget it. (Interview with Tree, female)

Some members of Pantip post to share their struggles with diabetes self-management, using the forum as a place to confess lapses in diet control or a failure to make or sustain lifestyle changes, and share how they feel about this. Most confession stories are about diet control, the participants sometimes cannot do it and may be reluctant to admit this to their doctor or family. Individuals share these stories and difficult emotions on Pantip, such as feeling "guilty", or out of control around their favourite foods, which they have had to try and stop
eating since diagnosis. As this member confesses, she can't completely stop eating sticky rice and sweets:

I have eaten sticky rice since I was born. Suddenly, I have to stop eating it, I can't do it. Some meals I still eat sticky rice but in a small portion around 3-4 bites... I love sweets but not too much, but I cannot stop eating it... I eat everything that I used to eat but just taste it because I really cannot stop eating it. (Reply posted by Jasmine, 25 December 2014)

Here is another example of a reply post to a confession about being out of control around food:

I cannot eat bland food, and I consume a lot of rice. I enjoy food that is tasty and salty. I'll add fish sauce if the food is tasteless. (Reply posted by Lazada, 14 September 2014)

The main cuisine in Thailand is rice, and in some parts of the country, such as the north and northeast, people eat sticky rice. The researcher discovers in the response posts that people have been accustomed to this food since birth. Individuals who have been diagnosed with diabetes are aware that they must adjust their eating habits, such as switching from white or sticky rice to brown rice, but they find it difficult to do so.

The interviewees discussed the difficulties of getting regular exercise in a large city like Bangkok and the reality of spending too much time traveling to and from work each day, leaving no time for exercise:

People who work in private companies currently finish work in the evening, return home late at night, eat late, and rush to bed. Then there's the issue of digestion, and diet control is quite tough... and there isn't enough time to work out. (Interview with Dark eyes, male)

I do not do exercise because there is no space for me to do it, therefore, I moved out to stay in the suburb of Bangkok. Here, I have a garden and I have space to exercise, take a walk, grow the trees, and water trees. (Interview with Yarmyen, male)

Members go to Pantip to share their difficulties with exercise. This member confesses that she occasionally 'falls off the wagon' of monitoring her diet and that she does not engage in any physical activity at all:

Normally, I keep track of my diet... (I occasionally go off the wagon, but I try not to). I still do not engage in any physical activity because I dislike sports. My knees are not in good shape if I run, and they hurt when I get up... I am unable to swim. The only sport I can play is badminton, but by the time I get home, it's already late ... I believe I can ride, and my family can come along. I would then prefer to purchase a folding bicycle. (Message posted by Kate, 8 February 2015)

Here are the examples of the reply to her post:

Java Mini is what I advise... You must purchase a Garmin watch model 510 or 810 if you have diabetes to help monitor it. It can be hard to find spare parts or post-sale services for folding bicycles. If you want to lose weight, cycle 14–16 kilometers in 45 minutes of exercise. Next, you can burn 500–600 calories. What's your age? The appropriate HR rate can then be determined. According to your Garmin watch, your heart rate should be in zones 3–4. (Reply posted by Ohaiyo, 8 February 2015)

Thank you. I am 34 years old, high 168 cm. weigh 85 kg. (Reply posted by Kate, 8 February 2015)

220-34=186 then your HR should be at 149 bmp but not over 168 bmp. (Reply posted by Ohaiyo, 8 February 2015).

The confession is accompanied by several justifications about why she cannot exercise, but she asks the community for advice on how to buy a folding bicycle with which she believes she can get more exercise. The respondents recommend an excellent bicycle and coach her on how to ride it. Pantip is a safe space to confess struggles and lapses and receive encouragement to persevere with diet control and exercise.

## 5.8 Discussion

This chapter examines how individuals with diabetes use Pantip to support the practical aspects of self-management such as how to do blood glucose monitoring, as a resource for problem solving when trying to understand the impact of exercise, diet, and medication on glucose levels (Colberg et al., 2010) and as a space to share stories of successful self-management and confess lapses and struggles.

Porter et al., (2020) revealed that each person's idea of normalcy acts as a foundation on which disease acquires meaning. The ability to "carry on as normal" is referred to in that study as 'living with' a condition. Living with diabetes requires the acquisition of new monitoring skills and effective control of glucose levels through diet, exercise, and medication as part of daily self-management. However, self-management can be challenging to undertake, even when people with diabetes know how vital it is, and involves medical management, behavioural management, and emotional management (Corbin & Strauss, 1985).

I found that diet control in Thailand is influenced and limited by local food culture. In the research on a Chinese online community Zhou et al., 2014 similarly found that people are pressured to consume alcohol because it shows respect for others. Furthermore, in Mexico, lowering traditional food servings feels like renunciation of culture (Magny-Normilus et al., 2020).

The Pantip community offers easily accessible, detailed, practical advice to support the daily task of monitoring and controlling glucose intake and taking regular exercise. Members use Pantip as a resource when clinical or formal health education advice has been forgotten or was perhaps not clear enough or helpful. Participants can gather information and advice about the details of what to eat, portion sizes, meal planning and food substitutions. Pantip members also promote the idea of exercise for weight loss and diabetes management and offer accessible practical advice about how to exercise safely. Pantip members sometimes offer different advice or different opinions about what counts as adequate or necessary levels of monitoring and control (e.g., the pros and cons of testing after every meal or every other day). Some members make claims about the quality of their advice based on their own expertise (e.g., medical opinions), experience as a successful self-manager or second-hand knowledge. Pantip members must therefore choose what advice they take from the site to action in their own daily self-management but the advantage of Pantip as an online

community is that it connects people with peers who have shared comparable experiences, so they can be helped with specific issues in a timely, sustainable, and proportional way (Penny, 2018; Fisher et al, 2012). Pantip encourage active self-management through acquisition of skills, knowledge, and empowerment, and as such acts as an alternative and unofficial source of self-management education (Hermanns et al., 2020).

The Pantip community is a readily accessible resource for practical advice and suggestions to support the daily tasks and decisions that are part of living with diabetes. It is also a place to find empathy, encouragement, reassurance, and an acknowledgement of how hard the reality of self-control and making lifestyle changes involving food and exercise can be. Living with a chronic condition makes people feel like it will never end. I saw how members post to share their struggles with diabetes self-management, using the forum as a safe place to confess about lapses in diet or a failure to make or sustain lifestyle changes, sharing difficult emotions of feeling out of control and receive encouragement or practical suggestions to move forward. Health specialists often cannot have lengthy conversations whereas self-managers can spend as much time as they need interacting with other community members in online communities (Panesar, 2016). Stories of success help provide motivation and reassurance and guidance for people living with diabetes (Frank, 1995).

Living with Diabetes	Key points of analysis (development of themes)
Experience of self- management in Thailand	Dietary control in Thailand is especially challenging given that Thai cuisine can be high in sugar and carbohydrates
Community Support for Diet Control	The Pantip community offers easily accessible, detailed, practical advice to support the daily task of monitoring and controlling glucose intake. Members can use Pantip as a resource when clinical or formal health education advice has been forgotten or was not clear or helpful.
	The community also provides empathy and emotional support in acknowledging that there are foods and drinks that self- managers are attached to which are difficult to give up. Advice about reasonable substitutes or moderation is offered as part of sustainable diet control.
Pantip as a problem- solving community: testing, exercise, diet, and medication	Pantip members promote the idea of exercise for weight loss and diabetes management and offer accessible advice about how to exercise safely. Members post testimony about how exercise has helped them.
	Members ask Pantip for help and advice with the practicalities of blood glucose self-monitoring and receive encouragement. Opinions about 'adequate' control differ - Pantip provides a place to consider and discuss how frequently to test and

#### 5.9 Summary of key themes and points of analysis

Living with Diabetes	Key points of analysis (development of themes)
	monitor and the relative merits of diet versus medicine for maintaining control.
	Pantip members offer opinions about the possible impact on glucose levels of varying different elements of diet and medication and (sometimes different) suggestions about recommended course of action. This helps with problem solving and planning self-management.
Sharing experiences of self-management (in control)	Members post stories of successful self-management; this encourages others that being in control is possible and worthwhile and inspires them to persevere with diet control and exercise (which can be challenging) and reinforces their own identity as a good self-manager.
Sharing experiences of self-management (not in control)	Other members post to share their struggles with diabetes self- management, using the forum as a safe place to confess about lapses in diet or a failure to make or sustain lifestyle changes, to share difficult emotions of feeling out of control and receive encouragement or practical suggestions.

# Chapter 6: Discussions about Thai Traditional Medicine and Self-management of Diabetes on Pantip

# 6.1 Introduction

In Chapter one I noted that in Thailand individuals with chronic conditions commonly use Thai Traditional Medicine (TTM) instead of or as well as medical treatments prescribed within the health care system, but there may be a low rate of disclosure about the use of or interest in complementary and alternative medicine (CAM) to healthcare professionals, particularly if self-mangers are seeking approaches that may bypass or contradict medical advice. There is evidence that people living with diabetes use CAM because they believe that it helps to decrease the progression of diabetes (Yıldırım & Marakoğlu, 2018). Informal online discussion fora like Pantip may therefore be an important resource for self-managers and carers to explore complementary and alternative approaches such as TTM and check information about TTM that they may have come across following a Google search or similar.

In the sample collected for this programme of research, 12.5 % of the Pantip threads (n=176) and 13.91 % of replies to posts (n=992) concerned the use of complementary and alternative medicine in diabetes self-management. The most popular topics were the use of nutritional supplements (55.36 % of posts) and herbs (32.14 %), followed by general queries about TTM and practitioners (7.14 %), meditation (3.57 %), and Chinese medicine (1.79 %). Members come to the community to ask for information about the advantages of TTM, the reputation of local practitioners, what to use and where to get it, how to use TTM, what the effects might be, how quickly it might work and any negative side effects. Members come to Pantip for information and advice about TTM based in the experience and local knowledge of the Pantip members.

The main themes that emerged from the analysis of the threads and interviews were (i) the appeal of TTM as CAM, (ii) Community advice in favour of TTM, (iii) Community advice against TTM and diet supplements, (iv) Community active on Thai traditional clinics, and (v) Pantip as a place to promote or sell CAM.

#### 6.2 The appeal of TTM as CAM

# 6.2.1 Lack of practical advice from doctors or perceived gaps in treatment

Some interviewees talked about the advice they were given about self-management from doctors and other clinicians and sometimes identified a lack of explanation or a lack of understanding about what to do next, and why, or how to apply advice in their daily routines. This lack of understanding can leave a gap to start looking for alternative sources of information and to discover alternative approaches to self-management. In Apple's interview, she says she was given medical advice that she should not lose weight and was given medication-but went away feeling uninformed and wanted additional knowledge, so she turned to the internet, which she has access to and can use to look for diabetes-related health information. This led her to websites selling herbal medicine claiming to decrease blood

glucose, and then to Pantip to ask the community about their experiences with this sort of TTM to help manage diabetes:

My doctor does not give any advice about my disease. She told me to not lose weight because I am thin... The doctor gave me medicines without any explanation... Then I search on Google... I found many websites selling herbal medicines related to diabetes. I do not know if it will help or not, but it is in the interest of the mind. I found many online shops that sell herbs which claimed to decrease glucose in blood and after that, I check on Pantip that anyone uses it or not. (Interview with Apple, female)

In this question post, a carer is similarly seeking help and advice from the community because their mother has not been prescribed the same medication that their father received, does not understand why, and is therefore seeking an alternative approach:

My parents have a high blood glucose level which my father has 200 mg/dL, and my mother has 211 mg/dL. My father gets medicine from the doctor, but my mother still has not taken it. The doctor still has not given any medicine to her (I don't understand why not, the doctor said that it is not dangerous) ... I've heard about T-Mixed, Laurel Clock Vine, and Lingzhi mushrooms. Which one would be best for my parents? Please inform me if you know. I am worried about them. (Message posted by Praw, 27 January 2015).

The community members respond to the topic poster with a question about his parents' weight and blood pressure. They suggest it may not be necessary to take medicine, they suggest losing weight and doing exercise to decrease the blood glucose level.

From these situations, when the physician and patient or their carers have a different perspective or do not understand medical advice, it can have an impact on actions and patient outcomes. Patients and carers need to know and understand diabetes and their particular recommendations for treatment and management and need to feel heard and understood by their doctors. Clinicians may not engage in lengthy discussions or be available to follow up on questions that arise away from a consultation, so self-managers and carers may instead seek information or help with interpreting medical advice and discover alternative approaches, which can be further explored be seeking opinions in an online community like Pantip.

# 6.3 Community advice in favour of TTM

Like many carers, this interviewee takes responsibility for her husband's food preparation (carer's experiences are explored in more detail in Chapter 7). She described how he has blurry vision even though his blood glucose level is in control. She therefore searched on the internet for information about herbs which may reduce diabetes progression and then grew them in her garden such as Stevia, Pandan, Butterfly pea, and Lemon basil. As she describes:

I searched on internet to seek for herbs that can help to maintain with diabetes disease... We have Lemon basil seed, I grows Stevia, makes Pandan leave juice, grows Davinka grass, makes Pandan leave tea, make Butterfly Pea tea. (Interview with Jomalone, female) Searching for information about CAM such as TTM online and in social media was a common activity for self-managers and carers, as evidenced in the interviews and Pantip threads. As described in Chapter 1, TTM is a popular alternative to Western medical treatments. Some members on Pantip were very positive about the benefits of TTM, for example in this reply post:

My father-in-law has diabetes and has high blood glucose level. He used to take Lingzi. It helps to reduce glucose in blood, but it takes time, around a month. The doctor was confused about why it decreased. Herbal medicine takes time to see the result. Now he looks brighter, many people around him say that he looks fresh... I don't know if it's because of this or not but you can try it. The brand is Dr. Suraphol, you can buy it at Lemon Farm at the price of 700 baht (around GBP17). (Reply posted by Tiffany, 27 January 2015)

Even though Pantip users must make their own decisions, the Pantip community's comments can aid them in considering and weighing any positive or negative impacts as outlined by peers in the forum, based on their experience. Lingzi is presented as likely having a very positive effect on Tiffany's father-in-law, even surprising his doctor, and 'worth a try' (even though they cannot say for sure it helped). Some of these threads therefore function a bit like a product review and may help members decide what is maybe worth trying and what is to definitely to be avoided. In the question post below, Gib asks about different herbal tea options. The reply poster recommends Mulberry and issues a warning against East Indian screw tea:

Which one is the best: mulberry tea, oolong tea, and East Indian screw tree tea? I have diabetes and hyperlipidaemia. (Message posted by Gib, 29 September 2014)

Mulberry is the best. Do not take East Indian screw tree as someone claimed because it is toxic to the liver. (Reply posted by Ja, 29 September 2014)

In other threads, Pantip users ask about a specific product, Jiaogulan tea, and members help by offering information about its benefits and advice about how to use it and where to buy it.

As one individual asks:

Does anyone drink Jiaogulan tea? I heard that it helps to reduce high blood pressure and glucose in blood. Is it effective? In Bangkok, where can I buy it? I see only selling online via Facebook. I do not really trust them. (Message posted by Bizz, 14 January 2015)

In this topic post, there were nine replies. One of the community members responds:

It is effective and helps for sleeping. It reduces hypertension and glucose in blood level. But you have to do exercise and take care of yourself. You can buy it many places such as The Nine Centre, Se-Ree Market, or around Pratu Nam Market. (Reply posted by Star, 14 January 2015) The benefits of using Jiaogulan are discussed, as well as where to acquire it. The poster advises that herbal medicine is not a substitute for regular and vigilant self-management and recommends that the poster must continue to exercise and look after themselves regardless of whether they are taking TTM or not.

Another proposal agrees with Jiaogulan's effectiveness but adds the recommendation to use it only on the doctor's advice, i.e., as complementary to a medical treatment plan. As one replies:

Buy at Hua-Chiaw Hospital. You should take the prescription to buy it... The doctor says that it is not for everyone, it depends on the individual's condition. (Reply posted by Kara, 14 January 2015)

In this next example, the poster (a carer) reports that her father has turned his back on 'modern medicine' and is refusing to take the medication prescribed by the doctor and has instead 'looked for herbal medicine'. The carer says that she has turned to Pantip as a possible source of knowledge and experience about TTM and practitioners:

My father has high blood glucose level at 300 mg/dL, his age is 56 years old. He took medicine as the doctor prescribed for around one month and after that he refused to take it. But he looked for herbal medicine. I assume that he doesn't do diet control... He really stopped taking modern medicine... I would like to know if Thai traditional medicine practitioners treat diabetes? If yes, I would like him to go there perhaps he will listen to TTM doctor...I don't know what to do so I come here to find more information from someone who knows about TTM practitioners, thank you. (Message posted by Saba, 7 December 2014)

The replies give her information about doctors, TTM clinics, herbs, and diet supplements. As the members reply:

I suggest Doctor Ton. You can watch on Youtube at https://www.youtube.com/ watch?v=opr-eZO8iws. (Reply posted by Junjao, 7 December 2014)

You can try supplementary food which this one is famous in Malaysia. It is Oat BG22. It is now in the market in Thailand. (Reply posted by Malaya, 7 December 2014)

Believe it or not... You can try Thai herb... Take the green leaf of the Malabar tree, boil it until it turns to the brown colour like you make a tea, and drink it. It is not dangerous but you maybe pee more often and sweat... (Reply posted by Baba, 7 December 2014)

Are you interested to try GlucosCare Tea? It is a tea for people living with diabetes to control blood glucose level. My grandfather has DM... He takes it for a year and can control his glucose in blood level... If you are interested in it, you can see more information from this website http://www.glucoscarethailand.com. It is very good tea that why I would like to tell you. (Reply posted by Sasiwan, 7 December 2014)

One suggestion is to try Doctor Ton's Clinic (Avatar Clinic) along with a link to a YouTube film advertising the clinic. The Avatar clinic in fact has negative feedback from other Pantip members (see below). The reply about GlucosCare tea also has internet links to more

information about the product (claimed that GlucosCare tea is made from '100%' natural ingredients and helps to reduce sugar absorption in the body) and opportunities to buy it. Some of the answers that recommend TTM are therefore potentially examples of latent advertising, and we return to this topic below.

# 6.4 Community advice against TTM and diet supplements

Many of the threads about TTM on Pantip were asking for further information about herbal medicines or diet supplements (sometimes discovered via an internet search) or real-life experiences from other forum users before deciding to use it, often instead of consulting their doctor. Some visit Pantip looking for advice from the community about the effectiveness of specific herbs or products they have found themselves or have been recommended by others, in the example below, by a co-worker.

