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**Illness Perception of Type 2 Diabetic  
Patients in Malaysia  
&  
A Portfolio of Professional Practice**

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**Portfolio submitted in fulfilment of the requirements for the degree of Doctor of  
Health Psychology**

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**November 2015**



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**pp 248-263:** **Appendix 2.** Images in presentation.  
**pp 264-271:** **Appendix 3.** Images in presentation.  
**pp 272-277:** **Appendix 4.** Images in presentation.  
**pp 278-284:** **Appendix 5.** Images in presentation.  
**pp 296-304:** **Appendix 1.** Images in presentation.

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- pp 216-223:** **Appendix 2.** Consultancy contract.

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# ACKNOWLEDGEMENTS

Firstly, I owe my deepest gratitude to City University, London and NHS South West (SW) Essex who jointly funded the first two years of my training. I would like to thank my Doctorate supervisor Dr Vanessa Bogle for her patience and support. I would like to extend my deepest gratitude to my other University Supervisors, Dr.Catherine Sykes and Dr Claire Howard for their guidance and support throughout this journey.

I wish to thank my workplace supervisor at NHS SW Essex, Dr Henna Ali for all the support she provided throughout my employment at the organisation. I would also like to thank my external supervisor in Malaysia, Dr Sharimini Ramanasamy for providing me with the opportunity to conduct my research project at Prince Court Medical Centre, Malaysia. My sincerest appreciation goes out to Dr Parmpreet Kalsi for her guidance with the systematic review and also for the ongoing support she provided.

I would like to say a huge thank you to my parents, sibling, nephews and nieces for the incredible amount of support and encouragement they have given throughout the whole process. A special thanks to Nimalan Ethirma who motivated me to embark on this training.

Last but not least, I would like to thank all the diabetic patients who participated in my study.

# **DECLARATION**

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# **Section A**

## **Preface**

This portfolio documents evidence and reflection on gaining competency in research, generic professional competency, consultancy, teaching and two optional competencies. The doctoral research focused on illness self-regulatory experience of type 2 diabetic patients in Malaysia. Diabetes is a global pandemic of the 21st century. The International Diabetic Federation (2013) estimated that 8.3% of adults – 382 million people – have diabetes and the number of people with the disease is set to rise beyond 592 million in less than 25 years. Diabetes imposes substantial economic burden on society. American Diabetes Association (2013) reported that the total estimated cost of diagnosed diabetes in 2012 is approximately \$245 billion. This includes \$176 billion in direct medical costs and \$69 billion in reduced productivity. Hex, Bartlett, Wright, Taylor and Varley (2012) reported that in United Kingdom (UK), direct and indirect cost of diabetes in 2010/2011 was approximately £23.7bn. This cost is estimated to raise to £39.8bn in 2035.

The following sections reflect my development throughout the Stage 2 training.

## **Section B: Research**

The research component of this thesis investigates the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia. Diabetic research in Malaysia has rarely adopted a patient centred approach. Further to this, the application of theoretical frameworks within diabetes research is also rare. This research triangulates both qualitative and quantitative methodologies to gain understanding on illness self-regulatory experiences of Type 2 Diabetes patients in Malaysia. Phase one of the research applies Leventhal's Self-Regulation Model (Leventhal, Meyer & Nerenz, 1980) to investigate the factors effecting diabetes management in Type 2 diabetes patients in Malaysia. This study employed a qualitative research methodology. Principles of grounded theory was applied to the analysis of the data obtained. Phase two of the research was a quantitative study which utilised the IPQ-R to investigate the relationships between patients' illness perceptions and their adherence to self-care regimens. As Malaysia is a country with diverse ethnicity, the secondary aim of this study was to determine whether there are cultural differences in the way in which different ethnic group patients with Type 2 diabetes conceptualise their illness and treatment. This research served as a crucial first step to gain an insight on how diabetic patients in Malaysia deal with their illness. The outcome of this thesis emphasises the importance of addressing diabetic patients' illness perceptions to optimise diabetic self-management.

## **Section C: Professional Practice**

### **Generic Professional**

The professional practice component of the thesis firstly includes the generic professional competency. This discussion explores how professional conduct was maintained during the 2 years placement at NHS SW Essex. The case study explores a variety of projects that were undertaken during this placement for the public health directorate of NHS SW Essex. Throughout the two years practice, measures were taken to strictly follow the guidelines of the British Psychological Society Code of Ethics and Conduct (2006), the Health Professions Council's Standards of Proficiency (2010) and NHS policies and guidelines.

### **Consultancy**

The next section of the professional practice component discussed a consultancy work. I served as a research consultant on an evaluation project to be conducted by the client (Institute for Health and Human Development at University of East London). The aim of the evaluation project was to develop specifications and deliver an evaluation of Tower Hamlet Primary Care Trust's (PCT) pilot vascular check programme.

### **Teaching and Training**

This portfolio includes two teaching and training case studies. The first case study provides a discussion on various teaching and training sessions designed, delivered and evaluated for two groups of student population (MSc Health Psychology students and BSc Psychology students) in two countries (London and Malaysia). Teaching topics included Social Marketing, Research Practicalities in Health Psychology and Stage 2 Health Psychology Training. The teaching session conducted for the MSc Health Psychology students at City University was video-recorded a part of the assessment procedure.

The second teaching and training case study provides a discussion on a training session which was conducted for the Health Trainers of NHS SW Essex. Health trainers are local people with a genuine understanding of local communities. These professionals are equipped with the wealth of knowledge that comes from living in our communities and who are aware of the challenges of everyday life (North East London NHS Foundation Trust, 2009). The training session was on Individual Differences in Health and Behaviour Change.

## **Optional Units**

The first optional case study explores a community engagement project which was undertaken to engage with hazardous/harmful alcohol consumers within Basildon and Brentwood in order to obtain information about current attitudes and behaviours towards alcohol and to develop behaviour change interventions aimed at reducing harmful alcohol consumption. It was anticipated that the community engagement initiative would also provide a platform to understand areas of unmet needs and provide a clear set of objectives to work towards to meet these needs. Furthermore, the findings would highlight how to use resources to improve the local population's health in the most effective and efficient way. Importantly, it would provide a method for monitoring and promoting equity in the provision and use of health services and addressing inequalities in health. This project was jointly funded by The Drug and Alcohol Reference Group of Brentwood and Basildon.

The second optional case study is based on a systematic review finding dissemination activity. The title of the systematic review was the effectiveness of cognitive behaviour therapy for depressed patients with diabetes. The findings of the systematic review was presented at the Asian Diabetes Conference, 2012. The conference was held in Kuala Lumpur, Malaysia between 17- 21 October 2012. This conference is held annually and is organised by The National Diabetes Institute, Malaysia also known as NADI. This presentation was awarded 3rd Prize for the Young Investigator Award.

## **Section D: Systematic Review**

A systematic review was conducted to investigate the effectiveness of cognitive behaviour therapy for depressed patients with diabetes: a systematic review of recent evidence. Depression is common among patients with diabetes. The presence of diabetes doubles the odds of comorbid depression. Depression for those with diabetes has a negative impact on their quality of life. Depressed diabetes patients have higher risk of diabetes related complications such as diabetic retinopathy, nephropathy, neuropathy, macrovascular complications, and sexual dysfunction. Cognitive behaviour therapy has been proven to be effective in treating depression. Although research has focused on applying cognitive behaviour intervention for depressed diabetes patients, thus far the effectiveness of this intervention has not been systematically reviewed.

Systematic literature searches were performed using Ovid, CINAHL EMBASE, PUBMED, PsycINFO, Web of Science and Cochrane Library to retrieve published article which fulfilled all inclusion criteria. Methodological quality assessment and data synthesis were then performed. The outcome of this review indicated that Cognitive behaviour therapy has demonstrated some level of favourable outcomes, specifically in reducing depressive symptoms among depressed diabetes patients. However, cognitive behaviour therapy did not have a significant impact on diabetes related outcome such as glycaemic control. Limitations and areas for future research were discussed.

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# **Section B**

## **Research**

## **Abstract**

### **Background**

Diabetes prevalence rate in Malaysia has risen much faster than expected. The prevalence of diabetes in Malaysia is above average when compared to the estimation by the International Diabetes Federation (IDF) for all regions in the world and has already reached the projected prevalence for the year 2030. The latest Malaysian National Health and Morbidity survey (2011) indicated that the prevalence of diabetes is 15.2% for population above the age of 18 years old. Various studies in Malaysia have demonstrated poor diabetic self-management among patients and high complications. Research on diabetes in Malaysia has mainly adapted a biomedical and epidemiological approach. Thus far, research in Malaysia has failed to assess patients' personal beliefs about their illness. This study employs a mixed- methods approach that triangulates findings from two data collection methods to gain a coherent insight into illness beliefs among Malaysian Type 2 diabetes patients using a psychological approach grounded in self-regulatory theory.

### **Aims**

Study 1 was conducted to investigate: (1) the cognitive representations of illness among patients suffering from type 2 diabetes in Malaysia, (2) the emotional representations of illness among patients suffering from type 2 diabetes in Malaysia, and (3) the management/coping styles adopted by patients suffering from type 2 diabetes in Malaysia. Study 2 was conducted to investigate the relationships between patients' illness perceptions and their adherence to self-care regimens. As Malaysia is a country with diverse ethnicity, the secondary aim of this study is to determine whether there are cultural differences in the way in which patients with type 2 diabetes from different ethnic groups conceptualise their illness and treatment.

### **Method**

In study 1, data was obtained by conducting semi-structured one-to-one interview with participants. The data obtained was analysed using principals of grounded theory.

In study 2, data was obtained using structured questionnaires. Participants were required to fill in 3 questionnaires (demographic questionnaire, IPQ-R Diabetes questionnaire and summary of diabetes self-care activities). Data were analysed using SPSS version 22.0. Various analyses, such as descriptive analysis and Pearson correlations, were conducted. Group differences were examined by a Kruskal–Wallis H test.

## **Results**

Study 1 found that patients adopted positive cognitive representation, such as determination. The findings also suggest that patients viewed their relationship with their healthcare provider positively, which supported disease management. Patients with determination and good health provider support adopted problem based coping. Some patients had negative emotional representations towards diabetes, such as fear. In addition, patients' management of diabetes was affected by various psycho-social factors, such as the lack of understanding of family and stress. All patients expressed that Malaysian food culture had a negative impact of diabetes management. This study also revealed that some patients adopted emotional focused coping, specifically by keeping their diabetic status a secret.

Results of Study 2 indicated there was a strong negative correlation between the self-care total score and consequences subscale, personal control subscale, treatment control subscale and emotional representation subscale. There was a significant negative correlation between the self-care total score and illness cohesion subscale. There was also a significant negative correlation between the self-care total score and identity subscale. This study also found that there was a difference in the ways in which different ethnic groups conceptualise their illness.

## **Chapter One: Introduction**

### **1. Introduction**

The World Health Organization (1999) defines diabetes as a chronic disease that occurs either when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces. According to National Institute of Clinical Excellence (NICE, 2014), there are four major types of diabetes. Type 1 diabetes, which is also known as insulin-dependent diabetes, occurs when the body fails to produce any insulin at all. Type 2 diabetes occurs when the body is still capable of producing insulin, but the insulin produced is insufficient for the body to function properly. This form of diabetes also occurs when the body's cells do not react to insulin produced. Type 2 diabetes is also known as non-insulin-dependent diabetes. Type 2 diabetes is more prevalent than Type 1 diabetes. Around 95% of all people with diabetes have Type 2 diabetes. The third form of diabetes is known as secondary diabetes. This form of diabetes occurs as a result of pancreatic destruction. The fourth form of diabetes is known as gestational diabetes and occurs during pregnancy. Gestational diabetes is caused by the presence of high levels of glucose in the blood resulting in the body being unable to produce enough insulin to absorb it all. This form of diabetes affects approximately 2-7% of pregnant women. This form of diabetes is reversible after childbirth. However, women diagnosed with gestational diabetes would remain at a high risk of developing Type 2 Diabetes (Peacock, Bogossian, McIntyre & Wilkinson, 2014).

An estimate by Wild, Roglic, Green, Sicree and King (2004) indicates that 171 million people had diabetes in 2000 this is projected to increase to 366 million by 2030. The prevalence of diabetes is highest in India (31.7 million people with diabetes), followed by China (20.8 million people with diabetes) and United States of America (17.7 million people with diabetes). Yoon et al. (2006) explained that the prevalence of Type 2 diabetes in USA has almost doubled, with three to five-fold increases in India, Indonesia, China,

Korea and Thailand (Yoon et al., 2006 cited in Atkins & Zimmet, 2010). Danaei et al. (2011) estimated that currently there are 347 million people worldwide with diabetes.

In a recent study, Guariguata et al. (2013) conducted a literature search of studies reporting the age-specific prevalence of diabetes and used the Analytic Hierarchy Process to systematically select studies to generate estimates of the disease in 219 countries and territories. One hundred and seventy four data sources, representing 130 countries were reviewed. Data sources were inclusive of national health surveys conducted by governments, or non-governmental organisations such as the World Health Organization (WHO) or World Health Surveys. The outcome of this review indicated that in 2013, 382 million people had diabetes and predicted that this number would increase to 592 million people by 2035. This study also found that Diabetes prevalence and numbers of people with diabetes vary substantially by the World Bank income group. The researchers projected that the greatest proportional increase in the number of adults with diabetes was expected in low-income countries (108%), followed by lower middle-income countries (60%), upper-middle-income countries (51%), and finally high-income countries (28%). In a separate literature review Zabetian, Sanchez, Narayan, Hwang and Ali (2014) collated data from 109 population-based surveys involving 1,100,746 individuals to investigate diabetes prevalence in rural areas globally and how it has changed over time in high-income countries (HIC) and low-middle income countries (LMIC). The outcome of this review indicated that diabetes prevalence has increased in all rural areas globally, but relative growth was faster in LMIC than HIC rural areas.

An ecological analysis conducted by Oggioni, Lara, Wells, Soroka and Siervo (2014) of diabetes prevalence showed a direct association with the degree of exposure to a westernised dietary pattern. In this analysis, the researchers gathered various data such as the most recent information on prevalence rates reported for each country obtained from WHO Global Info Base database. In addition, country-specific Food Balance Sheets (FBS), urbanisation, physical inactivity and smoking rates, obesity prevalence, and per capita Gross domestic product (GDP) estimates were also retrieved. The most recent diabetes prevalence rates were extracted for each country up to 2010. The ecological analysis

included data obtained from 96 countries. This study found that age was an independent risk factor for type 2 diabetes. The researchers found a higher incidence of Type 2 diabetes among older patients and explained that this could be caused by age-related modification of glucose tolerance. Hence, the expected increase in life expectancy in emerging nations may represent a critical factor contributing to the forecasted rise in worldwide cases of diabetes. Furthermore, physical inactivity was identified as an independent risk factor for Type 2 diabetes and appeared to have a direct effect on diabetes risk. The ecological analysis revealed that as countries become more affluent and urbanised, sedentary habits are more likely to be adopted.

Diabetes imposes substantial economic burden on society. Various countries have undertaken costing analysis to estimate the economic burden of diabetes. For example, American Diabetes Association (2013) reported that the total estimated cost of diagnosed diabetes in 2012 is approximately \$245 billion. This includes \$176 billion in direct medical costs and \$69 billion in reduced productivity. Hex et al. (2012) reported that in the UK, direct and indirect cost of diabetes in 2010/2011 was approximately £23.7bn. This cost is estimated to raise to £39.8bn in 2035/2036.

Ng, Lee, Toh and Ko (2014) systematically reviewed 30 articles from MEDLINE and Scopus reporting the cost of type 1 and/or 2 Diabetes Mellitus that were published in English from 2007 to 2011 to ascertain the economic impact of Diabetes Mellitus. Studies included in this review originated from various countries such as USA, WHO African region, Brazil, Canada, the Caribbean region, China, Germany, Greece, India, Iran, Japan, the Netherlands, Norway, Sudan, Sweden and the United Kingdom. The outcome of this review indicated that there was a huge variation in reported cost of Diabetes Mellitus. For example, the annual direct costs for the total population in country ranged from an annual total of US\$112.4 million in Iran to US\$116 billion in the U.S. Individual cost per patient-per annum varied from US\$150 in India to US\$14,060 in the U.S. This review also found that in comparison with a patient with no Diabetes Mellitus, a patient with diabetes would incur an excess health care cost of approximately US\$123.1 to US\$10,837 per patient per annum. In a separate study, Zhang et al. (2010) estimated the global health expenditure on

diabetes among people aged 20–79 years for the years 2010 and 2030. These researchers estimated the global health expenditure attributable to diabetes is the sum of the expenditure of 193 individual countries. The expenditures of 23 countries or regions that were members of United Nations but with no appropriate health expenditure data available were not accounted to in the sum. The outcome of this estimation indicated that the global health expenditure on diabetes is expected to total at least USD 376 billion in 2010 and this amount would increase to approximately USD 490 billion in 2030.

## **1. 2 Diabetes Related Complications**

Well managed diabetes ( $HbA1c \leq 7$ ) dramatically reduces the risk of diabetes-related complications. There are various aspects of diabetes management which includes managing the relationships between food, physical activity, medications, self-monitoring of blood glucose, blood pressure, regular retinal screening and targeting goals tailored to individual need, for example around foot care, weight loss, injection technique and managing acute complications such as hypoglycaemia and hyperglycaemia. Poorly controlled diabetes is associated with the development of other chronic illnesses. Diabetes leads to macrovascular complications (e.g. stroke and heart disease) and microvascular complications (e.g. diabetic retinopathy and kidney disease). Diabetes also increases other complications such as depression and causes a decrease in life expectancy. According to Reynolds, Haley and Kozlenko (2008) patients with depression and diabetes lose approximately 3 years of life in comparison with patients with diabetes and no depression.