An example from the Pantip forum is as follows:

My boss hands me a bottle of Enzyme Qualities 1 and urges me to try it because it's a new supplement. I have diabetes and hypertension... I tried horseradish, turmeric, and Bios-life, but none of them worked... I'd like to speak with anyone who has dealt with it before. Is it effective? ... Exercise, in my opinion, is the most effective method. I used to go to the gym on a regular basis...but it is no longer feasible... I'd like to look for a different approach to self-management. Please make some recommendations for me. (Message posted by Frank, 17 September 2014)

Frank tells the community that although he knows that exercise is valuable, it is 'no longer feasible' for him to get regular exercise and that he is therefore exploring approaches to self-management including a diet supplement recommended by his boss. A food supplement can present itself as an appealing alternative or a quick fix, but Frank is cautious as he has not had much success with diet supplements in the past and is looking for more hopeful evidence from other members based in their experiences. Tangkiatkumjai et al. (2014) found that Thai patients with chronic kidney disease are influenced in their use of diet supplements because of positive attitudes towards herbal and dietary supplements held by others in their social networks including friends, family, and their acquaintances.

In their responses to the post, forum members ask for further information about the product, owing to the unknown name. They firmly advise and reinforce diet control and taking prescribed medications and the correct approach and cite evidence that herbs and supplements are dangerous. This is an example of where CAM is undermined by the community who instead attempt to steer the poster back towards medically authorised methods of self-management. Here is an example of a reply post:

Have you had an English name? I never heard about it. For sure, you have to control your diet and take medicine as prescribed. Some of the herbs and supplementary foods cause liver hepatitis or include steroids. It is not worthwhile to try. I have witnessed individuals become ill after ingesting herbs and supplements. (Reply posted by Mr. Spain, 17 September 2014) This next example is a post from a carer, this time seeking advice about Chao Krom Poe, an herbal medicine. Her father is due to have an operation for cataracts during which time he must stabilise his blood glucose levels. If not, there will be higher risks of wound healing complications. She therefore looked for extra help from herbs or alternative medicines to try and thought that the Chao Krom Poe was helping, but now report to the community that the doctor has advised against it. Ignoring the doctor's advice, she want to know if the community can instead recommend any decent TTM for controlling blood glucose and how to get it:

As this participant states:

First and foremost, my father has diabetes; he follows a strict diet and exercises consistently, but his blood glucose level fluctuates between 160 and 250 mg/dL. The problem is that he needs cataract surgery and thereafter must keep his blood glucose levels in check. Because I read on Pantip that 'Chao Krom Poe' is helpful for diabetes, I got some for my father to drink. His blood glucose level has been normal since then. But my father says he has neck problems, and when I questioned his doctor about it, he said Chao Krom Poe isn't right for him. Can anyone recommend a decent Thai traditional medication, such as Chao Krom Poe, for controlling blood glucose levels? And where can I get it? Thank you very much. (Message posted by Siri, 20 December 2014)

Most of the response comments agree with the doctor that this herbal medicine, 'Chao Krom Poe', does not help to lower blood glucose levels and that the topic poster should seek medical advice rather than attempting to cope with it on her own. One person with diabetes replied with the view that the herb's help is 'insignificant' and challenges the poster quite strongly on the evidence and belief that the herbal medicine was effective, adding that 'no doctor accepts it':

What the doctor said is true about people living with diabetes. If his blood glucose level is high, he cannot get the operation. This herb's help is insignificant. Did you meet the diabetic specialist? How can you know the blood glucose level? Or did you test it by blood Monitor yourself? If yes, it can be a mistake in the result. In general, I check Fasting Blood Sugar (FBS) and HbA1C to check the average blood glucose level over a period of months. it is a longer deal than just checking it tomorrow and then giving up sugar for a week. I answer you as I am a diabetic person. I usually take Minidiab medicine before meal and take Metformin and Utmos medicine after meals. It depends on how many milligrams you will take. What is your father's level of diabetes? Do you have to get opinion from the doctor? I think he must consult the doctor. For this drink, I am not sure if it helps or not. You can tell the doctor that this drink is really helping to decrease the glucose in blood. I am sure that no doctor accepts it. The best way is to discuss with the doctor. (Reply posted by Thomas, 20 December 2014)

Interestingly, the topic poster does not reply to this post. There is one reply post to Thomas' comment which is a piece of latent advertising for herbal supplements.

We can see how Pantip is a place where the effectiveness of something like Thai herbal medicine as a complementary or alternative treatment for blood glucose control can be actively disputed and debated by members. In the reply above, the Pantip member argues against TTM and in favour of clinically recommended approaches to self-management and the importance of not acting against doctor's advice.

In this next example, the poster seeks advice from the community about the effectiveness of a specific diet supplement that claims to help with blood sugar control that he has discovered on the internet. He notes how expensive it is and asks if anyone has any experience of taking it and if it is value for money, or potentially dangerous. This poster considers that either of these options may be possible, which indicates that self-managers are sometimes caught between the appeal of TTM at the same time as recognising the risks of using it, and turn to Pantip to help figure out what action to take:

I would like to ask people who have experienced taking this diet supplement whether it has positive or negative effects. The price beside the jar is 3 Bath (around GBP 7x) with 60 tablets. The dosage is: take two tablets four times a day, then one pot lasts only about a week... (Message posted by Robert, 17 September 2014)

A reply post asks for more information about the supplement but firmly advises that 'herbs and supplementary food are not necessary' and questions the poster if it is worth it to use them, not just in terms of cost but because of a risk to health like developing hepatitis. The reply is very specific about the type and severity of 'possible negative effects' of TTM:

Do you have the name in English? For sure, you have to do diet control and take medicine prescribed by the doctor. Herbs and supplementary foods are not necessary and some of them lead to hepatitis or have steroids. Is it worth it? (Reply posted by Marai, 17 September 2014)

The topic poster adds more details about the product by posting the advert for it:

*I have a photo of this product and the doctor who claims that he is the researcher. I found it on the internet. You can see and consider it. (Reply posted by Robert, the topic poster, 17 September 2014)* 



**Figure 10:** Example of supplementary food label (Image posted by Robert, 17 September 2014)

The topic poster is interested in investment value, while the Pantip member was more concerned about safety, based on these exchanges. Members of the group are concerned about the adverse effects of CAM, which they believe should be discussed with a doctor prior to use. The response supports standard diabetes self-management advice such as diet control and prescribed medication as the most effective method for glycaemic control, and argues that if people with diabetes follow it, they won't need to take any traditional medications.

So far, we have seen that there are contrasting views on Pantip about the value and effectiveness of TTM and CAM in general. Some are attracted to the idea of CAM and positive about the potential benefits in helping to lower blood glucose levels, while others disagree and recommend that people shouldn't use them because of negative side effects or that they should only be used under medical advice and supervision.

This post from Tempura about the value of bitter gourd juice for lowering blood glucose sparks a lively discussion amongst community members, who hold opposing viewpoints and criticise the poster for implying that it is possible to replace medical treatment with TTM such as bitter gourd juice:

It's efficient... Blood glucose levels drop from 260 mg/dL to 124 mg/dL after drinking bitter gourd juice. I'd like to inform individuals who have diabetes, but you must also exercise. (Message posted by Tempura, 26 November 2014)



**Figure 11:** Bitter gourd juice that someone claimed it helps to reduce blood glucose level (Imaged posted by tempura, 26 November 2014).

Dr.Orange (a Pantip member who is a doctor but posts informally on the site) is the first to respond. She queries if Tempura means that gourd juice can be responsible for reducing blood glucose alone and underlines the importance of medical supervision for any plan, noting that she must advise this for his own good and feels so strongly that she says she does not want it on her conscience if something went wrong and she had not tried to prevent it:

You dare to stop taking medicine and drink only bitter gourd juice for 14 days? [...] Do you dare to try? If yes, first, you should tell your doctor who treats you, if something goes wrong with you and you cannot see the doctor in time, I will have sinned. (Reply posted by Dr.Orange, 26 November 2014)

This reply post agrees with Dr.Orange:

... She warns that... if he dares to [drink bitter gourd juice], he must tell his doctor before. I agreed with Dr. Orange because this thread "guide" was very dangerous for others (Reply posted by Support Guy, 26 November 2014).

We can see from this reaction that some Pantip members strive to keep an eye on any advice that may be confusing or harmful to forum members who are looking for information about TTM or are planning any action that strays away from medical supervision. Dr.Orange provides a means to test and get proper evidence about whether drinking bitter gourd juice will help to reduce blood glucose levels in a safe manner. As she explains:

Stopping taking diabetes medication is too risky. You can stop drinking bitter gourd juice for a month and do a blood test. Then drink bitter gourd juice for a month and do a blood test and compare. Check FBS and HbA1c. (Reply posted by Dr. Orange, 26 November 2014)

The Pantip community provides a forum for members to exchange CAM-related information and knowledge. As a health practitioner, Dr.Orange is a constructed as a gatekeeper by the other contributors to this thread, advising the online community on whether TTM has any benefits. Another forum member replies:

I concur with Dr.Orange because the topic poster led others in a dangerous direction. It should be used in conjunction with contemporary medications...Never use herbs at random. (Reply to post by 26 November 2014)

The remaining answers in this thread consist of other members recommending that persons with diabetes eat the fresh bitter gourd instead of drinking its juice and stating that exercise is the most important thing they can do to control their blood glucose levels. Few participants believe that Thai traditional medicine and herbs can cure diabetes, and some believe that people profit from selling them to patients (also see section 6.6).

# 6.5 Community advice on Thai traditional clinics

TTM is permitted in Thai hospitals, although it is always utilized in conjunction with (complementary to) conventional therapy. Some private clinics offer solely TTM, and some people are hesitant to go there. This post in Pantip enquires about Doctor Ton, his qualifications, treatments, and the costs and results of the Avatar Thai traditional clinic. Here is the opening post in a specific thread, followed by a sequence of posts from the same thread.

Has anyone have been treated at Doctor Ton Clinic (Avatar Clinic)? I would like to ask my friends in Pantip if anyone has been treated by Doctor Ton? I read his book about diabetes, and I think, it can be cured but I do not know how to get healed

and to get rid of diabetes. I would like people who have been treated by Doctor Ton to share the experience about the medicine you have taken. Is it good? What is your symptom? Do you have any chance to stop taking medicine from the hospital? How many percentages of it? Did the doctor graduate about diabetes? What kind of treatments did they recommend? What is the estimated expense? Please give me this information. Ps. my father has diabetes. I really want this information. Thank you everyone for your attention. (Message posted by Supergirl, 9 February 2015)

This carer has a lot of questions about the claims made in Dr.Ton's book, including whether diabetes can be cured and whether it is possible to stop taking 'medicine from the hospital'. She wants to learn about members' experiences with this local clinic, the cost, and the results before deciding to take her father to a TTM facility.

There was a total of twenty-four responses to this question. The responses first challenge the idea that diabetes can be cured and advises against stopping medication from the hospital. Individuals with diabetes can stop taking medication, but they must maintain a healthy diet and exercise routine. As one replies:

Diabetes cannot be cured...I suggest that you please continue to go to the hospital because if people with diabetes cannot control the blood glucose level for a long time, they will have other complications such as stroke and coronary artery disease.... In some cases, people living with diabetes can stop taking medicine, but they have to do diet control and exercise. They must be very strict...but it does not mean that diabetes is cured. (Reply posted by Kirei, 9 February 2015)

The topic poster replies to this response that she did not know that diabetes cannot be cured. As she asks back:

Does this mean diabetes cannot be cured? What about the advertising which claims that there are some examples of patients who can be cured of diabetes? I am confused now...I am worried and cannot decide. I am afraid that if my father goes there and it cannot be cured, I worry about that cost of medication. Please give me more information. (Reply posted by Supergirl, the topic poster, 10 February 2015)

Supergirl believed that diabetes could be healed because of adverts claiming this. While she was looking for information about the Avatar clinic, she also learns that diabetes is a lifelong disease. Members of the community clarify to the topic poster that diabetes is not as frightening as she had imagined, but that persons with diabetes must closely monitor their blood glucose levels to reduce the risk of secondary consequences. Pantip members provide her with knowledge and emotional support. The site's users also reassure her that diabetes can be controlled through self-management.

Other members share their experience of the Avatar Clinic, describing it very negatively as a scam. Tulip says there was no proper consultation, and she was given a very expensive

prescription for what turned out to be collagen. She did not feel better so (only after this experience) went to the hospital for standard treatment. As she explains:

I have been here... I sent a message to the clinic via Facebook Messenger then the staff told me to go to the clinic and check what is my disease? If I have to take the medicine, the cost starts from 390 Bath (around GBP 9.5). If I do not take any medicine, no charge... When I arrived, no staff paid attention to me. I have to tell them that I would like to get treatment. Then the staff asked me to have I been here before? I said no...I was called to the room to answer about the patient history but not with Doctor Ton... Without any use of medical instruments. Only ask questions and told me to wait to pick up the medicine...I have to pay, I am shocked, It is almost 5,000 Bath (around GBP 122)... When I got back home, I searched on the internet to find more information about the medicines I get... It is collagen... Almost a week, I am still not feeling better so I decided to go to the hospital... Taking medicines for only three days, I feel much better. In conclusion, I was cheated to take the collagen. (Reply posted by Tulip, 9 February 2015)

Tulip reports that the Avatar Clinic claims to be offering an effective alternative treatment to western medical approaches, but they are charging those who visit them without seeing a doctor, and they run the system like a pharmacy. Furthermore, their medicine is ineffective (actually, it is collagen). People talk about their terrible experiences at Avatar Clinic, and one person thinks it's a terrifying and pricey place to visit. Some members, though, continue to believe in TTM. This could be due to the influence of TTM culture in Thailand, which has persuaded many to believe it, and Avatar clinic may be taking advantage of this by 'passing' as a reputable herbal TTM clinic for diabetes when they are just selling collagen."TTM can cure diabetes," one poster still claims, "and there are many good Thai Traditional clinics instead than Avatar Clinic."

People can inquire on Pantip about and gather information about the reputation of Thai Traditional Clinics based on the actual experiences of those who have used them. Pantip seems to be an important resource to learn more about TTM and TTM providers to inform decisions about their own approach to self-management.

# 6.6 Pantip as a place to promote or sell CAM

When individuals search Pantip for information, they will come across advertisements for supplemental herbs or extra meals. There are rules about selling in Pantip. If members want to sell items in the forum, they are supposed to make this transparent by choosing the appropriate type of post, and it will not appear on the main page until members click to allow it to appear.

However, advertising, or promotional posts often appear elsewhere in the forum, less explicitly, as latent advertising in replies or as discussion topics. This will sometimes be called out as inappropriate by Pantip members, and posters may in turn defend themselves against accusations that they are trying to sell something and not a genuine Pantip member:

Please do not have drama about my question. I do not sell anything here. I am not a stand-in; you can check my profile and history. (Message posted by Goffy, 17 September 2014)

Three types of latent advertising were observed on Pantip, as follows.

### 6.6.1 Latent advertising based on real-life stories.

This kind of latent advertising is the one found most in Pantip. The format is typically that the participant posts a reply message in the guise of sharing a story of someone allegedly in their family who has diabetes, saying they use a particular TTM product and have had a positive result, followed by a link to purchase the product. As this participant states:

Are you interested to try GlucosCare Tea? It is a tea to control the blood glucose level for diabetic patient. My grandfather has diagnosed with diabetes, but he cannot control his eating behaviour, he sometimes eats the forbidden food. When he meets the doctor, he always gets blamed because he has high glucose in blood. Since I give him GlucosCare Tea for drinking, his blood glucose level has reduced a lot and he never get scolded. The doctor reduces the dose of his medicine which is the cause of kidney disease. If you take a lot of medicine, it will affect your kidney. If you are interested, you can go to this website. http://www. Glucoscare thailand.com. It is very effective, which is why I would like to tell you. (Reply posted by Praw, 13 January 2015)

As Pantip provides space for people living with diabetes to meet, it is easy for the advertising company or personal selling to target TTM advertising to this group. The threads that Praw replies to tend to be about or from 'stubborn' self-managers who do not want to see the doctor, sneak food to eat, take medicine for a long time and cannot control glycaemia. Therefore, the message to promote GlucosCare Tea is presented as the answer for those problems along with the result that the poster claims is from her own experience, potentially convincing the forum members who have the same problem to try it. This type of latent advertising looks on the surface like it answers the question, seems to be based in the experience of a genuine carer, and is presented as a recommendation, even though the function of the post is to push members through to the online store to get more detail about this tea and make a purchase.

#### 6.6.2 Problem-solution

This method is used by the seller to respond to a complex problem posed by a poster by agreeing there is a problem and offering the product they are promoting as the solution. One poster asks the community what his father, who suffers from hypertension and hyperlipidaemia, and has recently been diagnosed with diabetes, can do if the doctor refuses to provide any medication. The point is that his father only has one kidney, and they are concerned that his father's kidney will work too hard, putting him at risk. Then, in the reply post, the latent advertisement shows:

Yes, it is dangerous. Diet control is very difficult because your father has only one kidney. It is risky. There is one product name is "Bios life C" which helps to control

blood glucose level without diet control. You can check glucose in blood before and after your father taking it. You just brew it for your father for fifteen minutes, three times a day before meals. Bios life will help to control glycaemia into the normal level... 100% guarantee from the blood test. Please ask Parinya for more detail, contact number 093-3187887, email:wannamik888passive@gmail.com, http://xn--c3cuk9a5fbi0a4m.com/wp-content/uploads/2009/05/unicity-company-unicitythailand12.jpg. (Reply posted by Muk, 4 November 2014)

It is clear that this individual is attempting to sell Bios Life C, an herb product, because the post largely contains a set of claims about the effectiveness of the product rather than the poster's personal experience with self-management and includes contact details for more information about the product. However, nobody reports to delete it, it may be that the individual appeared to answer the question, and the community members may be interested in the product.