### **1. 2.1 Diabetes and Macrovascular disease**

Epidemiological and longitudinal studies indicate that diabetes is a major risk factor in the development of cardiovascular diseases (CVD) such as heart disease and stroke (Grundy et al., 1999; Hu, Pan, Malik & Sun, 2012). This is because diabetes accelerates vascular aging (Hill, 2014). Adults with diabetes are at a 2 to 4-fold increased risk of CVD (Fox, 2010). According to Goldfine and Fonseca (2014), CVD is the leading cause of morbidity and mortality in diabetes mellitus. By using a nationwide survey methodology of 6,032 women and 5,612 men, type 2 diabetic patients regularly attending diabetes clinics in Italy,

Avagaro et al. (2007) found that CHD was twice more frequent in men than women and microvascular complications (renal, ocular, or both) carried an independent risk of incident CHD.

According to Idris, Thomson and Sharma (2006) patients with diabetes have significantly worse stroke outcomes as patients tend to have increased hospitalization and long-term stroke mortality, more residual neurological and functional disability, and longer hospital stays. The presence of diabetes also increases the risk of stroke mortality (Hu et al., 2001). However, the association between stroke and diabetes is varied widely according to race/ethnicity and gender (Karsito, 2008). For example, a systematic review conducted by Peters, Huxley and Woodward (2014) found that the excess risk of stroke associated with diabetes is significantly higher in women than men.

### **1.2.2 Diabetes and Microvascular disease**

Microvascular diseases are caused by damages to small blood vessels (WHO, 2015). Diabetic patients can experience various kinds of microvascular complications such as diabetes retinopathy and kidney disease.

#### ***Diabetic retinopathy***

Diabetic retinopathy is a complication of diabetes in which the retina, a part of the eye, becomes progressively damaged. Diabetic retinopathy remains the most common cause of blindness among adults (Tatti, Di Mauro, Masselli, Longobardi & Barber, 2010). Nearly all patients with Type 1 diabetes and more than 60% of those with Type 2 have some retinopathy after 20 years (Mohamed, Gillies & Wong, 2007). Yau et al. (2012) conducted a systematic review on the global prevalence and major risk factors of diabetic retinopathy. Thirty-five population-based studies published between 1980-2008 were included in the review. The studies included in the review were conducted in various parts of the world such as the U.S., Australia, Europe, and Asia. The pooled participant sample was 22,896. The findings indicated that the overall pooled prevalence of diabetes retinopathy was 34.6%. The risk factors that contributed to diabetes retinopathy was diabetes duration, HbA1c, and blood pressure levels. Furthermore, this review also found that the prevalence

of diabetic retinopathy was higher in people with type 1 compared with type 2 diabetes. The rate of diabetes retinopathy was 21.1% among patients with less than ten years of diabetes. The prevalence was a staggering 76.3% among patients who had diabetes for 20 years or more. Other studies have also found that the number of years of diabetes significantly increases the risk of diabetic retinopathy (Bansal, Gupta & Kotecha, 2013; Tapp et al., 2003; Hammes et al., 2011). Research has also found that higher HbA1c contributes to the increased risk of diabetic retinopathy (Tsugawa et al., 2012).

Empirical evidence suggests that people of a certain ethnicity are more susceptible to diabetes retinopathy. For example, a multi-ethnic cohort study in the USA found that diabetic retinopathy was significantly higher in blacks and Hispanics than in white and Chinese populations (Wong et al., 2006). Other studies found the prevalence of diabetes retinopathy was higher in African Americans and lowest in Asians (Yau et al., 2012).

The Kumamoto Study conducted by Shichiri, Kishikawa, Ohkubo and Wake (2000) found that intensive glycemic control can delay the onset and progression of the early stages of diabetic microvascular complications in Japanese patients with type 2 diabetes. The longitudinal randomized controlled trial (RCT) consisted of 110 patients with type 2 diabetes. Fifty-five participants had no retinopathy, the primary prevention cohort and 55 had simple retinopathy, the secondary intervention cohort. Participants were randomly assigned to multiple insulin injection therapy (MIT) groups and administered three or more daily insulin injections or were assigned to conventional insulin injection therapy (CIT) groups and administered one or two daily intermediate-acting insulin injections. After eight years, the cumulative percentages of worsening in retinopathy were significantly lower in the MIT group than in the CIT.

There are various factors that can prevent the onset of diabetic retinopathy. The UK Prospective Diabetes Study Group (1998), conducted a RCT to determine whether tight control of blood pressure prevents macrovascular and microvascular complications in patients with type 2 diabetes. One thousand one hundred and forty eight hypertensive patients with type 2 diabetes participated in this trial. Seven hundred and fifty eight patients

were allocated to tight control of blood pressure (aiming at a blood pressure of <150/85 mm Hg) and 390 patients to less tight control (aiming at a blood pressure of <180/105 mm Hg) with a median follow-up of 8.4 years. The group assigned to tight blood pressure control had a 37% reduction in the risk of microvascular disease compared with the less tight group. Regular eye screening and early treatment is also crucial to prevent the progression of diabetic retinopathy and diabetes-related blindness (Stefánsson et al., 2000; Ciulla, Amador & Zinman, 2003). A recent study conducted in Japan found that an increased fruit intake was associated with a reduced incidence of diabetic retinopathy among patients adhering to a low-fat energy-restricted diet (Tanaka et al., 2013).

### ***Kidney disease***

Diabetes is the most common cause of end-stage renal disease (Middleton, Foley & Hegarty, 2004). End-stage renal disease is a condition that affects the kidneys that requires either dialysis or a kidney transplant as the kidneys stop functioning well. Brancati et al. (1997) postulated that patients with diabetes have approximately a 12-fold increased risk of developing end-stage renal disease.

According to Diabetes UK (2014), about one in three people with diabetes might go on to develop kidney disease, although, as treatments improve, fewer people are affected. Recent research findings have found contradicting evidence. Seven million Americans have diabetes-related kidney disease despite increased use of medication to prevent the prevalence of diabetes-related kidney disease (De Boer et al., 2011). According to US Renal Data System (2007), Type 2 diabetes contributes 30% to 50% of new cases of end-stage kidney disease in the world. A study conducted by Young, Pugh, Maynard and Reiber (2004) found that greater mortality is observed among diabetic patients with renal disease compared with those without renal disease. By examining data obtained from 82,933 patients undergoing maintenance hemodialysis, Kalantar-Zadeh et al. (2007) found that higher blood sugar level (A1C) values were incrementally associated with higher death risks among diabetic patients. Further to that, diabetic dialysis patients are characterised by a high prevalence of diabetic complications. A case-control study of 53 diabetic patients on chronic dialysis in Copenhagen conducted by Sørensen et al., (2007) found that diabetic

dialysis patients were more susceptible to diabetes complications such as acute myocardial infarction, stroke, angina pectoris, retinopathy, maculopathy and impaired vision.

Diabetes patients with high-blood pressure are more susceptible to kidney disease (Hsu, Iribarren, McCulloch, Darbinian & Go, 2009; Klag et al., 1997). Thus, many researchers have investigated if treatment for lower BP levels is associated with slower progression of chronic kidney disease among diabetic patients.

### **1. 2.3 Diabetes and Other Complications**

#### ***Diabetes & depression***

Depression refers to a wide range of mental health problems characterised by the absence of positive affect (e.g. loss of interest and enjoyment in ordinary things and experiences), low mood and a range of associated emotional, cognitive, physical and behavioural symptoms (NICE, 2009). There are various psychological (e.g. continuous low mood or sadness, low self-esteem, helplessness/ hopelessness, suicidal thoughts), physical (e.g. change in appetite or weight, disturbed sleep, lack of energy or lack of interest in sex) and social (e.g. lack of interest in social activities, avoiding contact with friends, having difficulties with family life) symptoms associated with depression.

According to the WHO (2012), depression affects 350 million people worldwide. Depression is common among patients with diabetes (Lustman, Anderson, Freedland, De Groot, & Carney, 2000). However, the relationship between diabetes and depression is not straightforward as both these major health issues have an adverse bi-directional interaction (Coleman, Katon, Lin, & Von Korff, 2013; Patel, 2014). The presence of diabetes doubles the odds of co-morbid depression (Egede, Zheng, & Simpson, 2002; Anderson, Freedland, Clouse, & Lustman, 2001). Researchers from various countries have rigorously investigated the prevalence of depression among patients with diabetes. For example, Ali, Stone, Peters, Davies and Khunti (2006) conducted a systematic literature review of ten controlled studies which included a total of 51,331 patients to estimate the prevalence of clinical depression in adults with Type 2 diabetes compared with those without Type 2

diabetes. This review found that the prevalence of depression among Type 2 diabetic patients to be 8.9% higher compared with those without diabetes.

Depressed diabetic patients have a higher risk of diabetes-related complications such as myocardial infarction (Scherrer et al., 2011) and retinopathy (Roy, Roy, & Affouf, 2007). De Groot, Anderson, Freedland, Clouse and Lustman (2001) used a meta-analytical approach to examine the strength and consistency of the relationship between depression and diabetes complications in studies of type 1 and type 2 adult patients. Twenty-seven studies were included within this meta-analysis. This study found a significant association between depression and a variety of diabetes-related complications such as diabetic retinopathy, nephropathy, neuropathy, macrovascular complications, and sexual dysfunction. Recent studies have also provided evidence that depression among diabetic patients increases the risk of mortality (Park, Katon, & Wolf, 2013; Coleman, Katon, Lin, & Von Korff, 2013).

### ***Diabetes & Life Expectancy***

Diabetes also significantly reduces patients' life expectancy (Narayan, Boyle, Thompson, Sorensen, & Williamson, 2003; Jonker et al., 2006). Using computerised generic formal disease model (DisMod II) software, Roglic et al., (2005) estimated that in the year 2000, 2.9 million deaths worldwide were caused by diabetes. In a separate study, Morrish et al., (2001) examined the mortality rates, excess mortality and causes of death in diabetic patients from ten diabetic centres across the world. They found that CVD was the most common underlying cause of death, accounting for 44 % of deaths in Type 1 (insulin-dependent) diabetics and 52 % of deaths in Type 2 (non-insulin-dependent) diabetics. Renal disease accounted for 21% of deaths in Type 1 diabetics and 11% in Type 2 diabetics.

Investigations of behavioural factors that serve as a protective factor of early mortality in diabetic patients have also been investigated. For example, Sadarangani, Hamer, Mindell, Coombs and Stamatakis, (2014) found that regular exercise behaviour was associated with a better prognosis in diabetic adults. In this pooled analysis of 10 population-based cohorts, researchers found that compared with those individuals who were inactive, participants who reported some activity, but

below the recommended amount, or who met the physical activity recommendations had approximately 26%-35% lower all-cause mortality.

## **1.3 Diabetes Self-Management**

Various interventions have been conducted to improve diabetes self-management. A meta-analysis conducted by Minet, Moller, Vach, Wagner, & Henriksen (2010) pooled together findings of 47 self-management interventions consisting of 7,677 participants and concluded that there were improvements in glycemic control in people who received self-care management treatment. Univariate meta-regression analysis revealed that interventions with educational approach produced better glycemic outcomes than interventions behavioural psychosocial approach. However, this difference was not significant.

### **1.3.1 Psychosocial Interventions**

Psychological interventions are very common in diabetes management. For example, Fall et al. (2013) conducted a randomized controlled trial to test the effects of brief psychological interventions based on diabetes threat and mastery perceptions in terms of adherence to diabetic regime, acceptance of diabetes and motivation to adhere to self-care activities. In this study, 80 participants were randomly assigned to one of four groups. Two intervention groups were asked to recall diabetic events based on mastery and threat perceptions, respectively, whereas those in the two control groups recalled non-diabetic events based on positive and negative emotions, respectively. Patients in the two experimental groups underwent either mastery or threat perception. Those in the mastery group were asked to recall a personal event during which they felt able to effectively control their diabetes (such as by adjusting insulin doses), whereas those in the threat group were asked to remember a personal event when they perceived diabetes as a threat (such as at the time of diagnosis). This form of intervention is expected to be beneficial regardless of the type of event recalled. The outcome of this research indicated that patients in the threat group reported less adherence, less avoidance, and perceived diabetes as less threatening than those in the mastery group. Similar results were obtained

when the threat group was compared with its matched negative-emotion control group. Patients in the mastery group reported feeling a stronger sense of mastery than those in their positive-emotion control group and greater treatment acceptance than those in the threat group. The researchers concluded that health professionals should take threat and mastery perceptions of diabetic patients into account during regular consultations with a view to improving treatment acceptance and adherence. This brief intervention also revealed that it was also more effective in alleviating emotional difficulties than enhancing perception of mastery.

In a separate study, Clark, Hampson, Avery and Simpson (2004) conducted a randomized controlled trial to investigate the impact of a brief, tailored lifestyle self-management intervention for patients with Type 2 diabetes. To facilitate tailoring various assessment tools were utilised to assess patients' stages of change in physical activity, stages of change for dietary fat reduction, barriers to healthy eating and physical activity, individual self-efficacy for performing physical activity and cutting down on the intake of high-fat food. The key features of the intervention were assessment, patient participation in goal setting, selecting personalized strategies to overcome barriers, and follow-up contacts. Patients were guided to develop dietary and one physical activity goal. Principles of motivational interviewing were used within this intervention. Conforming to the principles of motivational interviewing, following the principles of brief motivational interviewing, ambivalence about behaviour change was explored, personal goals and self-motivational statements were elicited and a personalized programme was formulated in which manageable goals for lifestyle change were negotiated, and specific individually tailored intervention strategies to increase self-efficacy and decrease barriers to change were developed. Patients in the intervention group also completed a self-efficacy scale to indicate how confident he or she was that he or she could achieve the eating and physical activity goals that had been set. Before patients left, they received booklets reinforcing the general essentials of healthy eating and the importance of increasing physical activity. These had been specially prepared for this intervention but were not tailored to an individual's specific goals. Maintenance issues were addressed by follow-up telephone calls made by the same interventionist who met with the patient at the assessment visit, at one week, three weeks and seven weeks post-assessment. These calls lasted for about 10 minutes and focused on the extent to which patients had achieved their goals since last contact. Patients were reinforced or assisted in problem-solving additional strategies as

appropriate. The outcome of this trial indicated that the intervention was successful in helping patients to reduce fat intake and, to a lesser extent, increase lifestyle physical activity levels.

In recent years, problem solving interventions have also been used to enhance diabetes self-management. Problem solving interventions originate from the principles of cognitive behaviour therapy, which aims to help patients gain necessary skills and ability to manage their illness. This could include generating a set of potential strategies for problem resolution, selecting the most appropriate strategy, applying the strategy, and evaluating the effectiveness of the strategy (Mulcahy et al., 2003 cited in Fitzpatrick, Schumann, & Hill-Briggs, 2013). Fitzpatrick et al. (2013) found that problem solving skills were delivered in numerous different ways. For example, some studies address problem solving as an educational topic, among several other topics of education (Wysocki et al., 2008; Glasgow et al., 2009). Others describe the use of problem-solving as a process that is support-group based or as a therapeutic modality, either in an informal manner or as a more structured approach within an intervention (Trief et al., 2011; Klug, Toobert, & Fogerty, 2008). Studies have also delivered structured patient problem-solving training largely as a standalone behavioural intervention (e.g. Hill-Briggs et. al., 2011). Regardless of the lack of homogenous problem solving intervention, the outcome of this intervention seems favourable in diabetes management.

Sabourin & Pursley (2013) presented an overview of psychosocial issues and approaches that healthcare providers (HCPs) from all disciplines could consider in supporting patients with the challenges of diabetes self-management. For example, they highlighted the importance of normalizing the challenges of diabetes management and necessity of readiness to change assessment before making specific plans and providing advice and recommendations for behaviour change. The paper also outlined the need for HCPs to address major psychosocial issues such as distressing emotions, including anxiety, depression, and distress specifically related to diabetes care, and fear of hypoglycaemia. These authors further emphasized that HCPs could use behaviour change strategies such as behavioural shaping, goal setting and emotional management, such as stress management strategies and emotional distress management strategies within their practice. This paper suggested that addressing these psychosocial factors efficiently would allow HCPs to better support patients in their efforts at diabetes self-management.

### **1.3.2 Diabetes Education**

Diabetes education has been effective in improving depressive symptoms in newly diagnosed diabetes patients. Chen et al. (2013) conducted a research on 1200 newly diagnosed male adult patients with type 2 diabetes before and after a two-week diabetes education program delivered by professionally trained nurses in China. In this study, patients completed two questionnaires to evaluate diabetes-related depression/distress. The Center for Epidemiologic Studies Depression Scale (Radloff et al., 1977) scale was used to assess depression and the Problem Areas in Diabetes (Welch, Jacobson, & Polonsky, 1997) survey was used to measure emotional distress. All patients were given a two-week diabetes intervention which consisted of diabetes education, an individualized diabetes care program and a group intervention which encouraged patients to communicate with each other to share their experiences of diabetes and management. At baseline, 28% of patients displayed depressive symptoms and diabetes-specific emotional distress was prevalent among 65.5%. After two weeks of diabetes education the incidence of depression and diabetes-specific emotional distress decreased significantly to 20.5% and 11% respectively.