## 6.6.3 Trust me, I have premium quality herbs.

In some circumstances, participants are interested in using TTM and have decided to give them a try, but they are confused where they may get them from a reputable source. To market their herbs, the seller employs this strategy. The topic poster stated that:

I see only selling online via Facebook. I do not really trust them. (Message posted by Baseball, 14 January 2015)

Then the seller replies:

Trust me. We find it from nature, planted in the forest. There are no chemicals. If you are interested in jiaogulan from the garden on Doi Ang Khang, both retail and wholesale, please contact me at 083-323-7323 or line id cching68862. (Reply posted by Elephant, 14 January 2015)

All three types of latent advertising in Pantip are direct-to-consumer advertising, meaning that the products are sold directly to potential customers and made available to meet the needs of the patients or their carers. This Pantip member however does recommend caution in responding to adverts or promotional posts:

Do not buy any medicines as advertised or by the words of others. Do not believe it. Do not try it with your loved ones. The best way is to consult with the doctor. Ask for a detailed consultation... To the people we love. Changing your eating habit is the most important thing. Remember to take care of your feet for diabetics and diet control... (Reply posted by Yim, 20 December 2014)

Many members of Pantip, as we have seen advise against using TTM because of the negative side effects and advise if someone wants to try it, recommend contacting a doctor first to recommend a dosage or purchasing from a reputable source (rather than responding to promotional posts or adverts). As in these examples:

You can buy it at Huachiew hospital, take a prescription to see the dose that you have to take it. The doctor says not everyone can take it; it is different for all individuals. (Reply posted by Rabbit, 14 January 2015)

Safe herbal medicines should come from reliable sources, such as from famous hospitals, Chaophraya Abhaibhubejhr hospital, or the provincial hospital. We can see that there is small portion of CAM provided by hospitals because they have to research that CAM does not cause adverse effects in treatment. (Reply posted by Pringle, 14 January 2015)

Even though the Pantip community has a regulation to govern advertising posts by reporting them and having them deleted by administrators there are still forms of latent advertising in the forum. Forum members do warn against advertising, but latent advertising nevertheless goes unchecked on the site, particularly in the form of replies that appear, on the surface, to be from genuine members of the Pantip community.

#### 6.7 Discussion

CAM is acknowledged and authorized to be used in hospitals, and the government has a policy supporting CAM, which is still commonly used in rural regions. However, because of the possible adverse effects of herbs that might lower blood glucose, notably kidney illness and liver disease, health professionals advise consulting them before using it.

Self-managers and carers who perceive gaps in medical advice or treatment, or reject medical treatment, may seek alternative approaches such as TTM, which can be further explored by seeking opinions on Pantip. I saw how posters may find TTM appealing as a quick fix in comparison to the daily grind of monitoring, diet control and exercise, or as a less invasive or just preferable approach to medical treatment options or even as a potential cure for diabetes. The examples from Pantip showed that posters typically turn to Pantip to explore TTM without notifying or to bypass their doctors. This is comparable to the findings of Yldrm and Marakolu (2018), who discovered that nearly 98% of CAM users did not disclose their CAM use to their doctors. Yldrm and Marakolu (2018) identified the following causes for nondisclosure: doctors would not suggest these therapies, doctors' negative response to CAM therapy, and doctors do not need to know. It is also comparable to earlier research among diabetics in Thailand, where there's evidence that patients with diabetes do not tell their doctors about their use of CAM (Putthapiban et al., 2017; Wanchai & Phrompayak, 2017; Wanchai & Phrompayak, 2016). Diabetes patients in other countries, such as Israel, do not tell their doctors about their CAM use (Ali-Shtayeh, et al., 2012) and people with diabetes in Dubai also utilize CAMs without a doctor's prescription (AlAlami et al., 2017).

According to a report by the National Centre for CAM, numerous nutritional supplements have been shown to be inefficient in the treatment of diabetes and are connected to hyperglycaemia and kidney disease as adverse effects (ALAlami et al., 2017). Ernst (2001) argues that CAM therapies cannot be trusted in cases of diabetes. This suggests that TTM is not likely to be a 'quick fix', but there are nevertheless many TTM products and specialist clinics that claim to be effective in the management of diabetes. Pantip therefore provides a

forum where users may ask questions, share experiences, and actively dispute and debate TTM products and services. This is comparable to the findings of Alzahrani et al. (2022) that people looking for information specific to the advantages of CAM, frequency of use, or how long CAM takes, and the negative impacts they may have had.

Members bring questions about TTM to the Pantip community including questions about specific products, services, and clinics that they may be considering. Members offer opinions based in their own experience about what is 'worth a try' but reply posters are sometimes cautious about claiming proof for effectiveness of herbs other than saying it worked for them and usually recommend that TTM be used as complementary (not alternative) to medical advice or treatment. Some advice posts very clearly warn against herbs and supplements as dangerous whilst others argue there is no proof for their effectiveness in reducing glucose levels and are a waste of time and resources. Community members can be quite chastising in response to the idea that there are viable alternatives to monitoring glucose, diet control, exercise, and medical management.

The analysis showed that latent advertising of TTM products and services is present on the Pantip site, often in the form of replies to question posts. The strategies include referring to the effectiveness of the product as allegedly experienced by a family member who shares the same experience as the topic poster or claiming the product will be effective as a solution to a problem posed by the topic poster. Latent advertising also occurs by offering reassurance about the quality of products or services in replies to posts expressing doubts.

Pantip therefore acts as a resource to learn more about TTM and TTM providers, to inform decisions about self-management. Some members are cautiously positive but most caution against the use of TTM as an alternative to medical management, encouraging members to consult their physician about whether TTM might be a complementary approach appropriate for their individual circumstances. Pantip members may be susceptible to latent advertising of various TTM products and services, particularly if they reveal themselves as vulnerable or dissatisfied with their current approach to self-management.

Thai Traditional Medicine (TTM) & Self- management	Key Points of Analysis (development of themes)
The Appeal of TTM in self-management of diabetes	Self-managers and carers who perceive gaps in medical advice and treatment, or reject medical treatment, seek alternative approaches such as TTM, which is further explored by seeking opinions on Pantip. TTM is positioned as appealing as a quick fix (versus self-management) or less invasive than medicine.
TTM as complementary or alternative to medical	Self-managers and carers visit Pantip in search of information about TTM products (mostly herbs or supplements), including

#### 6.8 Summary of key themes and points of analysis

Thai Traditional Medicine (TTM) & Self- management	Key Points of Analysis (development of themes)
approach (advice in favour)	which are effective and how to source them. Members offer opinions based in their own experience about what is 'worth a try' but reply posters are sometimes cautious about claiming proof for effectiveness of herbs other than it worked for them and/or recommend that TTM be used as complementary (not alternative) to medical advice, treatment, or supervision.
TTM as complementary or alternative to official medical approach (advice against)	Some advice posts very clearly warn against herbs and supplements as dangerous; others argue there is no proof for their effectiveness in reducing glucose levels. Community advice against TTM chastises members for thinking there are alternatives to monitoring glucose, diet control and exercise and medical management. Pantip is a place where the effectiveness of TTM is actively disputed and debated.
Advice about TTM clinics	Pantip members can provide information about the reputation of Thai Traditional Clinics based on the actual experiences of those who have used them. Pantip acts as a resource to learn more about TTM and TTM providers to inform decisions about their own approach to self-management.
Pantip as a place to target promotion of TTM	Latent advertising on Pantip appears in replies under the guise of a) claiming a product has helped a family member then pushing the member through to an online sales website b) acknowledging the poster has a tricky problem and offering the product as a solution c) claiming to be a reputable supplier of good quality products.

# **Chapter 7: The Role of Pantip in Supporting Carers**

# 7.1 Introduction

The previous chapters examined how the online community at Pantip.com (Pantip) supports self-management in the early stages of diabetes, in daily life, and the use of Thai Traditional Medicine (TTM) as complementary or alternative to medication (CAM), diet control and lifestyle changes as recommended by clinicians in the Thai health care system. In Chapter 1 it was argued that carers can be extremely important in supporting the self-management of diabetes, family members frequently become involved in a family member's self-care, especially when individuals with diabetes require immediate assistance (Gunn et al., 2012). They may do this in quite practical ways such as helping with testing, medication, or diet control e.g., by taking responsibility for shopping, meal planning and cooking and are likely to be highly significant in offering emotional support and active concern about the selfmanager's quality of life. In Thailand, family members play an important role as carers, caring for and assisting their aging or sick relatives and adult children are frequently the primary carers (Knodel & Teerawich, 2017). The Thai family is structured in a hierarchical manner, with the parents at the top and the father as the family's head. That parents are expected to support their children with food, clothing, and housing, education, support them with marriage arrangements, and transmit property to their offspring. In return, the child's responsibility to their parents is to care for them as they grow older, assist them with their work and protect the family's good name (Embree, 2009).

The internet is one of the technologies that carers can use to get more knowledge and to support them in their caregiving role (Shaffer et al., 2018) and in the familiarisation stages of the netnography it became evident that carers were visiting the diabetes forum on Pantip just as frequently as self-managers. James et al. (2007) found that carers are far more proactive information seekers than people with disabilities, and they rely on the information offered by online forum members. This chapter therefore explores what the role of Pantip is for carers as they adjust to and deal with responsibilities in supporting a family member with diabetes. Why do they turn to Pantip, what kind of support are they looking for from the online community and what kind of responses or help do they receive? The data also gives us an insight into the experience of carers and the challenges they face in supporting self-management of diabetes.

Five themes related to the carer's experience and role of Pantip.com are discussed in this chapter: (i) Pantip as a place of induction into the caring role (ii) caring for wellbeing in the context of self-management (iii) community support for the job of caring (iv) community support for managing self-managers (v) dealing with crisis and seeking professional help.

# 7.2 Pantip as a place of induction into the caring role

When people learn that a member of their family has been diagnosed with diabetes, they seek help online through Pantip, where they can meet other individuals with diabetes or carers. They can assist one another by sharing their experiences of caring for a family member, in terms of information, advice and emotional support and in this way Pantip can

play a role in helping family members become involved in care and adjusting to the new responsibilities that a family member with diabetes can bring.

In the interviews, carers explained that they seek out assistance from their peers on Pantip and try to offer help to those going through a similar situation. As one interviewee said:

I come to Pantip because I get sincere answers from here. I know more people here and they help me to make a decision easier from their experience. (Interview with Number, female)

In another of the interviews with carers, a participant described how they used Google and visited Pantip to find information about food for her elderly grandma, who has diabetes:

*I use Google and Pantip to look for food-related information for my grandma, who has diabetes. (Interview with Karisa, female)* 

This interviewee says that she does not go to see the doctor with her husband so visits Pantip instead to learn more about the disease and so she can better care for him e.g., by knowing how to prepare food. As she states:

I come to Pantip to seek for information about diabetes because my husband having it. I don't go to see the doctor with him so that why I come here. I prepare food for him and also look for information that related to his symptoms. (Interview with Jhom, female)

This participant on Pantip also says he does not go to see the doctor with his father, so is not getting direct information to help his role as a carer from physicians. As he states:

Normally, I am not going to see the doctor with my father as I must work. (Message posted by Strawberry, 14 November 2014)

When carers do not accompany the patient to the doctor, they see Pantip as a good option for information and advice seeking as it is quick, simple, and accessible anytime or anywhere for the information carers need to help them make decisions about what foods are allowed, what to buy and how to serve it.

There were several question threads on Pantip from people who had just found out their family member has been diagnosed with diabetes. In this example, Buxton posts to Pantip to ask for advice about what to do next to help his father having found out the unwelcome news that he has been diagnosed with diabetes. The topic poster's initial response is to start looking for information and advice. He asks:

What should you do if you find out that your father has diabetes? Nobody wants to hear this question, but what should we do if it arises? My father is obese, weighing 75 kg, and he eats a lot. Is there anything that can be done to help him? Please give me some suggestions. Thank you very much. (Message posted by Buxton, 12 September 2014)

This reply poster introduces himself as a carer and discloses personal information about the person they are caring for, including diabetes information. Many of the reply comments are empathetic and reassuring, matching the experience of the topic poster by revealing that they are also caring for their parents "I understand how you feel because my father/mother also has diabetes". They offer practical advice and steps to take with exercise and diet control and offer emotional support to the carer not to be worried and as below, offering reassurance that it is possible for their relative to live a fulfilling (with sweets if he wants them), long life, if they follow advice about how to look after themselves:

My father has been diagnosed with diabetes as well... He weighs 90 kg and consumes a lot of food... Normally, he keeps his diet under control by avoiding carbs and sweets. He does, however, eat it on occasion. Take the medications as doctor recommends... Exercising, abstaining from alcohol, and quitting smoking are all good things to do. There are currently many sugar-free items on the market to replace sugary foods. You can buy sweets for your father if he wants them. Please don't be worried; persons with diabetes can live longer if they take good care of themselves... (Reply posted by Coconut, 12 September 2014)

These encouraging responses from other carers support the new carer in planning ahead and supporting their father's diabetes self-management. Furthermore, informational support is found in the response comments. This Pantip member replies by telling Buxton what to prioritise and how to make a straightforward start. The advice is to eliminate all high sugar and starchy foods and some specific examples of high sugar fruits to cut out that are commonly eaten in the Thai diet (e.g., durian) are given. Panama also gives relevant general advice about meal planning and portions, and to be alert regarding wound care:

Start with stopping eating starchy foods and sugar. Stop drinking soft drinks, desserts, high-sugar fruits such as durian, grapefruits etc. Food should comprise of 4 portions: rice 1 portion, meat 1 portion, and vegetables 2 portions. Be careful about wounds, especially in the foot, because diabetes leads to delayed healing. (Reply posted by Panama, 12 September 2014)

Drawing from community experience, new carers can get a sense of the scope of their role and a checklist of what to consider with suggested actions, as in this example, in reply to Coconut's post asking for help as a family member of a newly diagnosed person with diabetes. This reply is from a self-manager:

1.Medicine: take medicine strictly as the doctor prescribes and carry candy all the time (If your father can follow the doctor's instruction, the blood glucose level will decrease rapidly. If you do not do blood drawing, you will not know it. Your father can be shocked.)

2.Diet control: divided into 6 meals. Breakfast depends on your father's choice, between the meal eat guava or apple...stop drinking soft drinks...I suggest Malee (Juice company) with 30 calories and use Stevia. 3. Exercise: at least 30 minutes a day, swing arms as the health promotion from TV is ok.

From these instructions, my weight slightly decreased but I am much stronger, in better shape, and have normal blood pressure. I bought the blood glucose monitor...Exercise is too boring, you have to do it with your father (I also do it with my husband) ...This is my experience. (Reply posted by Frog princess, 12 September 2014).

Frog Princess points out in her comment that people with diabetes require more involvement from their families who should participate in activities with them rather than just giving them the tools they need for self-management. This is an important insight into the human experience of living with diabetes from a self-manager as she highlights the importance of staying motivated when she is bored.

# 7.3 Caring for well-being in the context of self-management

As previously said, when carers are confronted with a new circumstance of people living with diabetes for the first time, the learning process is crucial. Pantip, as a health forum, serves as a resource for carers who want to assist persons with diabetes. It also provides education from peers with experience of helping to manage diabetes, which carers can utilize to broaden their knowledge and increase confidence in caring for someone with special needs. A common concern that carers bring to Pantip is how to manage diet, particularly if the self-manager is struggling to cut out or restrict certain favourite foods or drinks. This presents a challenge for carers who may then have to balance the requirement for diet control with concern for a family member's quality of life and day to day experience, as related to a e.g., a passion for certain foods, eating habits or cultural expectations about diet. Moments of care involve looking after a family member's morale at the same time as dealing with the routines of testing, monitoring and control over diet and lifestyle. Pantip is a place where carers can share these experiences and support (or criticise) each other for the approaches they take.

Thai food contains hidden sugar and Thai people are often accustomed to the sweet flavours. Furthermore, many people with diabetes are 'addicted' to their previous tastes and preferences from before they were diagnosed with the disease. According to one of the interviewees:

The biggest difficulty is diabetes food. It is very difficult to cook for my mum because she is addicted to the previous taste. (Interview with Flower, female)

This carer posts to Pantip to ask for help with their father, who avoids sweet foods but as a result is getting bored with what seems to him to be bland and 'tasteless' food. They are sympathetic to this and want to try new dishes but want to check the community's advice first, including options for an 'easy menu':

My father has diabetes..., he avoids sweet foods, but he sometimes wants to eat something new. He is bored of eating tasteless food. I understand him but I don't dare to cook a different dish for him. Please give me some suggestions, which foods he should eat or not eat, please give an easy menu which is suitable for someone with this disease, I will make a new menu for my father. (Message posted by Yoko, 28 October 2015).

In the responses, there are some people who are also looking for this type of help. One member gives an answer with a YouTube link (https://www.youtube.com/watch?v=B3dNNhJ A\_Ks&feature=youtu.be) of the TV programme, in which a doctor gives information to one actress who has diabetes on what kinds of food she should eat. In brief, he suggests eating unrefined carbohydrates like brown rice and whole wheat, and not eating white rice and sugar. Eat berry fruits, guava, pomelo, almond, walnut, Brazil nut, cinnamon, Turkey berry, a protein that contains thyronine such as fish and chicken, and to drink he suggests green tea. Moreover, in this clip there is a demonstration of cooking for people with diabetes where the chef creates a Singapore-style fruit salad with shredded chicken.

Carers may feel concerned to strict to 'safe' dishes but lack confidence in their ability to make eating more appealing. There is a conflict between wanting to prepare delicious meals that the person will like - where food acts as a gift to express love and care - while also ensuring that it meets the dietary needs of a person with diabetes. The Pantip community both empathise with this conflict and offer practical suggestions and advice, that may include, as in the next post, strong advice not to go ahead with the plan to prepare sweet foods at all, such as the bakes this carer wishes to make for a family member with diabetes:

As this carer asks on Pantip:

Can people with diabetes eat food that is made from glucose syrup? I would like to do some baking...but someone in my family has diabetes. I have an idea to bake something that diabetic people can eat...I don't know what to use instead of sugar, but sweetener is very expensive. (Message posted by Bew, 30 November 2014)

All the comments in the responses to the post state 'no', and one participant adds that glucose syrup is a basic sugar that will rapidly absorb into the body if consumed. The topic poster thanks them and says she believed she would be able to make it for them, accompanied by a sad face emoji.

The next example emphasises how it is not always easy to stick to strict rules regarding diet control in complex care situations. Dominic describes how he actively considers his elderly mother's happiness and quality of life when making decisions about whether she should eat durian, her favourite food, and reaches what he feels is an acceptable compromise in his mother's best interests:

My mother is 79 years old, has diabetes. Latest durian season, my mother eats durian, one seed a day. I pull out the seed and put only the pulp into a small bowl for her. Her face is very happy. My friends are puzzled by what I did. I think, if I give her one of her favourite things but limit the portion, it should be okay. I told myself, my mother is old...therefore before she dies, she should live happily with her favourite things. It is better than being too tense because then elderly people will wither. I dare to do this because I take care of my mother and myself. No matter what will happen, I have to take responsibility. Seeing my mom's happy face while eating durian which is her favourite fruit, I am okay. (Reply posted by Dominic, 9 September 2014)

This reply to Dominic is sympathetic to Dominic's view that care should be compassionate and responsible:

Thank you very much for your recommendation, I agree with all comments. (Reply posted by the topic poster, 11 September 2014)

We can see that the poster is torn between on the one hand, knowing (and being reminded by puzzled friends) that durian is a poor choice for people with diabetes, and on the other, he wants to please his mother by giving her a favourite food. The compromise is to reduce the portion and adopt a moderately flexible diet. Sowattanangoon et al. (2009), found that older Thais saw ageing as the end of life's journey, and that they should enjoy life during this period. Food is a delightful aspect of their lives, which is probably why his mother enjoys eating it.

As the carer states, "I have to take responsibility" and since he is the only person who takes care of her, he will be the only one who takes responsibility in case something goes wrong. He shares the view that a carer's duty is not only to take responsibility in the management of individuals with diabetes, but also take responsibility for the quality of life of the one they love.

This carer seeks help from Pantip because he is concerned about his mother not sleeping and being tired and not eating. He is also worried that she takes too much medicine but is looking for recommendations for medicine that might help with her exhaustion. As he explains:

My mother has diabetes, cannot sleep, and tired, how to cure it? My mother is 55 years old...has diabetes. Her latest blood glucose level is 130 mg/dL. She cannot sleep day or night. For her eating, she cannot eat, and it seems that her body is exhausted. Can anyone suggest a doctor and good medicine? I think my mother takes too much medicine and it may be some toxins in her body. Please give me some suggestions. (Message posted by Peter, 23 October 2014)

This reply post expresses empathy and then goes on to suggest that the problem might be with the family adjusting to long-term diabetes management and medical routines, which are demanding and require motivation, and may become 'boring' and stressful. This carer shares how to solve this problem from her own experience, which was for the family to spend time with her mother, eat with her and look after her morale. This stresses the importance of gentle care and looking after a family member's emotional wellbeing. As she explains:

I understand your mother. You should take her out to relax or travel...Diabetes cannot be cured. Maybe she is bored of managing it if she often meets the doctor and it is not in control. My grandmother, at first, she was like this. Taking medicine from many hospitals but she did not feel better. She was bored, she takes medicine but not a rest. It happened for a while then her children often visited her, took her to relax, made her happy. After that, she can eat, sleep...Then her blood glucose level is decreased, she is happy. At the start, you have to take care of her very closely but don't force her. I see my mother and my aunt talk to my grandmother, they talk to make her have a good mood, have a meal together, take the day off to stay with her, be social with her, and always tell her to eat more if you want to stay longer with us... (Reply posted by Nana, 23 October 2014)

Pantip is therefore playing a role in supporting carers to reflect on and balance the relative importance of helping with practical routines of monitoring, medication and diet control and helping them to have a good quality of life, which in turn helps sustain self-management in the long term.

# 7.4 Community support for the job of caring

Some carers on Pantip post to share with each other how difficult it is sometimes to do the job of caring which can involve witnessing or participating in day-to-day care activities such as blood testing that some find distressing. In the thread below, Blueberry posts to Pantip to ask if anyone knows of a way to monitor blood glucose without drawing blood. She shares with the community that she is 'afflicted' by having to do this 'many times a day' for her father, on doctor's instructions, and having to see it all the time. She confides that she does not want to do blood drawing:

Do not want to do blood drawing! My father is 76 years old, has type 2 diabetes, injects insulin and takes medicine every day. Have to do blood drawing many times a day following the doctor's instruction. I see it and feel afflicted...I see some website but cannot remember that there is in a process of blood monitor checking which does not need to do blood drawing, uses tears instead, or ear clamp. Anyone knows about it please tell me. Thank you very much. (Message posted by Blueberry, 10 November 2014)

Carers may also turn to Pantip to share the emotional burden of worry and concern that a family member may suffer dangerous side-effects from too much or long-term use of medication, without, in the example below, what seems them to be an adequate explanation:

My father [...] He sees the doctor at XXX hospital and takes medicine for more than ten years. The doctor makes an appointment every six months and he always checks kidneys and liver, and everything is ok. Normally, I am not going to see the doctor with my father as I must work. Lately, I have doubts because I see him taking a lot of medicine after meals. I always ask him, since your blood glucose level normal, your blood pressure is normal, why you cannot stop taking medicine. My father says that he cannot stop taking it and has to continue taking it. I am afraid that if it remains like this, his kidneys and liver will be destroyed. My grandmother started from this symptom and took medicine all the time then finally she had to do haemodialysis...I'm surprised that the doctor still gives him medicine. Is there any way for him to stop taking it? [...] My father is 65 years old. He has been taking medicine since before he retired. (Message posted by Strawberry, 14 November 2014) In two replies, community members offer reassurance that taking medicine will not affect her father's kidneys and liver and stress the importance of medication in controlling diabetes and much greater risk of not taking them. The second post is from Dr. Orange, a frequent contributor to discussions about medical management of diabetes on Pantip. Consistent with Thai cultural norms, they also stress the role and responsibility of the poster to cook appropriate meals for their father and ensure he is taking the correct medication. This is contrary to the advice the poster was looking for and contradicts her view that her grandmother needed dialysis because of taking medication over a long period of time. The view that medication can be harmful is often cited as a reason for seeking CAM approaches (see Chapter 6). The advice from Potato and Dr. Orange is however strongly in favour of continued medical management, and may reassure Strawberry that nothing has to change, or conversely frustrate or vex them further if they do strongly believe that the medicine is a problem.

Since I've had diabetes for ten years, neither my liver nor my kidneys have been destroyed. I have questioned why so many individuals believed that taking numerous medications would cause the liver and kidneys to be destroyed. Nobody enjoys taking a lot of medications. It is used by us to treat our ailments. I believe your father will experience liver and renal issues if he doesn't take his medications.... (Reply posted by Potato, 14 November 2014)

Because your father takes medications, his blood pressure and blood sugar levels are normal. Your father's eyes, kidneys, and liver will be ruined if he doesn't take his medication. These organs are affected by diabetes, not by taking medication. You must cook for your father, learn about the diabetes diet, and prepare meds for him as a child ... His liver and kidneys are in grave danger. (Reply posted by Dr. Orange, 14 November 2014)

Carers post on Pantip that their caring role is stressful especially when they do not know what to do. In the next thread, the poster shares a difficult decision that the family must face about whether her elderly father should have surgery which carries a risk of complications from his diabetes:

Now, my life is very bad. Many problems come to me especially about my grandfather. He has cancer at the last stage...The doctor says that he can live not over three months if he does not get operation. If he gets it, he can live longer around nine months. But my grandfather has diabetes, there is high risk of an infection from operation...I do not know what to do. (Message posted by Sad Guy, 28 September 2014)

The Pantip's members give him support and advice. As one replies:

Spend the rest of the time with him by creating smiles and making him happy until the last minute of his life. We do not know the result that we choose for him...Do not be drown in the grief...I am supporting you and your grandfather. (Reply posted by Monaco, 28 September 2014). An oncologist also replies to this thread with an explanation of the reasoning behind the operation. From the explanation of the oncologist, we can see that this carer receives a very clear answer and a suggestion to discuss the case with his father's doctor. He gets informational support from the doctor in Pantip while he may not have an opportunity to communicate with his grandfather's doctor at the hospital. He also gets emotional support to not worry too much and trust the doctor, who knows and is responsible for the condition of his grandfather.

Carers also turn to Pantip for help with interpreting symptoms or test results that they don't understand and haven't had explained by the person with diabetes or their clinicians. The first example involves a carer trying to understand why his mother has swollen legs, and why a doctor and later the hospital did not explain the cause, nor seem concerned to provide a solution or treatment. He knows that there is a reason not to provide a diuretic, but overall is confused about the meaning of the swelling in the context of diabetes and her prognosis:

My mother has diabetes, weighs 120 kgs. Her legs have been swelling for 2 months. When she met the doctor, she used the Universal Health Coverage Service and told the doctor that her legs swelled up. The doctor did not say what happened to her. When she became sick and was admitted at the private hospital with the symptom of pulmonary edema, shortness of breath, and Hypercapnia, she also told the doctor about her swollen legs. The doctor did not say anything about it. Informed her only that if he gave diuretic drugs then it will lead to more hypercapnia. When she left the hospital, she had carbonyl oxides 60...I do not know whether, with this result, my mother will recover or not. Where should I take her to see the doctor? I would like to know what the cause of swelling legs is, but she does not feel pain. (Message posted by Good Boy, 11 November 2014)

Communication between the patient/carer and the doctor is essential. Any symptoms that arise with them or someone in their family are crucial in the eyes of any patient or carer. As a result of the doctor's failure to fully explain what is wrong, the above carer turned to the Pantip community for help. This reply from the community offers a possible explanation for the swelling and practical advice on diet control such as eating less salt. The reply post also encourages the carer to be proactive and go back to the previous clinicians who treated their mother for an answer and better explanation. Community advice can therefore be helpful and supportive for members in knowing when it is reasonable to go back and question and/or ask for clarification from clinicians:

It is from various causes such as heart disease, kidney disease, low albumin level. Or maybe the effect of a medicine that she has taken, especially some hypertension drugs. As a suggestion, eat less salty food or flavourless food. The doctor who can give the best answer is the one who treats your mother at that private hospital or asks for the previous doctor at the government hospital to treat her swelling legs. (Reply posted by Dr. Dean, 11 November 2014).

# 7.5 Community support for managing self-managers

Caring for a family member with diabetes involves a sometimes-difficult transition into the caring role, learning about the condition and what symptoms mean and as we have seen, the Pantip community of fellow carers are there to express empathy, offer reassurance, an opinion and/ or practical advice about what to do next and possible strategies to try. Carers also visit Pantip when they need help with how to support a family member who they worry is not looking after themselves or don't seem to be engaging with or coping with self-management activities.

For example, this carer posted about their father who has diabetes but is 'very stubborn' and refuses to see a doctor for check-ups. He has had a fall, and the carer is worried about the injuries and further complications and is asking Pantip for help and advice about what to do next:

My father is 60 years old; he drinks heavily and smokes...I know that he has diabetes but any other diseases I do not know. He is very stubborn. I told him to do a medical check-up, but he did not do it. Now, the problem is...he fell off the chair and his legs swell. The skin is dark and painful. He still does not see the doctor. I do not know how to solve this problem. I am afraid that he will have an operation and cannot walk. Does anyone know a doctor who does home visits? Or does anyone have a solution, please tell me. Thank you so much. (Message posted by Tim, 30 November 2014)

Diabetes is one of the leading causes of impaired wounds and most of them involve the feet. As this carer worries about that, some replies try to help him to interpret what has happened to his father. As one member explains *"This symptom seems to be peripheral blood clots. Please hurry to see the doctor". (Reply posted by London, 30 November 2014).* 

Most of the comments recommend him to take the father to see the doctor. One of the physicians replies and tells him to post the picture of his father's legs but he does not know how to upload it onto the forum. Tim agrees to take his father to the doctor as advised by community members. Pantip can play a role in support for caring by prompting members to action e.g., as here, by indicating when medical assistance is definitely and urgently required, regardless of how stubborn or reluctant the self-manager is.

Because persons with diabetes are advised by health professionals to adjust their lifestyles, particularly their eating habits, some of them may restrict their food intake excessively, and carers may need support with managing extreme approaches to self-management. One interviewee said it was difficult to get her husband to eat more, as he was 'terrified' of high blood glucose levels harming his vision, which has become blurry:

I have to coerce him into eating because he refuses to eat. I believe it is insufficient. His mother also lends a hand and encourages him to try new foods... He is terrified of high blood glucose levels, of how they would harm his vision. He just eats one ladle of rice at a time. His mother attempts to feed him more rice, but he refuses and places it on my plate. (Interview with Jo Malone, female) To support him and try to make him eat more, Jo Malone is trying to do everything and teams with his mother to reassure him and help him make less restrictive decisions about what and how much he can eat. She cooks for him and eats the same food as her husband. She also grows some plants related to diabetes by herself. As she explains:

I cook for him, take him to see the doctor...My husband can control his blood glucose level...I grow everything that someone claims that it helps to reduce glucose in blood such as lemon basil seed, Stevia, pandan leaves, davinka grass. I make pandan leaf tea and butterfly pea tea... (Interview with Jo Malone, female)

Jo Malone's husband has been diagnosed with diabetes for approximately three months. Newly diagnosed individuals with diabetes can be very serious about maintaining their health and very aware of the development of complications as with Jo Malones husband being concerned about his eyes, Maclean calls this the honeymoon phase (Maclean, 1991). But eating too little is not good for people living with diabetes especially in case of controlled glycaemia. Jo Malone described how she seeks knowledge about food and the plants that have beneficial effects to lower blood glucose levels from the internet and from Pantip.

One of the obstacles to dietary adherence for people with diabetes is the temptation to relapse (Schlundt et al., 1994). There is a role for carers in trying to help individuals living with diabetes to keep on track with diet control but sometimes it is very difficult, especially with elderly people and carers may visit Pantip to seek help with family members who are concerned they are eating 'forbidden' food.

This topic poster comes to the forum and asks for help to solve a problem with an elderly relative with diabetes who eats 'forbidden' food:

Elderly is stubborn by eating forbidden food and the relatives support them, what should I do? (I warn them already, but they do not listen to me). (Message posted by Laura, 9 September 2014)

This carer is trying to do her best to do the right thing to help the self-manager adhere to diet control as strictly as possible. The reaction from this Pantip member however demonstrates that the question of 'how strict does diet control need to be?' is a live one for carers and a topic of discussion on Pantip. The reply suggests less rigour and more flexibility and sympathy with the self-manager, noting that happiness from the food – if eaten occasionally – is a good thing and questions the practicality of something being completely forbidden. As one member replies:

Who is not allowed? If it is not too dangerous, give it him/her to eat once. Please do it, do not be too strict. Rigorous adherence is not certain to make him/her live longer...I am a doctor...Only one meal which gives him/her happiness, please do it. (Reply posted by Dr. Orange, 9 September 2014).

The carer shares her experience with diet control, which was very strict at the start, then relaxed on the doctor's advice as a strategy to help prevent her father from sneaking food:

The most important is diet, at first, I do not allow him to eat these, those, that. I always blame him about it then he sneaks to eat them. Lately, the doctor advises me to not tell him to stop eating it. If he would like to eat, let him eat a little bit...If you do not allow him to eat at all, he will feel motivated to eat. I follow this advice and it succeeds, he does not eat forbidden food and not sneak it...He is strong and does exercise every day. (Reply posted by Opa, 12 September 2014).

Carers take responsibility to assist individuals with diabetes to adhere to diet control and Pantip allows the space for carers to figure out the most sustainable approach to this, with help from the experiences of others. In the above examples, the members are quite pragmatic in their advice. They acknowledge that people with diabetes have a free view and know that extreme deprivation may lead them to want to eat the 'forbidden' food even more. This perspective can help other carers with how to weigh up the relative pros and cons of being strict diet-wise with the pleasure that can come from a certain type of food.

## 7.6 Dealing with crisis and seeking professional help

Some carers may have to deal with very difficult acute or crisis situations and decide what to do, plan or how to act on behalf of and in the best interests of their family member. This carer seeks advice from Pantip about his father-in-law who has had a fall and now has an infected wound, but refuses to seek professional help:

What to do with an elderly patient who does not want to see the doctor? My fatherin-law has diabetes. He falls...and has wound. After 2 days, this wound becomes a canker and eczematous. My husband worries because people with diabetic have to be careful and should not have wounds on feet. But he does not want to see the doctor. He buys medicine without a prescription, does not clean the wound, is very stubborn, never listens to us. I do not know what to do. Anyone has this experience, please recommend a solution. Thank you so much. (Message posted by Nich, 15 October 2014)

This carer offers advice based on his experience with his own stubborn father who left it too late to seek medical attention. He suggests a clear and unequivocal course of action, to 'carry him to the hospital'. This places the responsibility to act with the carer, if necessary, ignoring his father's wishes to physically transport him there - 'carry him'. The reply poster emphasises the importance of not delaying as it will get worse. He offers emotional support, recognising this will be a difficult thing for the carer to do, and urging him on: 'I am supporting you'. He replies:

Carry him to the hospital. If you leave it like this, it will get worse...My father has diabetes for a long time and does not see the doctor. In the end, his symptoms are severe...And finally, he agrees to get medication...But he comes to see the doctor very late because he has many other complications...He is very stubborn...I am supporting you. (Reply posted by Brown, 15 October 2014).

Unexpected situations can occur with people living with diabetes and the carers do not know what to expect or how to help and come to Pantip to seek advice from other people who may

have the same experience. This member chose to share the distressing situation regarding her father's admission to the ICU with the Pantip community, looking for reassurance that he might get back to normal:

My father has diabetes, is 57 years old...He injected insulin and fell asleep. In the morning, my mother noticed that it was quite late for him to wake up (5.30 am) then she wakes him up. While she tries to call him, he is shocked and bewildered. We hurry to take him to the hospital...He stays in ICU...3-4 days and he still does not wake up [...] Now, he can move arms and legs...can open his eyes, but he always sleeps. [...] Does anyone have a similar case? Please share your experience with me. I am very stressed. I would like my father to recover and get back to normal...Do I have any hope? Thank you so much for all comments. (Message posted by Piano, 13 September 2014)

Although her father now is with the doctor, this carer seeks other people's experiences on Pantip. She knows that his symptoms are at a crisis point and looks for some hope from experiences of other similar cases. One of the forum members replies to her:

My grandmother (90 years old) has hypoglycaemia shock at night-time...faint. We found her the next afternoon...She was admitted to ICU and stayed at the hospital for approximately one month. Now, she is almost back to normal around 95% but she still cannot really speak, speaks very slowly, walks slowly...I hope your father will recover. Elderly people take time for it. (Reply posted by Guitar, 13 September 2014).

This reply gives the topic poster hope that her father will recover but that it will be gradual. She not only shares the experience, but she also gives emotional support to the topic poster.