Although diabetes education is extremely crucial, some patients chose not to participate in educational interventions (Altenhofen, Brenner, Hab, & Siering, 2004). To investigate the reasons for the lack of participation in educational interventions, Schäfer et al. (2014) conducted a qualitative analysis of 14 diabetic patients in Germany. Data was collected via semi-structured face-to-face interviews. Four barriers to participation were identified. The first theme was related to the influence of physicians. Some patients expressed that they assumed that the physician does not support diabetes education and their physician is satisfied with physical examination results thus, there is no need for diabetes education intervention as they believe their diabetes is under control. Patients also expressed that they were satisfied with diabetes treatment by his physician and did not see the need for extra diabetes-related educational interventions. The second theme was related to the state of health of the patients. Responses from the patients indicated that certain co-morbidities such as severe problems with their back or legs, cancer, stroke, chronic ischaemic heart disease, and chronic polyarthritis prevented some patients from participating in the educational programmes. Some patients believed that diabetes did not have negative consequences on their life, deeming educational interventions unnecessary. The third theme generated was avoidance and refusal. Patients expressed that participation in diabetes education was low in priority for them and that they had no intention to

make behavioural adjustments (i.e. change in diet) that would be encouraged in the educational programme. Finally patients' knowledge was also a barrier to participation. While some patients had a lack of knowledge about the essence of diabetes education, other patients expressed that they have sufficient knowledge and do not need to be educated on diabetes. The study concluded that physicians should encourage patients to participate in diabetes. Further to that, patients with functional limitations might profit more from continuous individualized education adapted to their specific situation instead of group education.

Studies in developing countries have demonstrated a lack of diabetes education and care. For example, Sheikh, Hakeem, Asar and Shaikh (2015) conducted a cross-sectional to explore the care received by participants of middle-income groups with diabetes in Karachi. Despite the high prevalence of diabetes in this nation, the level of care received by patients was suboptimal. Based on the data obtained from 105 Type 2 diabetics, the findings indicated that physicians were the main source of diabetic information for more than 70% of subjects. It was also reported that various screening tests, for example, six-monthly HbA1c screening, fasting lipids, urine albumin, eyes and foot examinations were not conducted on a regular basis and that this could be attributed to various factors such as lack of regularity in visiting a health care facility, lack of suggestion by physicians and lack of compliance by patients. The study demonstrated that access to diabetes education was restricted and dependent on getting an appointment and paying a fee for consultations. Only 38.7% of the participants had immediate access to a healthcare worker in case of an emergency. Similar results were found in a study conducted in Oman by Elliott, Abdulhadi, Al-Maniri, Al-Shafae and Wahlström (2013), suggesting that approximately 50% of the 309 patients were unable to recognise hyperglycaemia and 60% did not know how to respond to it. Self-monitoring of blood glucose was practiced by only 38% of patients. Many patients desired further health education. This study also found that patients with a longer duration of diabetes and patients with a higher education level had better knowledge of diabetes.

In recent years, adapting to the increasing trend of technology use, diabetes educators have also tried to implement diabetes education using technology. For example, Heinrich et al. (2012) utilised a web-based Diabetes Interactive Education Programme (DIEP) for patients with type 2 diabetes. The web based programme used in this study consisted of seven chapters which included background information about Type 2 Diabetes Mellitus,

hyperglycemia (consequences & treatment), diabetes and lifestyle, treatment and management of the disease, hypoglycemia, blood glucose monitoring and living with diabetes. The web-based education materials were mostly presented in spoken language, supported by headlines, images, video and real patient experiences. A RCT was conducted to investigate the effectiveness of a web-based intervention. The results indicated that within the experimental group post-test knowledge scores were significantly higher compared to the baseline. However, similar changes in knowledge were not observed in the control group. Further to that, users of the web-based educational intervention rated the programme favourably. The majority of patients were satisfied or very satisfied with the information provided in the website and described user-friendliness as good to very good.

In a separate study McMahon et al. (2006) conducted a RCT in the USA to investigate the effectiveness of Web-based Care Management in patients with poorly controlled diabetes mellitus. Prior randomisation, all patients received diabetic self-management education. Patients were randomised to receive treatment as usual or web-based care management. Patients receiving usual care continued with ongoing care by their primary care provider as needed. Patients who were placed in the treatment group received a notebook computer, a glucose meter and blood pressure monitor. Patients were encouraged to measure their blood pressure at least three times weekly. Recommendation for glucose testing varied according to patients' health status. A website was developed and this website accepted uploads from blood pressure and glucose monitoring devices and displayed these data in graphic and tabular form for the participant and a care manager to review. An internal messaging system allowed participants to send and receive secure messages to and from the care manager via the website.

The care manager responded to queries within one working day during office hours. In addition, a senior practice nurse and certified diabetes educator reviewed participant data from the website and, using treatment algorithms for glucose and hypertension management, provided recommendations to the primary care provider and participants. Outcome measurements were collected at baseline, 3, 6, 9 and 12 months after randomization. The results of this study indicated that there was a greater decline in HbA1c

over time in the web-based care management group. Changes in HbA1c over 12 indicated that participants in the web-based care management group had a significantly greater change in HbA1c over time. Hypertensive participants in the web-based care management group had a significantly greater decline in systolic blood pressure after 12 months.

Saffari, Ghanizadeh and Koenig (2014) conducted a systematic review and meta-analysis of health education interventions via mobile text messaging which provided assistance to adult type 2 diabetic patients with achieving glycemic control. A literature search of five electronic databases was conducted to access RCT studies carried out in the English language that used text-messaging educational interventions in patients with type 2 diabetes during an 11-year period (2003–2013). Overall, ten studies were identified that fulfilled the inclusion criteria. The pooled sample size was 960 participants. The studies included in this review originated from Taiwan, Korea, USA, India, Bahrain and Iran. Interventions were conducted in hospitals, community health centre, diabetic centre and diabetic association. The review revealed a reduction in HbA1c of approximately 50% post intervention in participants in the experimental groups compared with controls. Meta-analysis findings indicated that the effect size for glycemic control in studies that used text-messaging was 44%. For studies that used both text-messaging and Internet, the effect size was 86%. Further to that, the effect size found in younger patients indicates a higher reduction in HbA1c than in patients over 55 years old.

In a separate review, Krishna and Boren (2009) systematically reviewed 18 studies with a pooled sample of 1176 participants to establish the efficacy of diabetes self-management care via mobile phone. Among the studies included in this review, 6 studies involved children with diabetes, and 12 studies were conducted with adults with diabetes. Sample sizes ranged from 7 to 274 participants for adult studies and 11 to 92 participants for studies involving children. Three studies enrolled more than 130 participants. Management care via mobile phone was utilized to facilitate regular treatment advice and to provide support in between clinic visits or to deliver regular alerts and reminders to achieve desired goals. The review findings indicated that nine out of ten studies that used mobile phone technology showed significant decreases in HbA1c values. Further to that, educational

interventions providing personalized advice and support delivered through a mobile phone can help avoid diabetes symptoms by providing timely treatment adjustments and can lead to improved health outcomes. In a separate review, Pal (2013) also found HbA1c improvements in patients who participated in a web-based intervention programme. In addition, the review which included 16 RCTs with a total of 3,578 participants found that four studies showed beneficial effects on lipid profile. The impact of the intervention on improving depression, health-related quality of life and weight of diabetes patients was also investigated within the review. Web-based interventions did not significantly improve depression, health-related quality of life and weight of diabetes patients. A systematic review by Ramadas, Quek, Chan and Oldenburg (2011) found that goal-setting, personalised coaching, interactive feedback and online peer support groups were successful approaches utilised within web-based interventions to manage type 2 diabetes mellitus. In addition, e-interventions underpinned by theoretical frameworks such as social support Theory, Health Belief Model, Transtheoretical Model and Social Cognitive Theory found to produce positive results. In addition, the use of other technologies such as e-mail or short messaging service was found to be an excellent method of reinforcing web-based interventions. Finally, longer duration of intervention were also proven to be successful.

Studies have also investigated the utility of web-based platform to promote physical activity among diabetic patients. For example, McKay, King, Eakin, Seeley and Glasgow (2001) conducted a RCT to investigate the effectiveness of Diabetes Network Internet-Based Physical Activity Intervention. Participants in the intervention group received an 8-week personalized physical activity program tailored to their individual needs. The physical activity levels of participants were assessed on-line and specific feedback was provided on their baseline activity level in relation to national guidelines for regular moderate-level physical activity. In addition, participants in the intervention group had access to a private personal database, from which they could enter and track their total minutes of physical activity per day as well as generate graphs of their progress. The intervention group also received online personal coach counseling and were able to communicate with other members in the intervention group through the web. Participants in the control group only received internet based information. This trial was conducted with

a small sample of participants (78 participants). The outcome of this trial found no significant between-condition differences in outcomes. However, the intervention appeared effective in increasing activity levels among those patients who used the service with sufficient regularity. In a separate study Kim, Hwang and Yoo (2006) conducted a RCT consisting of seventy-three adults with type 2 diabetes. Patients were randomly assigned to a web-based intervention, a printed-material intervention, or to usual care which aimed to increase physical activity levels. After 12 weeks, both the web-based and printed material interventions, compared with usual care, were effective in increasing physical activity and in decreasing fasting blood sugar and glycosylated haemoglobin. Analysis for change scores indicated significant differences between web-based intervention and usual care and between printed material intervention and usual care, but not between web-based and printed materials interventions.

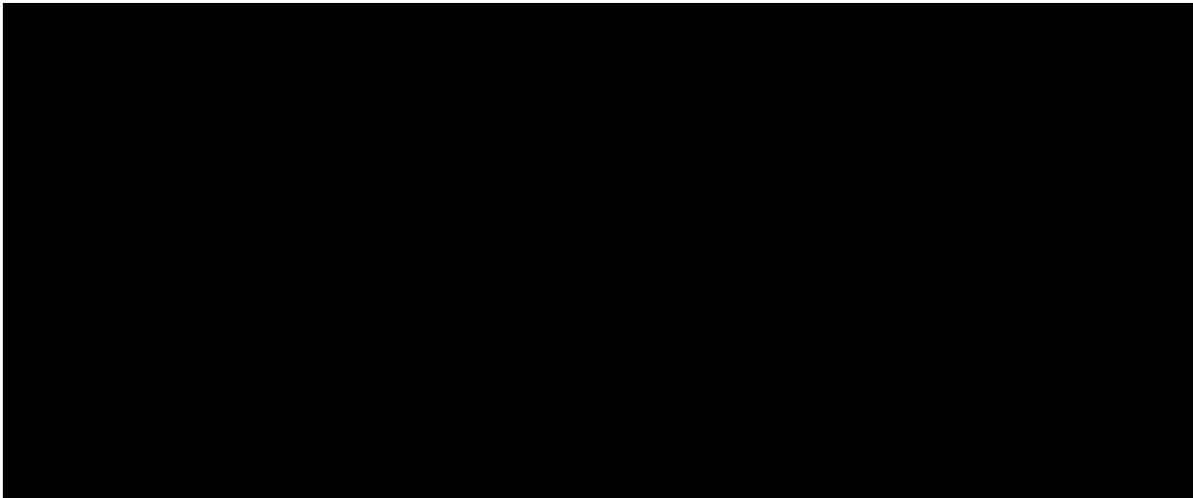
Using qualitative research methodology, Ralston, Revere, Robins and Goldberg (2004) found that diabetic patients utilising a web-based diabetes support programme based on an interactive electronic medical record expressed that the web-based platform provided a unique environment where participants' concerns were actively valued. Patients expressed the web-based support provided environment where patients' concerns about their chronic medical conditions were uniquely valued. Participants expressed how much they appreciated an environment where their needs for managing their ongoing medical conditions were valued.

Patients also expressed that they experienced an enhanced sense of security about their health and health care. Patients expressed that the 'virtual presence' of the healthcare provider enabled them to feel secure that there were being monitored and actively taking measures to maintain their disease. Patients also felt that they were confident that the healthcare provider should immediately provide additional guidance and assistance if the patients monitoring outcome was not satisfactory. Having access to the electronic medical record, and particularly the results of medical testing were also important to patients. However, this study also highlighted that some patients were profoundly disappointed when their expectations of the technology and communications of the programme were not met. For example some patients had problem with technology and were not able to

participate fully. Patients also expressed disappointment when occasionally they did not get to establish the desired contact with the healthcare provider when needed. This study highlighted the importance of understanding patients' expectations prior to the implementation of web-based interaction interventions for diabetic patients.

#### **1.4 Diabetes the Malaysian Pandemic**

Malaysia is a country located in South East Asia and has a population of 30 million people (World Bank, 2014). This ethnically diverse country is populated by four main ethnic groups, namely Malays, Chinese, Indians and Aborigines. According to Jaafar, Suhaili, Noh, Ehsan and Siong (2007) significant strides had been made in the field of health care. This is demonstrated by the life expectancy in Malaysia which rose from 55.8 years in 1957 to 72 in 2012 for males (WHO, 2013). A decrease in infant mortality has also been observed, infant mortality rate (IMR) has declined from 16 per 1,000 live births in 1990 to 6 in 2009 (UNICEF Malaysia, 2011). Jaafar and colleagues also postulated that Malaysia has also made progress in the education sector, as the percentage of tertiary education has increased from a mere 3% in 1980 to 29% in 2005. Progress is being made to achieve a target of a 40% tertiary educated population by the year 2020. According to WHO-Malaysia Country Cooperation Strategy (2009 – 2013), both communicable and non-communicable diseases remain a burden to Malaysia.



**Figure 1: Malaysian Map**

According to the WHO (2014), in comparison to nine other regional countries (e.g. Vietnam, Cambodia, Laos, Singapore), Malaysia had the highest cases of obesity and raised blood sugar level. A prevalence calculation conducted by WHO (2008), indicated that 44.2% of Malaysians were overweight, with an obesity rate of 14.0%. Females have a higher rate of overweight and obesity. In addition, almost 64.8% of Malaysians are physically inactive (National Health and morbidity Survey, 2011).

Malaysia employs a two-tier health care system. A government funded healthcare system which is accessed by Malaysians and provides subsidised payment options and a privately funded system which is accessed mainly by the higher income group. Private General practitioner (GP) clinics are also very prevalent. These pay per service clinics are accessed by many in Malaysia as it is convenient, and the waiting time for treatment is much shorter than the government clinics. Patients have the autonomy to choose where they seek treatment, but there use is largely dependent upon economic status. The government funded system is accessed by 65% of the population. However, there are more private hospitals than government hospitals (Quek, 2009). According to the 10th Malaysia Plan 2011-2015, which is published by The Economic Planning Unit of Prime Minister's Department, the growing private sector poses various health care delivery concerns. This is mainly due to distribution of resources and workload. For example, Chee (2008) explained that the private sector constitutes employs around 55% of all registered doctors, but the services only cater for approximately 25% of the population.

The government funded system has to cater for a larger proportion of the population who are mainly from lower socio-economic groups. Hence there is a greater workload in terms of complexity and number of patients, particularly in-patients. A further problem with having dual systems of health care is the expertise of practitioners. Experienced specialists working in Malaysia are more often opting for the more lucrative private sector, resulting in shortages in the public sector. Furthermore, almost 40% of doctors are employed by the private sector. This contributes to the inequity of the doctor-population ratio. Although health care services are easily accessible in Malaysia, due to the number of the population that seek treatment from the government funded hospitals, long queues for outpatient services, diagnostic procedures such as CT-Scan examinations, treatment modalities such as endoscopic surgery and rationing of drugs to treat long-term conditions contributes towards inequity within the healthcare system in Malaysia.

The WHO Malaysia Cooperation Strategy (2013) highlighted some of the major challenges faced in Malaysia, such as the inadequate integration of public and private health service in surveillance and response to communicable diseases and inadequate human resources for health because of changing demographics and the emigration of skilled workers.

#### **1. 4.1 Diabetes Prevalence in Malaysia**

As aforementioned, rates of obesity and physical inactivity are increasing in Malaysia. It is therefore unsurprising that an estimate by the WHO (2011) revealed that 0.94 million Malaysians were affected by diabetes in 2000. This prevalence is predicted to increase by 164% by 2030. This estimate equates to 2.48 million Malaysians being affected by diabetes by 2030. The diabetes prevalence rate in Malaysia has risen much faster than expected. According to Letchuman et al. (2010) the prevalence of diabetes in Malaysia is above average when compared to the estimation by the International Diabetes Federation (IDF) for all regions in the world and has already reached the projected prevalence for the year 2030. The Malaysian National Health and Morbidity survey (2006) revealed that 3.4 million Malaysians were living with diabetes. The latest Malaysian National Health and Morbidity survey (2011) indicated that the prevalence of diabetes is 15.2% for population above the age of 18 years old. Approximately 2.6 million people are currently diagnosed

with diabetes. The prevalence of undiagnosed diabetes is 8.0%. The prevalence of diabetes is higher among the Indian population, followed by Malays and the Chinese.

There are many factors that contribute to the rise of diabetes prevalence in Malaysia, namely genetics and behavioural factors. Diabetes is strongly influenced by genetics. Many people of Asian descent have a first-degree relative with diabetes (Viswanathan, McCarthy, Snehalatha, Hitman, & Ramachandran, 1996; Ng et al., 2001 cited in Ramachandran, Ma, & Snehalatha., 2010). The high prevalence of diabetes among Indians could be attributed to an inherited risk among this ethnic group. Various studies have demonstrated that Indians have a higher prevalence of impaired glucose intolerance which is a high risk for diabetes (Ramachandran et al., 2010). These findings conform to the findings of Rampal et al. (2012) who found that impaired fasting glucose prevalence was higher in Indian compared to Chinese and Malays. The prevalence of impaired fasting glucose was higher among Indians (35.6%) compared to Malays (26.4%) and Chinese (26.2%). However, the National Morbidity Survey III (2006) revealed a different trend, and found that the national prevalence of impaired glucose was 4.2%. However, the prevalence was higher in the Chinese population. Prevalence was 5.1% among Chinese, 5.2% among Indians and 4.0% among Malays.