# 7.7 Discussion

The role of family members in the support of diabetes self-management is critically important, both day-to-day and in crisis, and it is vital that training and care plans reflect this (Gunn et al., 2012). In Pantip, the majority of carers are family members who care for people living with diabetes and are heavily active in helping people living with their chronic condition, which is comparable to the study of Rosland et al. (2010). Consistent with Thai culture and tradition, the data in Pantip demonstrates that most carers are adult children who care for their parents when they are elderly or become ill. People with diabetes spend most of their time at home managing their condition, so their families can have a significant impact on their experience, morale, and actions (Ory et al., 2013). Carers are in a difficult position because these are not their symptoms, and they may not have direct contact with a medical professional, so may only have the self-manager's (possibly incomplete) account of consultations or care plans to go on and have themselves little or no prior knowledge of diabetes or its management. There is evidence that the burden of providing care has a huge emotional impact from the stage of diagnosis (Mclaughlin et al., 2010) and that negative outcomes for the recipient of care may be linked to the carer's stress (McKechnie et al., 2014). Carers also require emotional support to reduce stress from caregiving (Clemmensen et al., 2020).

Carers therefore seek diabetes knowledge and advice and from more experienced peers on Pantip, and support with adjusting to caring for someone with diabetes. Some health professionals also post advice on Pantip in an informal capacity and seem to be trusted as experts by other members. Pantip serves as a platform to share experiences, challenges, and struggles, participate in discussions, ask for advice, seek solutions to their problems and receive emotional support and encouragement for those who provide daily self-care and take responsibility for people with diabetes. "The utility of the internet is to be used as a medium for social support groups," said Perkins & Lamartin (2012, p.53).

Pantip encourages information exchange and sharing of feelings among members, as well as hearing about other people's experiences. Carers share their experiences and struggles related to their responsibility for the wellbeing of the self-manager, including how to approach the complex and difficult challenge of balancing the expectation of strict diet control and monitoring with a concern for their family member's morale and quality of life. Carers share experiences and challenges in managing a family member who may be stubborn, is ignoring self-care or if their diet seems out of control. The forum provides opportunities to discuss and reflect on how strict diet control can or really needs to be. Overall, Pantip offers a place to share and figure out a responsible but compassionate and sustainable approach to care and to feel confident that they have thoroughly investigated all available information on a topic (Fan et al., 2010).

Carers also share their experiences and struggles related to the responsibility of day-to-day practical care including oversight of diet control, witnessing, or performing distressing procedures (e.g., blood drawing), worries about side effects of long-term medication use, a perceived lack of clarity about medical care plans or difficult decisions about treatment they may have to support their family member to make. Generally, Pantip members offer empathy and gentle practical advice but, and consistent with cultural norms, there is some evidence that other Pantip members will post (less sympathetically) to remind the poster of their obligation and responsibility (especially if they are children caring for parents) of providing care and that they have a duty to ensure that the person in their care complies with medical management.

Carers receive guidance and support from their peers, helping them to interpret and be resilient in their roles. This finding is comparable to Thoits (1995) and Mccann et al. (2015), who found that social support, particularly emotional and instrumental support, enhanced carers' resilience in coping with their roles. Carers in Pantip feel supported and understood because of emotional assistance from other members of the community. Pantip serves as a platform for consultation and emotional support for those who provide daily self-care for people with diabetes. Pantip provides social support and information sharing, comparable to Loane & D'Alessandro (2013)'s study, in which forum members engage in a dynamic exchange of knowledge and social support.

To summarize, online health communities such as Pantip benefit carers by providing a place of induction into the caring role, by supporting carers with the job of caring including balancing control with the wellbeing and quality of life of individuals with diabetes; by assisting carers to manage the self-manager and by assisting carers to deal with a crisis and knowing when to seek help from health professionals.

The Role of Pantip in	Key Points of Analysis (development of themes)
Supporting Carers	
Pantip as a place for induction into caring role	Carers go to Pantip to get an insight into diabetes and good diabetes management.
	Fellow carers on Pantip offer information, advice, and encouragement to posters with a newly diagnosed family member. This includes simple, practical advice about diet, taking medication, regular exercise, and complications. New carers receive empathic emotional support, insight into the experience of living with diabetes and the importance of being an active and involved carer.
Caring for wellbeing of self- manager	Carers share their experiences and struggles related to responsibility for wellbeing and receive help and advice about how to balance strict diet control and monitoring with attention to their family member's morale, quality of life and a compassionate approach to care.
Seeking help and support for daily work of caring	Carers share their experiences and struggles related to the responsibility of day-to-day care including distressing procedures (blood drawing), worry about side effects of long-term medication, lack of clarity about medical care plans and difficult decisions about treatment. Some members empathise and offer gentle practical advice but, consistent with cultural norms, other Pantip members remind posters of their obligation and responsibility of providing care and their duty to ensure compliance with medical management.
Managing self-managers	Carers share experiences and challenges in managing self- managers in their care and seek advice about what to do when they think the self-manager is being stubborn, ignoring self-care or their diet seems out of control. Pantip members offer advice about when to seek prompt medical advice and the forum provides a place to discuss how strict diet control can or really needs to be in practice.
Dealing with crisis situations	Carers turn to Pantip for advice and support when dealing with crisis situations such as hospital admission. Pantip members offer practical advice and/or a call to action based

# 7.8 Summary of key themes and points of analysis

The Role of Pantip in Supporting Carers	Key Points of Analysis (development of themes)
	on their own experience and emotional support including reassurance and empathy.
# **Chapter 8: Discussion and Future Research**

## 8.1 Introduction

The overall purpose of this thesis was to examine how Pantip.com (Pantip) supports people with diabetes in the self-management and control of their diabetes, how Pantip assists carers, to consider Thai culture in discussions about living with diabetes on Pantip, and to look at member accounts of the experience of adjusting to, living with, or caring for someone with diabetes in Thailand, including the motivations for visiting Pantip.

An investigation of the role Pantip plays in its users' diabetes self-management was presented in Chapters 4, 5, and 6, and the role of Pantip for of self-managers was the topic of Chapter 7, drawing on Pantip discussion threads and interview data. Self-management is a crucial approach for people living with diabetes, who are expected to take responsibility for managing and monitoring their health in day-to-day life (Donald et al., 2018). This PhD explored how Pantip influences and supports self-management in the context of Thai culture - including the challenges posed by Thai food such as white sticky rice and tropical fruits, the expectations on family members as carers and the allure of Thai traditional medicine (TTM) as complementary or alternative (CAM) to medical supervision of diabetes.

In the rest of the chapter, I discuss the findings' practical applications, recommendations for additional research, an evaluation of the research programme and reflections on the researcher's perspective.

# 8.2 Discussion of findings

# 8.2.1 How Pantip supports the self-managers

Self-managers have limited access to medical professionals, post-diagnosis, so are likely to seek alternative strategies for information, support, and assistance (Gordon et al. 2017).

The people I spoke with during my interviews also said that there are differences between self-management as described in health education guidance and the reality of self-management in everyday situations. For example, they may attempt to cut out carbohydrates and reduce sugar consumption (as advised) but find their blood glucose is still high. As a result, they may turn to internet communities, to understand what might be happening and seek advice or assistance based for peers (Hermanns et al., 2020).

The analysis in Chapter 4 showed that Pantip is an example of an internet community where individuals can go to seek support and advice about diabetes, and that people go there to seek advice even before they are diagnosed, to share worries about possible symptoms. The Pantip members played a role in advising posters against self-diagnosis and in encouraging them to engage with testing and medical services. A theme in the encouragement was to help people see diagnosis as a positive turning point, as an important first step in proactively managing their health. Acceptance of a chronic illness is important since it determines how quickly a person may begin to cope with their new condition. Pantip is also crucial in offering emotional support to people who have just received a diabetes diagnosis - and who might be anxious or afraid about how this will affect their lives. One way in which members do this is

to offer encouragement to "keep fighting," and not let the news of their diagnosis demoralize them and provide practical advice and actionable steps to start managing their condition.

Chapter 5 explored living with diabetes, and saw that members go to Pantip to share their experiences and challenges with self-management, such as difficulties with diet control. Some members use the forum as a safe space to talk about their challenges with managing their diabetes, using it to confess dietary lapses or failures to stick to lifestyle changes. Pantip thus plays an important role as an outlet for people to express uncomfortable feelings e.g., of being out of control with eating or discouraged about the daily grind of testing and monitoring, and where they can typically rely on receiving gentle encouragement and helpful guidance. Diet control is particularly challenging in Thailand because Thai food is typically high in sugar and carbohydrates and also because of the way food is embedded in habits and rituals. Wah et al. (2019) indicated that many individuals with diabetes struggle to modify their diets because they were used to their traditional eating habits. Similarly, Sapkota et al. (2017) discovered that high-carbohydrate meals, a lack of variety in the foods available, and poor food preparation techniques are all barriers to successful diet control in Nepal.

The Pantip community can be helpful as they offer simple and clear practical advice for diet control (based on their own experience) like food swaps e.g., members of Pantip recommended using sugar alternatives like sweetener or stevia and brown rice instead of white rice. They also offer empathy and emotional support, e.g., by acknowledging that selfmanagers are going to find it challenging to give up favourite food and drinks completely. Suggestions for suitable substitutions or moderations are therefore offered as part of a kinder, more sustainable approach to diet control. This theme was also evident in the advice the community offers about the frequency and intensity of glucose testing and monitoring activities in general, advising against testing after every meal for example as too distressing and unnecessary. Members of Pantip also inspire and motivate others by sharing their personal experiences of successful self-management such as a healthy daily menu plan and comprehensive, step- by- step guide for planning meals giving self- managers explicit instructions on how to implement clinical advice to monitor food intake and in general to show others that taking charge of one's life is achievable. In this way, some Pantip members are respected as "experts" and give advice. In common with other online health communities, Pantip users also seek medical advice online such as how to interpret test results or the practical detail of testing techniques (cf. Bach & Wenz 2020, Bujnowska-Fedak, Waligóra, & Mastalerz-Migas, 2019).

Overall, the findings from Pantip are consistent with other studies of online health communities e.g., Litchman et al. (2019), which show that peers provide interaction, knowledge, and support to promote changes that enhance health and Haik et al., (2019), which revealed that patients use a forum to connect with peers and exchange information, expertise, emotional support, and other resources. This is important because, as Adhikari et al. (2021) also argued, self-managers often say they are uncertain regarding blood glucose monitoring tests, how to eat and healthily, and adherence to medication. Pantip provides help and support to adjust to living with diabetes, regain confidence and achieve a (albeit new) sense of 'normality', through a sense of effective self-management. Naemiratch &

Manderson's (2008) study on Thai diabetes suggested that "normal" is viewed as an existential state of health. Porter et al. (2020) argued that "normal life" might serve as a goal, a measurement for development, or a somber reminder of what has been lost. According to research by McDougall et al. (2018) and Shepherd & Hattersley (2004), a sense of "normality" can be a sign of a successfully controlled, modified lifestyle and self-image, accompanied by feelings of relief. Being 'normal' was a theme in the interviews and on Pantip, as people adjust to daily life with a chronic illness. Peers on Pantip offer emotional support to achieve a sense of balance or normality. According to Hernandez et al.'s study (2020), people feel bad if they eat sweets or do not exercise. Peers on Pantip assist individuals in similar situations by acknowledging the challenges of maintaining self-management of diabetes and motivating them to achieve success. Emotional support frequently coexists with informational support and aids in acceptance, which is consistent with Kowitt's (2015) research.

A higher level of social support has been linked to better health self-management in several studies. According to Schitz et al. (2012), people diagnosed with type 2 diabetes will experience less emotional stress if they have a sense of social support and can therefore practice better health self-management. As we saw in the Pantip findings, people with diabetes can benefit from social support in order to, "increase diabetes control and provide support for changes in lifestyle behaviours such as physical exercise and nutritional adjustments" (Goetz et al. 2012). Such communities also encourage information exchange and sharing of feelings and experiences among members, offering reassurance that they have thoroughly investigated all available information on a topic (Fan et al., 2010).

## 8.2.2 Pantip as a source of information about TTM

One of the aims of this PhD was to consider support for diabetes self-management in Pantip, in the context of Thai culture. A common topic of conversation on Pantip related to the pros and cons of Thai Traditional Medicine (TTM) in diabetes self-management, particularly the use of herbal remedies and food supplements. The findings in Chapter 6 revealed that people post on Pantip to ask questions and join in discussions about TTM as a complementary or alternative approach (CAM) to medical management and advice for the control of diabetes. The Pantip community offered opinions and advice based in their own experience or their own research and knowledge on the topic. Some members were cautiously positive about the potential of TTM for lowering blood glucose levels and there was a lot of interest in trying TTM to offset the challenges of testing, monitoring, food restriction, and exercise (as explored in Chapter 4 and 5) or to avoid the perceived adverse effects of long-term medication, such as damaged kidneys, or even as a possible cure. I saw in the Pantip data and interviews that people were often interested in TTM because they felt that doctors were not providing them with helpful guidance or support, as was the case in Yldrm and Marakolu (2018) who discovered that nearly 98% of CAM users did not disclose their CAM use to their doctors. Pantip members discuss their views about TTM and share their experiences with particular TTM clinics or TTM remedies or supplements.

A key theme in the advice offered by Pantip members is that TTM is not a substitute for regular testing and monitoring, diet control and exercise and at worst, could be dangerous to

health, especially if experimenting without medical supervision. Pantip is a public space, and I say how latent advertising and promotion of TTM on the site is present and could take advantage of people's interest in herbal remedies via direct marketing of TTM remedies. For example, I saw how products are advertised in the context of 'reply' posts where salespeople can pose as self-managers or carers but leave links to commercial web-based shops. Pantip overall acts as one source of information, opinions, and advice on TTM for both self-managers and carers. The advice about TTM on Pantip does vary but overall, a cautious approach is advocated with many members offering clear advice against TTM.

#### 8.2.3 How Pantip supports carers

In Chapter 7, I saw how family members play a crucial role in supporting self-management in both daily life and times of crisis. This research indicates that diabetes self-management is very often likely to be supported self-management, especially in Thai culture. Thai social norms around care in the family mean that it is common for adult children to act as carers for their elderly parents at an older age. Therefore, they may become carers suddenly when someone in their family is diagnosed with diabetes, as is the case in some Asian countries, such as China, where family members are the primary caregivers for their sick relatives. (Chan & Yu, 2004). When their parents are elderly or in ill health, adult children are expected to provide care, and do visit Pantip for advice and to share experiences. Pantip can provide readily accessible help to carers, who don't tend to get direct access to medical consultations, planning of self-management education.

I saw how members ask about and are given advice about managing medications, nutrition, and exercise in relation to the person they care for. Community members also share their caring experiences with each other, and challenges involved in taking responsibility for the health and well-being of their family member. Beverly et al. (2018) discussed how self-managers can gave an unfavourable or conflicting relationship with food. We saw how Pantip provides a forum to seek guidance about how to make sure family members adhere to strict dietary guidelines and glucose monitoring without them being miserable, un-cooperative or lapsing. Carers receive support and guidance from the community regarding their family member's morale, quality of life, and how to practice compassionate caregiving and sustain self-management over time. This result is like the study by Knyahnytska et al. (2018), which also found that diabetes management should be based on the patient's perspective as they try to strike a balance between their social environment and their medical limitations. In this way, Pantip encourages carers to adopt a patient-centered perspective.

Carers use Pantip to discuss the difficulties they have in overseeing self-managers in their charge and ask for guidance on how to handle situations in which the self-manager exhibits stubbornness, neglects self-care, or appears to be eating excessively. I saw how Pantip members offer guidance on when to seek immediate medical attention and is very significant in offering emotional support, comfort and understanding. Through peer coaching and social support on Pantip, carers may be able to understand and adapt to their responsibilities with more resilience.

Pantip is a significant resource for carers as they adapt to the expectations attached to adapting to their new role as what the Ministry of Public Health in Thailand refers to as a

"family health volunteer," with the aim of looking after the elderly and those who have NCDs and assisting them in self-management and disease monitoring (Ministry of Public Health, 2017). Family members may become carers without any prior understanding or experience of diabetes. They might not visit the hospital with the diabetes self-managers and might not be familiar with it. The findings suggest that they turn to online health communities like Pantip for help, as Shaffer et al. (2018), also found. They argued that the internet is a useful platform for educating informal carers about caregiving-related subjects and offering them supportive services. Reading a response post from someone who has had a similar experience can help the carer understand how to do things the same way. Thoits (1995) and McCann et al. (2015) found that social support, particularly emotional and instrumental support, enhanced carers' resilience in coping with their roles. Carers in Pantip feel supported and understood because of emotional assistance from other members of the community. In some cases, it is considerably more difficult when the person they are caring for is in a severe condition. However, Pantip members offer support to one another by exchanging similar experiences.

In conclusion, Pantip can be used by carers to learn about diabetes self-management techniques from other members, connect with peers, and share knowledge and experience about diabetes on Pantip. This is comparable to the research by Treadgold et al. (2020), which discovered that family carers sought the advantages of online information and support, including feeling they had greater knowledge about the conditions they looked for, and many of them were successful in obtaining information and support online. Pantip supports those who have diabetes by also assisting their carers.

## 8.3 Pantip as a resource for sharing experiences of managing diabetes

Nowadays, the internet's technology makes it possible for users to share information online. At the same time, there has been a steady rise in the number of internet users searching for health-related information globally. The conclusion of the current thesis demonstrates that individuals can benefit from joining an online community that supports self-management,

This thesis outlined Pantip's potential for knowledge acquisition, social support, and empowerment of diabetes patients and carers. When self-management calls for immediate action within 24 hours or while they are waiting for an appointment, Pantip can fill the gap left by health care facilities. The benefit of an online community is that it gives self-managers and carers access to the forum at any time, allowing it to meet their needs quickly in the event that difficulties or questions arise.

Pantip is a place where people with diabetes and carers can go to seek information about the disease at any stage. They begin by looking for diabetes-related information online since they have some questions about the disease and are looking for answers. This feature of Pantip is comparable to that of the online health community (OHC), which gives patients a forum to interact with other patients and carers (as discussed in Chapter 2). OHC like Pantip has developed into a significant source of social support for individuals with health issues. Social support is one of the most beneficial aspects that Pantip offers, which is similar to Elnaggar et al. (2020), who found that a large majority of online members believe that social support is the most beneficial aspect of online networks. The top two reported reasons for the use of

social networking sites were to offer support or to share personal experiences. Elnaggar et al. (2020) also stated that four primary factors impacted the way users engaged with one another on the platforms: (1) seeking assistance or motivation from others with comparable conditions; (2) looking for information and guidance regarding clinical diabetes care; (3) obtaining advice about changing one's lifestyle; and (4) offering a sense of camaraderie.