As previously stated, many Malaysians adopt a sedentary lifestyle and do not regularly exercise. Physical activity is crucial in the prevention of diabetes (Hsia et al., 2005; Weinstein et al., 2004). The Malaysian Adult Nutrition Survey conducted between 2002 and 2003 found that only 14% of Malaysians regularly exercised (Poh et al., 2010). However, recent evidence suggests that the physical activity levels of Malaysians are on the increase (Cheah & Poh, 2014). By extracting data from the Third National Health and Morbidity Survey, Cheah & Poh (2014) found that 56% of Malaysians were physically active. Following the guideline of Ministry of Health (MOH) Malaysia, the respondents who spent at least 150 minutes/week in moderate or 60 minutes/week in vigorous physical activities (including work, travel, and leisure) were considered as physically active, otherwise they were considered as physically inactive. The findings of this study indicated that there are various factors that influence physical activity among Malaysians. Social

demographic evaluation revealed that high-income earners, females, and the well-educated were less physically active. Physical inactivity was also prevalent among widowed/divorced and unemployed individuals. In addition, Cheah & Poh also found that having a family history of chronic diseases is a determinant of exercising behaviour among Malaysians. Ibrahim, Aljunid and Ismail (2013) found that there are various barriers that contribute towards lack of physical activity among Malaysians, for example, personal barriers (e.g. lack of discipline), social environment barriers (e.g. lack of friends who are physically active and lack of time) and physical environmental barriers (e.g. very hot or rainy weather). Other studies have found that certain ethnic group are more physically active than others (Cheah, 2011). Specifically, the Chinese are more physically active than other ethnicities, for example, Indians who are amongst the least active.

The trend of obesity in Malaysia is increasing steadily. Obesity is classified as having a body mass index  $\geq 30 \text{ kg/m}^2$ . Within a period of 10 years, between 1996-2006 rates of obesity have increased from 4.4% to 14% (The Third National Health and Morbidity Survey, 2006). Khambalia & Seen (2010) conducted a systematic review of 44 studies conducted in Malaysia to investigate the trends in overweight and obese adults in Malaysia. The findings indicate that the prevalence of overweight and obesity is highest among Indians. The highest prevalence is also observed amongst participants aged 40-59 years old and females. Education level also influences the occurrence of overweight and obesity. Less educated individuals have higher rates of overweight and obesity (Tan, Juliana, & Sakinah, 2011). Some dietary patterns within Malaysians could shed light on the connection of food consumption and diabetes. For example, the findings of the Malaysian Adult Nutrition Survey (MANS), 2008 stated that cooked white rice was consumed by 97% of the population twice daily (average 2½ plates per day). Consuming white rice on a regular basis is extremely detrimental to health and contributes to increased risk of Type 2 diabetes. A meta-analysis and systematic review conducted by Hu, Pan, Malik and Sun (2012) found that among Asians a high consumption of white rice is associated with a significantly increased risk of type 2 diabetes. Another major deleterious dietary pattern occurring in Malaysia is the continued escalation of the availability of sugar and sweeteners. In 2006 the Malaysia Diabetes Association indicated that an average Malaysian

consumes 26 teaspoons of sugar per day in the form of food and drinks. In 2009, the Malaysian Trade and Consumer Affairs reported that Malaysia is the 8th largest sugar consuming nation in the world.

Unfortunately, trends of obesity and overweight among children in Malaysia is also rising. Secondary data analysis conducted by the National Health Morbidity Survey III (2006), found that one out of five of 7-12 year-old children in Malaysia were overweight (Naidu et al., 2013). Surprisingly, demographic analysis revealed that the prevalence of overweight was higher among the Chinese population. Overweight and obesity prevalence among Indian children are the lowest compared to the Malay and the Chinese (Moy, Gan, & Zaleha, 2004; Ghazali et al., 2006). The trend of overweight and obesity among children could be attributed to inadequate knowledge among parents on the food pyramid (a food pyramid guideline on the correct amount of nutrients – protein, fat, carbohydrates, vitamins and minerals needed to maintain good health) and preparation of low-fat meals (Muhammad & Awaisu, 2008).

A factor that may be contributing to the rise in obesity and overweight could be the increasing trend of Malaysians consuming food outside of the home. Heng & Guan (2007) found that Malaysians who regularly consumed food outside the home were male, of Chinese ethnic origin, affluent, aged between 36-56 years old and were more educated. Although the general trend of food consumption outside of the home does not coincide with the pattern of obesity in terms of ethnicity and gender, it does correspond with the age group with the highest rate of overweight and obesity. Food consumption away from home contributes to consumption of poor food quality and obesity (Ebbeling et al., 2004; Bowman and Vinyard, 2004).

#### **1.4.2 Problems with diabetes care in Malaysia**

CVD is the biggest cause of death in Malaysia (MOH, 2010). There are various forms of CVD, such as deep vein thrombosis (DVT), blood clots in the legs, peripheral arterial disease, a condition where the supply of blood to your legs is blocked which causing muscle pain, heart disease, stroke, and heart attacks. In 2010, 32% of mortality in Malaysia

was caused by CVD. The National Cardiovascular Disease Database (2009) indicated that in 2008, of 6,516 patients with CVD 43% had diabetes. In 2009, among 10,846 patients with CVD, 40% had diabetes.

A short-term study (8 months) conducted by Hamidon & Raymond (2003) at the Hospital Universiti Kebangsaan Malaysia (HUKM), found that the commonest risk factor for stroke was hypertension (76.1% of patients), followed by diabetes mellitus (55.2%). A longitudinal study in the same hospital found that diabetes may be the most important risk factor that could lead to stroke attacks in Malaysia. Over a four-year period (between 2010-2013), a staggering 60% of patients admitted at The National University of Malaysia Medical Centre (UKMMC) had diabetes. Shockingly, one in six patients were only identified as diabetic after experiencing a stroke. Studies have also indicated that diabetes increases the risk of stroke complications and mortality (Hamidon & Raymond, 2003).

As previously stated, diabetic patients are prone to various illnesses. Researchers in Malaysia have found that diabetic patients have a high prevalence of peripheral neuropathy. Azidah, Hasniza and Zunaina (2014) conducted a cross-sectional study among 288 elderly diabetes type 2 patients, and found that more than half the study population had peripheral neuropathy. This prevalence rate supports the findings of Mimi, Teng and Chia (2003) who found the prevalence of diabetic peripheral neuropathy was to be 50.7%. The presence of peripheral neuropathy increased the prevalence of falls among elderly patients. Further to this, it also contributes to diabetic foot ulcers and amputation.

The co-existence of high-blood pressure and diabetes contributes to the renal disease manifestation. Between a period of 8 years (between 2001-2009), the prevalence of End Stage Renal Disease (ESRD) has increased from 88 to 325 per million population. The 20th Report of the Malaysian Dialysis and Transplant Registry 2012 reported that in 2012, there were 5121 new dialysis patients. In Malaysia, 50% of ESRD is caused by diabetes. ESRD was more prevalent among diabetic patients with lower education and higher BMI scores (Sørensen et al., 2007).

The largest cohort study, conducted in Malaysia consisting of 70,889-adult Type 2 diabetes patients revealed that diabetes and its co-morbidities (hypertension and hyperlipidaemia) were poorly controlled (Mastura, Chew, Lee, Cheong, & Ghazali, 2011). The study findings highlighted that only 30.9% of the sample population had the desired HbA1c < 7.0%. In addition, blood pressure measurements indicated that 61.8% of participants had elevated values. The prevalence of obesity was also significantly high in this population; 81.9% of participants exceeded the Asian cut-off for obesity (BMI >23kg/m<sup>2</sup>). Other studies conducted on diabetes managements in Malaysian have consistently shown poor management and high prevalence of diabetes-related complications (Mafauzy, 2005; Mafauzy, 2006).

Mafauzy (2005) found that diabetes-related complications were high among diabetic patients. The commonest form of complication was neuropathy and retinopathy. The findings of this research indicate that only a small sample (37.4%) of participants adhered to the diabetes diet regime. Further to these, self-monitoring practices were less prevalent. A number of audits have been conducted in various states in Malaysia to investigate patients' adherence to diabetic care (Lee et al., 2004; Chan, Tan, & Tee, 1997). Audits conducted by Chan and colleagues (1997) revealed that diabetic patients received less than adequate care. Overall control and monitoring of diabetes was also found to be inadequate among patients. Between December 2001 and March 2003, Lee et al. (2004) conducted two audits of diabetic management in seven GP clinics. Eleven-assessment criteria were established to explore the structure of care indicators (e.g., diabetic register and reminder mechanism), the process of care indicators (e.g. weight and blood pressure measurement, foot examination) and outcome of care indicator which was fasting blood sugar. Participating GP surgeries implemented these criteria in October 2001. The first audit was conducted in December 2001 to determine the implementation of the outlined care criteria. The results of the audit indicated inadequacies in nine out of the eleven criteria assessed across the 7 GP clinics. Steps were taken to rectify these issues by reiterating the implementation of a diabetes register, and creating a checklist for doctors on measures that should be obtained from patients. Patients in the first audit were also educated on the importance of regular checks such as HbA1c. The second audit showed improvements in all

the criteria used. Consistent with the level of care given, patients' blood sugar control improved significantly. In addition, issues regarding the gap between knowledge and performance among doctors who participated in this audit were addressed. Most doctors were aware of diabetes mellitus guidelines and remedial measures. However, the application of this knowledge was sparse. Measures that should be taken to rectify these issues include educating patients and providing health care professionals with assistance and motivation to adhere to the guidelines and remedial measures outlined. This audit clearly indicates that a good level of care could help patients manage their diabetes efficiently. Other studies conducted in Malaysia have found consistent findings (e.g. Wong & Rahimah, 2004).