Peers provided the diabetes information on Pantip. Pantip helps people with diabetes and those who care for them satisfy their needs for controlling their disease by providing peer support. The participants are assisted with specific questions/situations about diabetes self-management, including helpful tips and details on how to manage one's lifestyle. Members frequently bring up subjects for discussion at Pantip, including diet control and changing one's lifestyle. These are similar to the study by Elnaggar et al. (2020), which found that forum members are more likely to accept advice regarding lifestyle changes and diabetes control that they get from online communities than from healthcare professionals. In Pantip, encouraging phrases like "we are in the same boat" help people feel empathetic toward one another, which is why they prefer to follow the forum's recommendations. Learning from peers is important and seems highly relevant to Pantip members as the advice and information is based on similar experiences so is trustworthy and members can ask about health situations or possible actions and outcomes in a way that makes sense to them.

Emotional support is also provided to Pantip's members at any diabetes stage. Stress feelings can occur any time during their diabetes journey especially, for newly diagnosed diabetics, the data show that people in this study are in a state of shock when they have heard that from the health professionals for the first time. Encouraging people to fight and be resilient is a common word that individuals give support to someone who seek for emotional support.

In addition, Fernandes et al. (2018) found that participation in diabetes forums fosters a sense of community among users and may help to encourage adherence by raising awareness and acceptance of the condition (as discussed previously in section 8.2.1). We are all aware that the sooner people with diabetes accept their condition, the better their chances of avoiding or delaying its other consequences.

Since people with diabetes learn more about their condition and share their experiences in online communities like Pantip, they may have better glycaemic levels than people who are less engaged, which is in line with a study by Litchman et al. (2018) that found that participation in the online community improves glycaemic levels.

To find further strategies for managing the blood glucose level, the result also shows that people go to Pantip to look for information about TTM as an alternative to diabetes self-management. The study's participants help by providing them with factual information, assisting individuals in understanding the disadvantages of using CAM, and recommending individuals speak with a doctor before using it.

In conclusion, Pantip provides a setting outside of the diabetes clinic where individuals can discuss their diabetes status, share their feelings, share their experiences, ask for advice, seek support, look for information, or give/receive opinions on how to handle their situation,

which can occasionally be challenging or complex. These are all the factors that the study suggests explaining why Pantip performs as a resource that individuals can use to share experiences of managing diabetes.

# 8.4 Reflecting on the thesis

I, along with my cousins and relatives, have not been diagnosed with diabetes. Before starting this research, I usually considered the number of calories in meals, but after gathering data and reading through other Pantip threads, I found that consuming sugar is associated with an increased risk of acquiring diabetes. Then I will read the label to determine the sugar content when I go grocery shopping.

Stories regarding the experiences of people with diabetes were shared with me when I was gathering the interview data. A few of them claimed to have been quite strong and to have never experienced any symptoms or indicators prior to receiving a diabetes diagnosis. Consequently, taking blood tests to check for diabetes should be viewed as a preventative measure, which is what I did. My blood test result confirmed that I do not have diabetes.

For people with diabetes at any stage of their disease, exercise is also essential. The personal stories that were exchanged showed that blood glucose levels can be lowered through exercise and food management. As much as I would like to work out for a longer time, I constantly put it off due to the weather or exhaustion at the end of the day. My motivation to work out came from the Pantip user stories about diabetes. I have never been a member of the gym before. It is great to be there without the reasons I avoided going earlier. I had a medical check-up after four months of exercise, and the results revealed that all my health check-up lists were within optimal ranges. My blood pressure was within normal limits, even though it had always been below normal. I now fully grasp what it means when someone says, "Exercise is the magic pill." However, prior to beginning this research, I was an extremely picky eater, and while it appears that my selections are healthy, it hasn't really changed the way I eat.

In addition, I discovered during the recruitment interview that, like offline communities, it could be challenging for someone to integrate into a virtual community if they are perceived as a stranger. When I posted to request volunteers for an interview, I was considered a stranger because I was a lurker and was not well-known to the community members. It was fortunate that a community member reached out to me and offered advice on why my employment posting would not succeed because it did not follow the same language conventions as Pantip users and how to ask for assistance. I learned that too many posts asking for participation were making the community members feel like the researcher was insincere. The process of getting into the new community took time because the forum's members wanted to make sure that there was no hidden agenda behind this situation.

This thesis has not only helped me gain academic knowledge for my PhD study, but it has also benefited me with knowledge of diabetes and self-management.

# 8.5 Evaluation and direction for future research

From the literature review in Chapters one and two, it was evident that most of the research using online communities to support patients and carers are from developed countries. In addition, as stated in Chapter one, Thailand's government has a policy to expand high speed internet covering rural areas. Both the benefit of online community and the Thailand policy to expand broadband access may provide support to do more research about using online communities related to health conditions. Further research would be to explore how online communities support people with other diseases in Thailand.

Further research can be developed to collect data from social media platforms such as Facebook and TikTok which are the most two popular social media sites among Thai people, along with Instagram, YouTube, and Twitter.

It is also possible to examine more insights into individuals' experiences in specific groups such as adolescents who are the majority population of diabetes Type I or elderly which is the majority group of diabetes Type II to deeper understand their needs in any groups, or health providers can use social media platforms to help people with diabetes improve health and psychosocial outcomes.

Additionally, as this study concentrated more on the information shared in the health forum than on interview data, future research might make far greater use of this data to gain additional insight into the experience of managing diabetes.

Another finding that can be developed for further research is health literacy. In this study, there were arguments debated in the forum about some health beliefs; therefore, exploring the relationship between health literacy levels and participation in online diabetes communities may help individuals with chronic diseases cope with their illnesses more efficiently.

# 8.6 Conclusion

This study contributes to the empirical literature by exploring patients' experiences of selfmanagement outside of the diabetes clinic environment in the context of Thai culture. Carers were also explored in the same study as patients, whereas previous research studied only patients or carers. Moreover, the literature review also shows limited work with online health communities set up by individuals who are health care professionals whereas this study explores real environments from patients and carers.

In contrast to traditional health education methods in Thailand, Pantip is an online health community that operates around the clock. This is advantageous for individuals with diabetes, as traditional health education centres may have restrictions on their availability or office hours. Panesar's (2016) study found that while health specialists cannot have lengthy conversations with self-managers, they can use forums to learn more about their illness, and self-managers can spend as much time as necessary chatting with other members. Members of Pantip can keep learning and sharing their most recent diabetes management issues because there is a time limit on accessing traditional health platforms. This enables people to facilitate interactive conversations and peer engagement in the online community, which is

similar to the findings of Corter et al.'s (2019) study, which showed that people can connect with others who have similar conditions and situations. It can answer user questions, provide knowledge, and motivate community members to help one another. In Thailand, healthcare practitioners often reserve their diabetes clinics for their patients. As a result, Pantip serves as a resource where carers can go to get assistance and information on how to care for those with diabetes. The study's findings suggest that medical professionals can assist carers who are assuming the role of diabetes by using the online health community. It is more difficult to decide how to handle it because it is not their sickness, although peers in the online health community can offer assistance. This is related to the research of Du et al. (2020), which found that family carers may seek assistance from an online forum to learn more about managing both their own lives as carers and the care receivers they support.

In particular, it adds to the growing body of research on patients' and carers' opinions on diabetes self-management. This study sheds light on how diabetes is managed by those who have the disease and by those who care for them, especially in the context of group learning outside of the clinic.

In summary, this thesis aims to investigate how Pantip.com (Pantip) supports individuals with diabetes in the self-management and control of their diabetes, how Pantip supports family carers and carers, to consider Thai culture in discussions about living with diabetes on Pantip, and to examine member accounts of the experience of adjusting to, living with, or caring for someone with diabetes in Thailand, including the motivations for visiting Pantip. According to Pantip's analysis of the diabetes forum and the interviews, people with diabetes and their carers can receive the support they require. They seek assistance in the form of knowledge, advice, and emotional support. To regain their identity as "normal persons", which is a sign of someone successful at controlling their glucose levels, the participants use these supports to manage and cope with their sickness.

People with diabetes would desire to get back to their "normal" lives. Despite its complexity, diabetes self-management is an essential part of treatment. The results also showed that some carers turned to CAM for additional help, which seemed to be a short-cut for them.

Peers have a chance to share their knowledge and experiences with participants in Pantip. They can gain knowledge from the experiences of others and apply it to their management. People with diabetes and their carers can make decisions about how to manage their diseases on their own when they have the information they need and the support they require. The self-care strategy is more successful since empowerment takes place.

Carers are important in assisting people with diabetes to do self-management. In this research, carers are adult children who do not have any knowledge about diabetes; therefore, they find it from Pantip, which provides the information and supports their needs.

Cultural factors are an influence on this study. The findings revealed that Thai food, family structure, and CAM are influenced by the self-management of people living with diabetes. People find it challenging to adapt because they are accustomed to the flavours of their food, and diet control is a component of managing their sickness.

Prior to the arrival of western medications in Thailand, CAM were already in use by Thais. Even though taking CAM without a doctor's recommendation can have certain side effects, Thais still assume that they are harmless. For people with diabetes who refuse medically prescribed medicine, CAM offers another choice.

In conclusion, an online community like Pantip offers insightful information on online health communities by demonstrating the unique features of this kind of discussion inside Thai culture, including Thai cuisine and TTM. Maintaining a healthy diet is the most challenging topic for most Pantip users to discuss and collaborate on. It may be simpler for people with diabetes and those who support them to understand the ingredients in Thai food, to discuss and debate the use of TTM, and to benefit from Pantip's role in providing care for carers. These actions may result in improved health and a higher quality of life, as well as better diabetes control.

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## **10. Appendices**

## **10.1 Appendix A: Message inviting participation in English** PARTICIPANT INFORMATION SHEET FOR PEOPLE WHO SUPPORTING NETWORK

#### **Title of Project**

Self-Management of People with Diabetes in an Online Community in Thailand

#### **Participant invitation**

You are being invited to take part in a research study. The overall aim of the research is to examine the ways in which people use the online community Pantip.com to exchange their knowledge and experience as part of the self-management of diabetes, including their friends or family who living with diabetes or supporting diabetes management. This research conducts for a Ph.D. degree. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask me if there is anything that is not clear or if you would like more information about the project. Please take your time to decide whether or not you wish to take part. Thank you for reading this.

#### Purpose of the research

The aim of this study is to examine the ways in which people use Pantip.com to exchange their knowledge and experience as part of the self-management of diabetes and to explore the motivations of the community members for participating in this online community as part of an overall strategy of managing their condition, including their friends or family in supporting diabetes management for people living with diabetes. In order for me to get the answers to my research questions, I need to interview you who are part of the network in diabetes self-management.

#### Why have you asked me to take part?

You have been chosen to participate in this project because you are from people who they refer to on Pantip.com and also you are with the experience of diabetes management. You have influenced on the outcome of this research, therefore, anybody can benefit from that from general purpose.

#### Do I have to take part?

It is up to you to decide whether or not to take part. Taking part in this research is entirely voluntary. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Refusal to participate will not affect you in any way. You may still withdraw at any time during the process. You do not have to give a reason why you have decided not to take part.

#### What is involved and what will happen to me if I take part?

For people living with diabetes, you will be asked to tell about your diabetes stories in general and your diabetes experiences. You will also be asked to tell about your experiences of selfmanagement in diabetes. For carers, you will be asked to tell about your experience of taking care people living with diabetes and how to support diabetes patient to do self-management, including the experience of seeking information and support for people living with diabetes. All the interviews will be conducted over the video call via Line, or Facebook or Skype depending on you. You will only record the audio.

#### How often will I have to take part, and for how long?

The interview process will take time approximately 45-60 minutes and maybe an option for the second time, and it will be recorded. The recording will only be listened to by the researcher. It will be transcribed and will be stored at least 10 years, and destroyed after that.

#### When will I have the opportunity to discuss my participation?

If you have any questions, you can ask and discuss with the researcher at any time during the interview process.

#### What are the possible disadvantages and risks of taking part?

There are no risks anticipated with participating in this study except that some of the questions posed to you in the interviews may sound personal. However you do not have to answer any question that you feel uncomfortable with. And you also have the right to have the interviews terminated if this is making you uncomfortable. I will put in all my effort to make you feel as free and as comfortable as possible. Also remember that anything you say to me will be strictly confidential and only used for the purpose of this research.

#### What are the possible benefits of taking part?

There are no direct benefits to participants for taking part in this research. However, diabetes is one of the country's major burdens of mortality and morbidity. Most Thai diabetes patients have poor treatment outcomes and their diabetes is not well controlled. Our conversation in this project could be educational in that provides an opportunity to learn other experienced in self-management for you.

#### Who will be responsible for all of the information when this study is over?

The data collected for this study will be stored securely in the university networked storage at ResearchStore (Q:\Research) and only the researcher conducting this study will have access to this data. The data will be stored at least 10 years and destroyed after that by the researcher.

#### Will anyone be able to connect me with what is recorded and reported?

Nobody can connect to you because your name and identifying details will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be able to be identified in any reports or publications.

#### Who has ethically approved this project?

This study has been ethically approved by the Cultural Communication and Computing Research Institute (C3RI) and the Sheffield Hallam University Research Ethics Committee.

#### **Contact for further information**

If you have any questions about the research, please contact:

Nittaya Boonchum-PhD research student Faculty of Arts, Computing, Engineering and Sciences Department of Media Arts and Communication Sheffield Hallam University

## 10.2 Appendix B: Message inviting participation in Thai

## เอกสารชี้แจงผู้เข้าร่วมการวิจัย (PARTICIPANT INFORMATION SHEET)

ชื่อเรื่องวิจัย: การดูแลตัวเองของผู้ป่วยเบาหวานในเครือข่ายสังคมออนไลน์สุขภาพในประเทศไทย

## (Title of Project: Self-Management of People with Diabetes in an Online Community in Thailand)

## คำเชิญเพื่อเข้าร่วมการวิจัย

ท่านกำลังถูกเซิญให้เข้าร่วมในการศึกษานี้ โดยมีวัตถุประสงค์เพื่อศึกษาวิธีการสื่อสารของผู้ใช้ชุมชนออนไลน์พันทิปในการแลกเปลี่ยน ความรู้และประสบการณ์ในการดูแลตัวเองของผู้ที่เป็นเบาหวานหรือผู้ดูแลผู้ที่เป็นเบาหวาน การศึกษาครั้งนี้เป็นการศึกษาวิจัยในระดับ ปริญญาเอก ของมหาวิทยาลัยเซฟฟิลด์ ฮาแลม ประเทศ สหราชอาณาจักร ก่อนที่ท่านจะตัดสินใจเข้าร่วมการศึกษานี้ ท่านจะต้องทำความ เข้าใจว่าการศึกษาในครั้งนี้จะดำเนินการอย่างไรและมีส่วนเกี่ยวข้องกับท่านอย่างไร ขอความกรุณาท่านอ่านข้อมูลดังต่อไปนี้และหากมีข้อ สงสัยหรือคำถามหรือต้องการข้อมูลเพิ่มเติม ท่านสามารถสอบถามผู้วิจัยได้ตลอดเวลา ขอความกรุณาท่านโปรดทำความเข้าใจเพื่อใช้เวลา ในการตัดสินใจที่จะเข้าร่วมในการศึกษาครั้งนี้หรือไม่ ขอบคุณค่ะ

#### จุดประสงค์ของการวิจัย

การวิจัยครั้งนี้มีจุดมุ่งหมายที่จะศึกษาวิธีการแลกเปลี่ยนความรู้และประสบการณ์ในการดูแลตัวเองของผู้ที่เป็นเบาหวานและผู้ดูแลผู้ที่เป็น เบาหวานในชุมชนออนไลน์พันทิป เพื่อสำรวจถึงสิ่งจูงใจที่สมาชิกเข้ามามีส่วนร่วมในชุมชนออนไลน์แห่งนี้และเพื่อตอบคำถามการวิจัยใน ครั้งนี้ ผู้วิจัยจึงต้องใช้วิธีการสัมภาษณ์ท่านซึ่งเป็นผู้ที่มีประสบการณ์ในการดูแลตนเองของผู้ที่เป็นเบาหวาน

#### ทำไมท่าหจึงต้องเข้าร่วมใหการตอบคำถามครั้งนี้

ท่านได้รับเลือกให้เข้าร่วมในโครงการนี้เพราะท่านเป็นส่วนหนึ่งของชุมชนโรคเบาหวานในพันทิป ท่านมีอิทธิพลต่อผลของงานวิจัยนี้ซึ่งจะ ทำให้ผู้สนใจทั่วไปได้รับประโยชน์จากการวิจัยในครั้งนี้

## ท่านจำเป็นที่จะต้องเข้าร่วมการวิจัยครั้งนี้หรือไม่

การเข้าร่วมในโครงการวิจัยครั้งนี้เป็นไปโดยความสมัครใจ หากท่านตัดสินใจที่จะเข้าร่วมในการศึกษาครั้งนี้ ท่านจะได้รับเอกสารซี้แจง ผู้เข้าร่วมการวิจัยและเอกสารลงนามเพื่ออนุญาตให้สัมภาษณ์เข้าร่วมโครงการนี้ การปฏิเสธที่จะมีส่วนร่วมจะไม่ส่งผลกระทบต่อท่านไม่ว่า ทางใดก็ตาม นอกจากนั้นแล้ว หากท่านไม่สมัครใจจะเข้าร่วมการศึกษาแล้ว ท่านสามารถถอนตัวได้ตลอดเวลา การขอถอนตัวออกจาก โครงการวิจัยจะไม่มีผลต่อการดูแลรักษาโรคของท่านแต่อย่างใด

## สิ่งที่เกี่ยวข้องและสิ่งที่จะเกิดขึ้นกับท่านในกรณีที่ตัดสินใจเข้าร่วมการวิจัย

สำหรับผู้ที่เป็นเบาหวานคำถามจะเกี่ยวกับประสบการณ์เรื่องโรคเบาหวานของคุณโดยทั่วไปและประสบการณ์การใช้เครือข่ายออนไลน์ สุขภาพ รวมถึงประสบการณ์ในการดูแลตัวเองในคนที่เป็นเบาหวานและเหตุผลที่เข้าร่วมในชุมชนออนไลน์สุขภาพ สำหรับผู้ดูแลคนเป็น เบาหวาน คำถามจะเกี่ยวกับประสบการณ์ของคุณในการดูแลผู้ป่วยโรคเบาหวานและวิธีการที่สนับสนุนผู้ป่วยโรคเบาหวานในการดูแล ตัวเอง การดำเนินการสัมภาษณ์ทั้งหมดนี้จะดำเนินการสัมภาษณ์ผ่านทางวีดีโอคอลผ่านโปรแกรม Line หรือ Facebook หรือ Skype ทั้งนี้ ขึ้นอยู่กับการตัดสินใจของผู้เข้าร่วมการวิจัย โดยระหว่างการสัมภาษณ์จะมีการบันทึกเฉพาะเสียงพูดเท่านั้น

#### ระยะเวลาในการเข้าร่วมโครงการ

ขั้นตอนการสัมภาษณ์จะใช้เวลาประมาณ 45-60 นาที และอาจมีการขอสัมภาษณ์เพิ่มเติมครั้งที่สองในกรณีที่ต้องการข้อมูลเพิ่มเติม โดย ระหว่างการสัมภาษณ์จะมีการบันทึกด้วยเครื่องอัดเสียง โดยผู้วิจัยจะเป็นผู้พังคำสัมภาษณ์นี้แต่เพียงผู้เดียวและเมื่อผู้วิจัยได้ถอดคำ สัมภาษณ์แล้ว ข้อมูลทั้งหมดจะถูกเก็บไว้เป็นระยะเวลา 10 ปี ส่วนไฟล์เสียงจะถูกทำลายลงทันทีหลังจากถอดคำสัมภาษณ์เสร็จเรียบร้อย แล้ว

#### การหารือเกี่ยวกับการมีส่วนร่วมของท่าน

หากท่านมีคำถามใด ๆ ท่านสามารถสอบถามและพูดคุยกับนักวิจัยได้ตลอดเวลาในระหว่างขั้นตอนการสัมภาษณ์

## ผลเสียและความเสี่ยงที่อาจจะเกิดขึ้นได้ระหว่างการเข้าร่วใในการวิจัยครั้งนี้

ไม่มีความเสี่ยงที่คาดว่าจะเกิดขึ้นในการเข้าร่วมการศึกษาครั้งนี้ ยกเว้นว่าบางส่วนของคำถามที่เกิดกับคุณในการสัมภาษณ์อาจเป็นคำถาม ส่วนบุคคลซึ่งท่านอาจไม่จำเป็นที่จะต้องตอบคำถามใด ๆ ที่ท่านรู้สึกอึดอัด และท่านยังมีสิทธิที่จะยุติการสัมภาษณ์ได้ตลอดเวลา และสิ่งที่ สำคัญที่สุดคือข้อมูลทั้งหมดจาการสัมภาษณ์นี้เป็นความลับอย่างเคร่งครัดและจะถูกใช้สำหรับวัตถุประสงค์ของการวิจัยครั้งนี้เท่านี้

## ประโยชน์ที่คาดว่าจะได้รับจากการเข้าร่วมการวิจัยครั้งนี้

ท่านอาจจะไม่ได้รับประโยชน์โดยโดยตรงจากการเข้าร่วมการวิจัยนี้ แต่เนื่องจากโรคเบาหวานเป็นปัญหาสำคัญด้านสาธารณสุขของ ประเทศไทย การศึกษาครั้งนี้มุ่งเพื่อประโยชน์ของการดูแลคนที่เป็นเบาหวานในอนาคตให้มีประสิทธิภาพมากยิ่งขึ้น

## ใครจะเป็นผู้รับผิดชอบข้อมูลทั้งหมดนี้เมื่อการศึกษาครั้งนี้เสร็จสิ้นลง

ข้อมูลที่เก็บรวบรวมเพื่อการศึกษานี้จะถูกเก็บไว้อย่างปลอดภัยในที่เก็บข้อมูลของมหาวิทยาลัยและมีเพียงนักวิจัยเท่านั้นที่เข้าถึงข้อมูลนี้ ข้อมูลจะเก็บเป็นระยะเวลาไม่น้อยกว่า 10 ปี และหลังจากนั้นจะถูกทำลายโดยผู้วิจัย

## มีใครสามารถที่จะเชื่อมต่อข้อมูลส่วนบุคคลของท่านจากการเข้าร่วมในการวิจัยในครั้งนี้หรือไม่

ไม่มีใครสามารถเชื่อมต่อกับท่านได้เพราะชื่อและรายละเอียดของท่านจะถูกเปลี่ยนเป็นชื่อสมมติเมื่อนำไปใส่ในรายงานหรือการเผยแพร่ แทนการวิจัยแทนชื่อจริงของผู้เข้าร่วมการวิจัย

## ใครเป็นผู้ดูแลการการอนุมัติจริยธรรมการวิจัยในมนุษย์ในโครงการนี้

การศึกษาครั้งนี้ได้รับการอนุมัติจริยธรรมการวิจัยในมนุษย์โดยคณะกรรมการด้านจริยธรรมของมหาวิทยาลัยเซฟฟิลด์ ฮาแลม ประเทศ สหราชอาณาจักร

## ติดต่อสอบถามข้อมูลเพิ่มเติม

หากท่านมีคำถามเกี่ยวกับการวิจัยกรุณาติดต่อ: นักศึกษาปริญญาเอก/ผู้วิจัย นิตยา บุญชุม คณะ Arts, Computing, Engineering and Sciences ภาควิชา Media Arts and Communication มหาวิทยาลัย Sheffield Hallam University

## 10.3 Appendix C: Consent form in English

#### PARTICIPANT CONSENT FORM

#### TITLE OF RESEARCH STUDY: Self-Management and Social Support in an Online Diabetes Community in Thailand

Please answer the following questions by ticking the response that applies

NO

YES

- 1. I have read the Information Sheet for this study and have had details of the study explained to me.
- 2. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any point.
- 3. I understand that I am free to withdraw from the study within the time limits outlined in the Information Sheet, without giving a reason for my withdrawal or to decline to answer any particular questions in the study without any consequences to my future treatment by the researcher.
- 4. I agree to provide information to the researchers under the conditions of confidentiality set out in the Information Sheet.
- 5. I wish to participate in the study under the conditions set out in the Information Sheet.
- I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes.

Participant's Signature:	Date:
- Participant's Name (Printed):	
Contact details:	

Researcher's Name : Nittaya Boonchum

Researcher's Signature: Nittaya

#### Researcher's contact details:

Faculty of Arts, Computting, Engineering and Sciences Department of Media Arts and Communication Sheffield Hallam University

#### Please keep your copy of the consent form and the information sheet together

## 10.4 Appendix D: Consent form in Thai

หนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย

## (PARTICIPANT CONSENT FORM)

ชื่อเรื่องวิจัย: การดูแลตัวเองของผู้ป่วยเบาหวานในเครือข่ายสังคมออนไลน์สุขภาพในประเทศไทย

(TITLE OF RESEARCH STUDY: Self-Management of People with Diabetes in an Online Community in Thailand)

กรุณาตอบคำ	ตอบต่อไปนี้โดยการทำเครื่องหมายขีดถูกในช่องที่กำหนด	<b>M</b> .	м.о.
1. ข้า ใน	าพเจ้าได้อ่านเอกสารชี้แจงผู้เข้าร่วมการวิจัย(Information Sheet) สำหรับการศึกษา เครั้งนี้และได้รับการอธิบายรายละเอียดอย่างเข้าใจ	ไช่	ไช่ ไม่ใช่
2. ข้า ว่า ตล	าพเจ้าได้รับคำตอบที่พึงพอใจจากข้อคำถามที่เกี่ยวข้องกับการศึกษาครั้งนี้และข้าพเจ้าเข้าใจ เหากข้าพเจ้ามีข้อคำถามเกิดขึ้นระหว่างดำเนินการวิจัยข้าพเจ้าสามารถสอบถามได้ ลอดเวลา		
<b>3.</b> ข้า แก่	าพเจ้าสามารถที่จะถอนตัวออกจากการศึกษาครั้งนี้ได้ตลอดเวลาโดยไม่ต้องให้เหตุผลใด ๆ า่ผู้วิจัย หรือสามารถปฏิเสธที่จะตอบคำถามใด ๆ โดยไม่มีผลกระทบต่อการรักษาในอนาคต		
<b>4.</b> ข้า ใน	าพเจ้ายินยอมให้ข้อมูลในการศึกษาครั้งนี้ภายใต้เงื่อนไขของการรักษาความลับที่กำหนดไว้ แอกสารชี้แจงผู้เข้าร่วมการวิจัย (Information Sheet)		
<b>5.</b> ข้า กา	าพเจ้ายินยอมเข้าร่วมการศึกษาครั้งนี้ภายใต้เงื่อนไขที่กำหนดไว้ในเอกสารชี้แจงผู้เข้าร่วม ารวิจัย (Information Sheet)		
<b>6.</b> ข้า ถึง	าพเจ้ายินยอมให้เก็บข้อมูลภายใต้วัตถุประสงค์ของการศึกษาวิจัยนี้ โดยไม่สามารถนำไปอ้าง งในงานวิจัยอื่นๆ ได้		
ลายเซนต์ผู้เข้า	ัาร่วมการวิจัย:วัน	ก็:	
ชื่อผู้เข้าร่วมกา	ารวิจัย (ตัวบรรจง):		
รายละเอียดที่อยู่:			

ผู้วิจัย: นิตยา บุญชุ่ม ลายเซนต์ผู้วิจัย: นิตยา รายละเอียดเพื่อติดต่อผู้วิจัย: คณะ Arts, Computing, Engineering and Sciences ภาควิชา Media Arts and Communication Sheffield Hallam University

## กรุณาเก็บเอกสารหนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย (consent form) และเอกสารชี้แจงผู้เข้าร่วมการวิจัย (information sheet) ไว้ด้วยกัน

## **10.5 Appendix E: Interview question guidelines**

#### A draft of interview question for people living with diabetes

- 1. Background
  - 1.1 Can you tell me when and how you were first diagnosed with diabetes?
  - 1.2 How did you react when you found out?
  - 1.3 Can you tell me about your experience of dealing day-to-day with diabetes?
    - 1.3.1 What kind of things do you need to do in self-managing diabetes?
    - 1.3.2 Where do you go for information about diabetes self-management?
    - 1.3.3 Is there anything you find challenging in self-managing diabetes? Can you give examples?
    - 1.3.4 What kind of support do you find helpful?

Can you give examples?

#### 2. Internet Experience/Engaging with Pantip.com

2.1 How often do you go online?

- 2.2 What kind of activity do you do online?
- 2.3 When did you join Pantip.com?

2.4 What kind of activities do you do in the forum? (post a question, answer, or just read in the forum, which boards?)

2.5 When was your last time visiting Pantip.com? And what did you do there?

2.6 Do you think that Pantip.com is useful in supporting your self-management? If so, in what ways? If not, why not? Ask for examples.

2.7 Do you trust the information you get from Pantip.com? Ask for examples.

2.8 What is like to be on there?

2.9 Will you continue to use Pantip.com in the future? If so, why? If not, why not?

#### A draft of interview question for carers

#### 1. Background

1.1 Who do you know/support that is self-managing diabetes? What is your relationship?

1.2 In what ways do you help or support their day-to-day self-management?

1.3 Where would you go for information about diabetes or self-management?

1.4 Do you face any challenges in helping X cope with their condition? Ask for examples.

1.5 As a Carer/Supporter is there anywhere you could go for support or information to solve that kind of issue? Where?

#### 2. Experience of using online

2.1 How often do you go online?

2.2 What kind of activities do you do online?

2.3 When did you join Pantip.com?

2.4 What kind of thing you do in the forum? (post a question, answer, or just read in the forum)

2.5 When was your last time visiting Pantip.com? And what did you do there?

2.6 Do you think that Pantip.com is a good place to find diabetes information to help you supporting people living with diabetes to do self-management? If so, then how? If not, why not?

2.7 How much you trust information you get fromPantip.com?

2.8 Has Pantip.com changed the way X approaches self-management of diabetes? In what ways?

2.9 Will you continue to use Pantip.com in the future? If so, why? If not, why not?

#### 3. Ending the session

Finally, summarize the discussions and thank participants for their time.



#### 10.6 Appendix F: Pantip's initial recruitment announcement

# **10.7** Appendix G: A recruitment announcement is generated in response to feedback from Pantip users



#### 10.8 Appendix H: SHU research ethic form



#### APPLICATION FOR RESEARCH ETHICS APPROVAL STAFF AND POSTGRADUATE DOCTORAL RESEARCH STUDENTS (SHUREC2A)

#### SECTION A

Important Note - If you have already written a research proposal (e.g. for a funder) that answers the methodology questions in this section please include a copy of the proposal and leave those questions blank. You **MUST** however complete **ALL** of Section B and C (risk assessment).

1. Name of principal investigator:

Faculty: Arts, Computing, Engineering and Sciences

Email address: b3040877@my.shu.ac.uk

**2. Title of research:** Self-Management of People with Diabetes in an Online Community in Thailand

3. Supervisor if applicable: Dr. Kathy Doherty

Email address: scskhd@exchange.shu.ac.uk

- 4. Proposal Tracking number (applicable for externally funded research):
- 5. Other investigators (within or outside SHU)

#### Title Name Post Division Organisation

#### 6. Proposed duration of project

Start date: 15 September 2014

End Date:

14 September 2018

7. Location of research if outside SHU: Thailand

#### 8. Main purpose of research:

Educational qualification Publicly funded research Staff research project

Other (Please supply details)

#### 9. Background to the study and scientific rationale (500 words approx.)

Globally, the number of people with diabetes is predicted to increase from over 382 million in 2013 to 592 million by 2035, with particularly high increases expected in Africa, the Middle East and South-East Asia (IDF 2013). In Thailand, the number of people with diabetes was 3.2 million in 2013 and it is expected to increase to 4.3 million by 2035 (Novo Nordisk 2013). Ultimately, diabetes is ranked in the top 10 causes of death in the world and is considered a major global health crisis (World Health Organization 2016). In developing countries, it was estimated that mortality from chronic diseases is predicted to rise from approximately 54% to 65% by 2030. As the proportion of people living with diabetes and mortality rates are increasingly correlated, every country is encouraged to take urgent action to address this issue (IDF 2011). In Thailand, non-communicable diseases are the country's major burden of mortality and morbidity (WHO 2014). To improve the health outcomes of people living with diabetes, self-management is one of the key factors to "delay devastating diabetes-related complications and save life" (IDF 2011).

Research has shown that online communities not only offer a greater chance of making diabetes self-management accessible than face-to-face communities, they also provide such accessibility with a lower cost (Milagros et al. 2014). The more people living with diabetes participate in online community activities, the greater they perceive the social support received from other members in the community (Oh and Lee 2012)

In Thailand, most diabetes management happens outside of healthcare centres (Wagner 2011), with assessments only happening four times a year, and a current shortage of health professionals. These two factors may contribute to people living with diabetes preferring to find support from other sources (Jansink et al. 2010; Kolasa and Rickett 2010).

This study aims to explore how forum users on Pantip.com share diabetes information on the site, their experience of diagnosis and living with diabetes in Thailand, and how they perceive the benefits of the forum. People living with diabetes and carers who have participated in Pantip.com will be recruited.

Pantip.com is a Thai language discussion website with an active forum and it is open to the public for reading and accessing data. Pantip.com gives users the opportunity to participate and access information relating to 35 topics of their interests, including Lumpini, or health topics. The diabetes forum (http://pantip.com/tag/โรคเบาหวาม) is one of the topics in Lumpini. Moreover, Pantip.com provides other features, including BlogGang (personal diary), Pantip Market (online marketplace), PanTown (online society), and PantipStore (online store). Nevertheless, the main purpose of the site is to provide web boards for the members. Pantip's main income is generated from selling advertising space on the main page and sub-forum.

To register, obtain membership status, and participate in the forum, Pantip.com requires a person to enter their national card number (ID number) and users must be at least 15 years of age. At first, this system received a lot of criticism about privacy and the security of personal information. Since there has been no indication of any harmful consequences or providing private information, however, and membership has grown sufficiently to improve the quality of content and discussion,

users have reported being quite satisfied. In addition, Pantip.com provides the facility to promote threads via other social networks including Facebook, Twitter, Google+, and Line (only when using Pantip.com on a mobile device). Readers can click on the thread page that they are interested in and click to share to one or all those channels. Users can choose to show or hide their member profile information and photo. For those who are happy to share their information, they can give their full name, occupation, workplace, hometown, and photo. For those who do not want to share their profile, they can use a pseudonym or membership number instead of their real name. Furthermore, the national media often picks some thread topics to publish in the news. It is obvious, therefore, that the nature of the website is public.

Even though Pantip.com is a public space and any individuals can access content, only members can post questions to the topics and reply to posts. To keep the online community safe and positive, there are two types of moderation on Pantip.com. One is the Pantip.com webmaster who can remove any offending posts and secondly, if a member finds some content on the forum offensive, they can click the "trash icon" to report it to the webmaster.

Some examples of posts that Pantip.com would remove from the forum:

1. Messages critical of the king and the royal family.

2. Foul language or sexually explicit content.

- 3. Personal insults or bullying.
- 4. Posts that are solely intended to cause arguments (trolling).
- 5. Attacks on religions or the teachings of any religion.

6. Using pseudonyms that resemble somebody else's real name with the intention of misleading others.

7. Messages that might cause conflicts among educational institutions.

8. Posts containing the personal data of others, including e-mail addresses or telephone numbers.

As stated in the Association of Internet Researcher(AOIR)2012 guidelines, which are relevant to this research and the term of service (TOS) of Pantip.com, the site is not considered a personal network, as users are aware that its content can be shared to third party sites such as social networks, including advertisements. Site users are therefore aware that anyone can read and share content; Pantip.com is public and it is often in the news. It is highly regulated space and measures are taken to protect site users in terms of prohibiting and acting on behaviour on the list as it revealed in the previous paragraph. To protect the privacy of participants, no usernames, pseudonyms, membership numbers, profile details, or photos/avatars of participants will be included in this study. Any quoted material from the site will be paraphrased and anonymised to ensure that nobody can search for it online. The website is not password protected, therefore anyone can download content with no permission needed. Even if the site requires registration to get permission to create threads and posts, these requirements are from the owner of the organisation. Since Pantip.com is fully in the public domain (Kozinets 2015), researchers do not need permission to collect threads on the site and there is no need to obtain a signed consent form to collect data from this site, as demonstrated by previous studies on this website (Kongcharoen 2015; Bodhibukkana 2013). This study takes ethical precautions to protect vulnerable persons, the definition of which is explained in section B4 (p. 8). No data from participants considered vulnerable according to this definition will be included in this study.

According to Kozinets (2002, p. 65), the selection of online communities for research is based on five criteria:

(1) a more focused and research question relevant segment, topic, or group;

(2) higher "traffic" of postings;

(3) larger numbers of discrete message posters;

(4) more detailed or descriptive, rich data;

(5) more between-member interactions with regards to the type required by the research question.

As such, the posts on Pantip.com were selected based on these criteria. As of 11th March 2016, there were 450,000 page views per month, the number of visitors to the website was 4,200,000 per day, and there were 34 million threads. Moreover, Pantip.com is in the top five most popular websites as rated by ALEXA (A California-based company that provides commercial web traffic data and analytics) and it is the biggest online community in Thailand. In addition, Pantip.com provides two-way discussion, which is similar to online health communities used in previous research (Zhou, Sun and Yang 2014). It also has a specific section for posting diabetes-related threads, which is the fundamental requirement for this research.

There are currently no existing studies on online communities for diabetes in Thailand. Several existing forums on different hospital websites only provide general information focusing on their services, while the Diabetes Association of Thailand's website provides a page to ask questions related to diabetes, but this was found to be inactive.

Since Pantip.com is the only active online diabetes community in Thailand, it might be the only opportunity for people living with diabetes "to receive information, advice, and support from peers" (Centola and Van de Rijt 2014, p.19). It performs a valuable peer support function (Gilbert et al. 2012). Both patients and caregivers actively seek support from other members (Yang et al. 2011). This might because the environment of the forums enhances the ability of people to interact with peers (Lewinski and Fisher 2015). Pantip.com may be a useful place for people living with diabetes, because "it supports critically important social interactions" (Yang, Ackerman and Adamic 2011). Furthermore, it might go some way towards mitigating the problem of unequal access to public health infrastructure and health personnel in Thailand (Pongpirul et al. 2009).

## **10. Has the scientific / scholarly basis of this research been approved?** (For example by Research Degrees Subcommittee or an external funding body)

Yes

No - to be submitted

Currently undergoing an approval process

Irrelevant (e.g. there is no relevant committee governing this work)

#### 11. Main research questions

How is Pantip.com used by members to support the self-management of diabetes?
In what ways, if any, does the commercial/public nature of Pantip.com impact on the nature of the posted content and interactions on the forum and the activities involved in the self-management of diabetes?

3. In what ways does Pantip.com fit into the broader self-management routines and activities of people self-managing diabetes and their carers/supporters (where applicable)?

4. How do people evaluate their experience of participating in Pantip.com, in the context of the range of resources available to diabetes self-managers in Thailand?

#### 12. Summary of methods including proposed data analyses

A qualitative research approach will be used to explore and explain the phenomena discovered on Pantip.com. To have a better understanding of such phenomena, two qualitative methods will be employed in this study.

The first phase involves the observation of threads and individual posts on the diabetes forum on Pantip.com. An initial observation for this first stage has already taken part from June 2014 to May 2015 as part of a familiarisation process with the site and the kind of data it yields. Up to this point, however, only a small portion of the data from the site has been reviewed, without downloading or collecting any of it. Data collection will only commence following approval of the proposed research by the Ethics committee. At this stage, all relevant threads will be explored and active threads will be examined to find the possible themes. Since this study's objective is to explore the interactions in the forum, threads based on diabetes self-management and social support that appear on the forum will be captured (Braun and Clarke 2006). The prominent themes emerging around Pantip's diabetes forum will then be generated, then all results will be translated and back-translated to present the data.

Even though Pantip.com is an online public space and there is no need to obtain consent to collect threads, steps will be taken to ensure the anonymity of the site's users. To do this, the quoted material will be paraphrased, anonymised, and checked using search engines to ensure that it is not detectable. Photos of participants and individual information from their profiles will not be presented in this study.

The analytical focus of the first phase of the study will be on how the online community members interact in ways that support the self-management of diabetes. The second phase will explore the reasons why individuals participate in the forum in more depth. Interviews will be used at this stage to explore users' experiences to investigate the significance of Pantip.com for the individual self-management of diabetes.

The main purpose for the second phase is to explore members' accounts of the experience of diagnosis and living with diabetes in Thailand and members' perceptions of the role and significance of Pantip.com in that experience. The sampling will thus be of individuals who "have had experiences relating to the phenomenon to be researched" (Kruger and Stones 1988, p.150). The participants or interviewees for this second phrase of study therefore need to have experience of reading the threads about diabetes on online community forums and utilising the assistance of informal online forums. A purposive sampling method will be used for the sampling. The interviewees will be people living with diabetes and carers who take part in the diabetes forum on Pantip.com. Carers play an important role in helping diabetes patients self-manage their condition and the balance between people living with diabetes and carers using Pantip.com appears to be roughly equal.

The criteria for recruitment is individuals who aged 20 years or older (Rungsin et al. 2011) because in Thailand, 20 is the age for becoming sui juris. Participants must be a member of the forum and must either have diabetes or be a carer for someone with diabetes. In this study, the aim is to recruit 20 people (10 people living with diabetes and 10 carers).

A semi-structured interview will be used for data collection in the second phase. A consent form will be provided to explain the details of the study to the interviewees and this will be signed by all the interviewees before interviews begin. Pilot interviews have been conducted with a personal friend living with diabetes and one carer to assess the advantages and disadvantages of video calls versus face-to-face interviews. Prior to the video call, the researcher phoned the proposed participants to ask for permission to record the call and obtained consent verbally. Once the recorder was switched on, the researcher and the interviewee went through the interview question themes and recorded the answers, then created both a digital sound file and digital video file. The results of this test were impressive. The interviewees were very active and felt comfortable. They chose the time and place by themselves and it was convenient for them. The quality of the audio and video were excellent.

From this pilot interview, it emerged that the interviewees did not want to get the interview questions before the interview starts. Both of them preferred being given the questions during the interview. In addition, both participants also expressed concerns regarding their appearance on the video, as they asked the interviewer if they looked good. Since the analysis of the study will not involve analysing any photos or visual content, the video call will be used for the interview process and only the audio will be recorded.

To recruit for participants for this study, an announcement to recruit interviewees for the study on Pantip.com's diabetes online forum will be posted before conducting the data collection. The Participant Information Sheet will be given to the interviewees to explain the details of the study and the consent form will be signed by all the interviewees before the interview begins. The interview process will take approximately 45-60 minutes and it will be conducted over a video call via Line, Facebook or Skype, which are common and widely used communication tools in Thailand, depending on the interviewees' preference.

Each participant will be asked to talk about their experiences of living with diabetes or taking care of people living with diabetes and will be advised by the researcher not identify themselves in the interview, including any third parties, their village, workplace, or other places. All participant interviews will be recorded using an audio recording device and subsequently transcribed. All audio files will be stored in the university's storage system in the Research Store drive (Q:\\Research) which requires a username and password before accessing any files stored there. All interviews will be transcribed word for word and will identify interviewees by a code rather than by name, for example 'Nittaya' would be presented as 'Ni' using the first two letters of the first name. The quoted material will be anonymised, paraphrased, and translated from Thai to English. Transcription will be undertaken only by the researcher. These processes will protect the participants from being identifiable.

#### Analysing interviews

Thematic analysis will be used in this study. Qualitative research software, such as NVivo 10, will be used to support the interpretation and management of the interview data. Six steps are taken to interpret the data, as applied by Creswell (2009):

• Data will be read and categorised to analyse in the same manner as the interpretation of the threads analysis.

- Initial codes.
- · Look for patterns, themes, relationships, sequences, differences.

At this stage, themes will be developed on the individual level, which will focus on the experience of people living with diabetes both in online and offline environments. The self-management of diabetes and social support exist both in the online forum and in healthcare settings. What kind of support are people living with diabetes and carers looking for? The reasons for participating in an online health community will be explored.

- Explore patterns.
- Elaboration and small generalisations.
- · Link generalisations to the body of knowledge to construct a theory

#### SECTION B

#### 1. Describe the arrangements for selecting/sampling and briefing potential participants. This should include copies of any advertisements for volunteers or letters to individuals/organisations inviting participation. The sample sizes with power calculations if appropriate should be included.

In the first phase of the project, the data collection will take the form of online posts made on the Pantip.com site. An initial sample over a six-month period will be collected, which may be extended if necessary. As discussed in section A (p. 3), Pantip.com is a public space; as such, there is no requirement to contact site users directly, in accordance with the AOIR guidelines (2012). The thread analysis in previous studies do contend that personal talk on the internet is open and is therefore not subject to human source requirements. Ethical approval from individuals in this context is hence not essential (British Psychological Society 2013). The threads on the Pantip.com forum are open to the public and can be viewed without registration, however, so anonymised datasets might contain enough personal information that could result in personal data being identifiable (AOIR 2012). To protect individuals when analysing these data, all the textual evidence will be imported into the database only after omitting any information that could identify an individual. Pseudonyms or codes will be used to select the cases when presenting the results of the research.

In the second part of the study, the researcher will post an announcement to recruit interviewees for the study on Pantip.com's diabetes online forum. The announcement will be posted on the forum before conducting data collection and the consent form will be acquired via Pantip's private message box (Zhou, Sun and Yang 2014). The criteria of recruitment for the interviewees are individuals aged 20 years or older (Rungsin et al. 2011), be a member of the forum, and either be living with diabetes or a carer. Individuals will be asked to sign the consent form before the interview begins.

In terms of the sampling, there are no specific requirements for the number of interviewees to be recruited for a qualitative research study (Creswell 2009). In this study, the researcher aims to recruit 20 people, based on the numbers used in previous studies (Zhou, Sun, and Yang 2014; Browne et al. 2013). To achieve data saturation, it is possible to conduct additional interviews if necessary (Browne et al. 2013).

In this study, the information sheet and the consent will be used in the interview session. First of all, the participants will get an information sheet explaining the aims of the research project, the description of what they must do, the amount of time that they will spend, a statement which addresses confidentiality and security of information, a statement that participation in the research is completely voluntary and they are at liberty to withdraw at any time without prejudice or negative consequences, a statement about any potential risks, harms and benefits to participants, and the contact details of the researcher in case the participants have any questions. After that, they will get a consent form to sign. A copy of the consent form and information sheet will be retained by the researcher.

- 2. What is the potential for participants to benefit from participation in the research? To take part in this research, the participants help to improve a diabetes self-management care in Thailand, especially to see the potential role of online communities in supporting people living with diabetes in Thailand.
- 3. Describe any possible negative consequences of participation in the research along with the ways in which these consequences will be limited. Some of the questions posed to the participants in the interviews may sound personal, however, they do not have to answer any question that they feel uncomfortable with. And they also have the right to have the interviews terminated if this is making them uncomfortable. Anything that the participants say to the researcher will be strictly

confidential and only used for the purpose of this research.

4. Describe the arrangements for obtaining participants' consent. This should include copies of the information that they will receive & written consent forms where appropriate. If children or vulnerable people are to be participants in the study details of the arrangements for obtaining consent from those acting in *loco parentis* or as advocates should be provided.

This study will not work with children or other vulnerable participants. The following points support that the participants in this study will not belong to any vulnerable groups. Firstly, from the literature review conducted for this study, in the UK, "on average, people living with a health condition spend just three hours per year with their health care team" (SelfmanagementUK 2013). This is comparable with diabetes self-management care in Thailand, where most of patients meet the doctor approximately once every three months, meaning they meet their physician only four times a year. In around 95% of diabetes management situations (Diabetes UK 2009), patients are managing day-to-day life with their condition by themselves (SelfmanagementUK 2013). It is obvious, therefore, that people living with diabetes are proactive and have the ability to take care of themselves. They are living independent lives and able to selfmanage their long-term condition. In addition, Pantip.com provides information about the age and gender of members to help an individual or organisation determine which forum is suitable for their advertising. In the health forum, the users are aged between 18 and 65+ years. From this data, the health forum does not have any members considered children and almost no users who aged 65+ (1%). The majority of the participants are aged between 25-34 years (36%), 35-44 years (26%), and 45-54 years (14%).

Furthermore, the participants in this study are people who use online communities. Hartzler et al. (2011) believe that online health communities are great resources for patients to gain knowledge and learn from each other. They also provide an alternative platform for people to connect with others living with the same condition, and to seek emotional support and mutual understanding that may not be available in their offline social circles, to encourage information exchange and share feelings, hear about others' experiences (which may differ from the information provided by professionals) and to be satisfied that they have examined every bit of information available about a topic (Fan et al. 2010). From this information, we can also deduce that people who use Pantip.com have the ability to use the internet, have ability to communicate in the forum and are able to make a decision by themselves.

In some previous research which studied patients' use of the internet for diabetes information (Wilson 2013), the researcher claimed that his project "did not have any clinical involvement with the participants and all gave informed consent to participate in the study" so it was not necessary to do formal ethical approval. Pantip.com is also a channel for people living with diabetes and carers, in which they can participate without any clinical involvement. In addition, from the pilot interview, the participant informed that he was comfortable answering all the questions and felt very valuable with himself therefore participating in this study might help people with diabetes to improve their self-esteem. During the pilot interview, the interviewee could think and make decisions independently. Some questions might involve sensitive topics, however, so communication with the interviewees will be open to ensure that they remain comfortable with the content of the discussion. It is possible that during the interview process, a participant may feel distress, anxiety, or embarrassment to answer the question. Should this occur, it could be mitigated by taking a break, switching off the audio recording, and trying to engage in enjoyable conversation outside of the research environment (Donalek 2005). Furthermore, in the information sheet and consent form, it will be made clear that the participants have the right to refuse to answer questions, stop the interview at any point, or reschedule it without any prejudice or negative consequences (Corbin and Morse 2003).

In conclusion, Pantip.com forum users are not considered to be vulnerable people and they have the ability to understand and sign the consent form.

- 5. Describe how participants will be made aware of their right to withdraw from the research. This should also include information about participants' right to withhold information and a reasonable time span for withdrawal should be specified. Taking part in this study is a completely voluntary, if the volunteers would like to withdraw, they can do it at anytime without giving a reason.Refusal to participate will not affect them in any way. If the volunteer decide to take part in this study, they will get the information sheet to keep and be asked to sign a consent form.
- 6. If your data collection requires that you work alone with children or other vulnerable participants have you undergone Criminal Records Bureau screening? Please supply details.

This study will not work with children or other vulnerable participants as it explained in section B4.

7. Describe the arrangements for debriefing the participants. This should include copies

of the information that participants will receive where appropriate.

- 8. Describe the arrangements for ensuring participant confidentiality. This should include details of:
  - $\circ\;$  how data will be stored to ensure compliance with data protection legislation
  - how results will be presented
  - $\circ\;$  exceptional circumstances where confidentiality may not be preserved
  - $\circ\;$  how and when confidential data will be disposed of

All data will be stored in the university networked storage at ResearchStore (Q:\Research) with requiring username and password before accessing the research store. Any individual data will identify by code or pseudonym. The data will be stored at least 10 years and destroyed after that by the researcher.

9. Are there any conflicts of interest in you undertaking this research? (E.g. are you undertaking research on work colleagues or in an organisation where you are a consultant?) Please supply details of how this will be addressed. No any conflicts in this research study.

#### 10. What are the expected outcomes, impacts and benefits of the research?

This research expects to get the data of the type of interaction involved in the self- management in a diabetes online community in Thailand, the function of social support and self-management in an online health community which is outside of the professional health context in Thailand and to understand the role of online health community in supporting people living with diabetes.

The impact of this research outcome will benefit both of individual levels such as people living with diabetes and carers to help them cope with their health condition and have a better life and national level such as health professionals and communicators can use this result to apply with their work in health promotion.

#### 11. Please give details of any plans for dissemination of the results of the research

This research will disseminate the result in different ways that only involve in this study. It will be used for a Ph.D. theisis and for publications such as conference, journal, and presentation.

However, these expansion will happened after the researcher have an agreement from a supervisor team.

#### SECTION C

#### **RISK ASSESSMENT FOR THE RESEARCHER**

1. Will the proposed data collection take place on campus?

- Yes (Please answer questions 4, 6 and 7)
- No (Please complete <u>all questions</u>)

#### 2. Where will the data collection take place?

(Tick as many as apply if data collection will take place in multiple venues)

Location	Please specify
Researcher's Residence	
Participant's Residence	
Education Establishment	
Other e.g. business/voluntary organisation,	
public venue	
Outside UK	Thailand

#### 3. How will you travel to and from the data collection venue?

- On foot By car Dublic Transport
- Other (Please specify) Line, or Facebook or Skype

Please outline how you will ensure your personal safety when travelling to and from the data collection venue

In the interview part, data collecting in this research is not face-to-face. The researcher will collect data by using the Line, or Facebook or Skype which popular common and widely used communication tools in Thailand.

- 4. How will you ensure your own personal safety whilst at the research venue? Data collecting in this research is not face-to-face therefore the researcher will be safely at the research venue.
  - 5. If you are carrying out research off-campus, you must ensure that each time you go out to collect data you ensure that someone you trust knows where you are going (without breaching the confidentiality of your participants), how you are getting there (preferably including your travel route), when you expect to get back, and what to do should you not return at the specified time. (See Lone Working Guidelines). Please outline here the procedure you propose using to do this. Not applicable

- 6. Are there any potential risks to your health and wellbeing associated with either (a) the venue where the research will take place and/or (b) the research topic itself?
  - None that I am aware of
  - Yes (Please outline below)
- 7. Does this research project require a health and safety risk analysis for the procedures to be used?
  - Yes
  - No No

(If YES the completed Health and Safety Project Safety Plan for Procedures

should be attached)

#### Adherence to SHU policy and procedures

Personal statement I confirm that: • this research will conform to the principles outlined in the Sheffield Hallam University Research Ethics policy • this application is accurate to the best of my knowledge		
Signature		
Date	January 2017	
Supervisor (if applicable)		
Signature		
Date	January 2017	

#### Please ensure the following are included with this form if applicable, tick box to indicate:

#### Yes No N/A

Research proposal if prepared previously Any recruitment materials (e.g. posters, letters, etc.) Participant information sheet Participant consent form Details of measures to be used (e.g. questionnaires, etc.) Outline interview schedule / focus group schedule Debriefing materials Health and Safety Project Safety Plan for Procedures