Rampal et al. (2009) conducted a population-based nationwide study to investigate the variation in the prevalence, awareness, and control of diabetes in a multi-ethnic population. Of the 3039 participants in this study, 15.2% had diabetes. However, only 42.7% were under treatment and only 25.1% had their fasting blood sugar under control. DiabCare Malaysia is a research study that is conducted periodically to assess diabetes-related complication and care. DiabCare was done in 1997, 1998, 2001, 2003 and 2008 (Mafauzy, 2011). Data for DiabCare was gathered from nineteen government hospitals from around the country. Data was generated through a review of medical records, clinical examination, laboratory assessments and interviews with patients. The findings obtained from the study in 2008 was published in 2011. Among the 1670 patients who participated in this cross-sectional study, only 22% of participants had the desired blood sugar level of less than 7. Maintaining a blood glucose level below 7 is crucial for diabetes management. DiabCare (2008) revealed that patients had various diabetes-related complications. Diabetes eye complications were prevalent in 67.9 % of participants, in addition to a high prevalence of nephropathy (97.3%), neuropathy (63.7%) and cardiovascular risk (99.5%). **Table 1** depicts the list of complications experienced by patients and their years of diagnosis.

Diabetic Complications	Duration of Diabetes			
	≤1 year	>1-5years	>5-10 years	>10years

Cataract (N=1015)	6 (0.6)	38 (3.6)	65 (6.2)	171 (16.3)
Non-proliferative diabetic retinopathy (N=1015)	6 (0.6)	38 (3.6)	53 (5.0)	139 (13.2)
Photocoagulation (N=1015)	2 (0.2)	14(1.3)	23 (2.2)	119 (11.3)
Microalbuminuria (N=433)	3 (0.7)	28(6.5)	28 (6.5)	44 (10.2)
Leg Amputation (N=741)	0 (0)	4 (0.5)	3 (0.4)	21 (2.8)
Absent foot pulses (N=741)	0 (0)	5 (0.7)	12 (1.6)	20 (2.7)
Neuropathy symptoms (N=986)	10 (1.0)	82 (8.3)	120 (12.2)	238 (24.1)
Myocardial infarction (N=1541)	2 (0.1)	43 (2.8)	54 (3.5)	84 (5.5)
Cerebral Stroke (N=1541)	1(0.06)	23 (1.5)	28(1.8)	53(3.4)
Angioplasty (N=1541)	1 (0.06)	36 (2.3)	50 (3.2)	109 (7.1)
N=number of patients for each complications in parentheses indicate % out of N				

**Table 1: Prevalence of Diabetic Complications (Data obtained from DiabCare, 2008)**

Based on **Table 1** it is clear that the prevalence of complications positively correlates with the number of diagnoses years. This research also found that many patients did not conform to diabetes lifestyle modification measures such as eating a diabetic diet and regularly exercising. Studies in Malaysia have consistently shown that only a small number of patients adhere to this recommendation. For example, Wong & Rahimah (2004) found that only 28% of patients conformed to the recommended level. Mafauzy (2006) found that 41% of patients had the desired blood sugar levels in government hospitals. The same investigation conducted across 19 GP clinics only found that 21% of patients were compliant (Mafauzy, 2006).

Other complications experienced by Malaysian diabetic population include depression and, erectile dysfunction. For example, Ganasegeran, Renganathan, Manaf and Al-Dubai (2014) investigated the prevalence of depression among diabetic patients in Malaysia. This was the first documented evidence on the prevalence of diabetes-related depression in this country. This study adapted a cross-sectional design. One hundred and sixty-nine patients with Type 2 diabetes were administered demographic questionnaire and Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Patients' clinical health information was

obtained from medical records. The outcome of this study indicated that anxiety and depression was present in 53 (31.4%) and 68 (40.3%) of patients. Factors that contributed towards depression among patients were the presence of diabetes-related co-morbidity (e.g. hypertension or dyslipidemia), ethnicity, education level, age and household income. Indian patients were more susceptible to depression. Higher rates of depression were also observed among patients who were more educated, older and who had an income of more than RM 3000. This study had a small sample group and was only conducted in one hospital. Hence the generalisability of the findings are questionable. However, depression among diabetic patients in Malaysia could be a factor that impedes optimal care. Other studies have found that financial barriers, forgetfulness, self-medication, and the quality of relationships with doctor and family members seem to be the factors that challenge adherence among diabetic patients (Al-Qazaz et al., 2011).

To investigate the barriers to optimal control of Type 2 Diabetes among Malaysian Malay patients, Ali (2009) adopted qualitative methodology and conducted in-depth interviews with 18 Malay diabetic patients and 13 HCPs. The study provided rich information on the barriers faced by patients in managing their condition. The study identified several barriers such as the knowledge factor (e.g. low diabetes management knowledge), external physical factors (e.g. poor physical health, personal finance issues), psychological factors (e.g. poor motivation and, low self-efficacy) and psychosocial factors (e.g. lack of family support, lack of community support). In a separate study, Ong, Chua and Ng (2014) used qualitative methodology to investigate barriers and facilitators to self-monitoring of blood glucose in people with type 2 diabetes using insulin. One-to-one interviews with 15 patients revealed that patients faced many barriers to self-monitoring of blood glucose levels. Barriers faced include frustration related to high-blood glucose reading, perception that self-monitoring of blood glucose was only for insulin titration, stigma, fear of needles and pain, the cost of test strips and needles, inconvenience, unconducive workplace, lack of motivation, knowledge, and self-efficacy. Factors that contributed to self-monitoring of blood glucose were experiencing hypoglycemic symptoms, desire to see the effects of dietary changes, and desire to please the physician and family motivation. The findings suggest that participants did not monitor their glucose level on a regular basis. Participants

engaged in self-monitoring behaviour only as compensation after poor diet adherence. Patients also got more involved in self-monitoring behaviour when experiencing symptoms that indicated heighten glucose levels, such as tiredness, giddiness, uneasiness, and body ache. Further to these, cost factors associated with self-monitoring were also commonly mentioned by all patients. It was felt that regular self-monitoring would be costly. To date Malaysia does not provide subsidisation for test strips and needles.

Various studies have shown poor medication adherence among diabetic Malaysian patients. For example, Ahmad, Ramli, Islahudin and Paraidathathu (2013) found that factors associated with poor adherence were age, medication knowledge and co-morbidities. Poor medication adherence was also attributed to the prevalence of complementary and alternative medicine use among Malaysian diabetic. Ching, Zakaria, Paimin and Jalalian (2013) conducted a cross-sectional study to study the prevalence of complementary/alternative medicine use among patients with type 2 diabetes mellitus in the primary care setting in Malaysia. The findings of this study indicated that 62.5% of participants actively used complementary and alternative medicine as a form of self-medication for diabetes. Complementary and alternative medicine used included herbs such as bitter melon, Orthosiphon Stamineus (Java Tea), Garlic, Basil Leaf, Ginseng and Clinacanthus Nutans Lindau. Complementary/alternative medicine use was more prevalent among Malays and females. Patients with lower educational status used Complementary/alternative medicine more than patients who had tertiary education. Other studies have found that complementary/alternative medicine was more prevalent among higher income groups (Aziz & Tey, 2009). Patients using complementary/alternative medicine perceived this practice to be beneficial in controlling diabetes and better value for money. This research did not investigate whether patients using complementary/alternative medicine were also adhering to western medicine. However, it could be speculated that the high usage of complementary and alternative medicine could be one of the major factors that contributes towards non-adherence to western medicines.

Another factor that could be preventing diabetic patients from fully adhering to their medication could be the lack of diabetes-related knowledge. Tan and Magarey (2008)

found that almost half of their study population had poor knowledge of their illness and rarely monitored their blood glucose. Older patients and those who were less educated portrayed poor knowledge of diabetes. Further to that, studies have also found that patients have poor knowledge of desired fasting blood glucose levels (Juwita, Suraya, & Azwany, 2012). However, not all studies have found consistent findings, Najib et al. (2013) conducted a cross-sectional survey in the Malaysian East Coast state of Kelantan and found high diabetes-related knowledge among survey respondents. However, this finding should be interpreted with caution as over half (55%) of survey participants had received a tertiary education (55%).

#### **1. 4.3 The economic burden of diabetes in Malaysia**

According to the Malaysian Burden of Disease and Injury Study (2013), the total years of life lost (YLL) for the Malaysian population in 2008 was 1.51million. Sixty-eight percent (68%) of the burden of premature death was caused by non-communicable diseases and diabetes mellitus was one of the top ten causes of years of life lost (YLL).The rising prevalence of diabetes has a huge economic impact. According to Ahmad (2013), establishing a cost of diabetes burden is not a straightforward endeavour. Various factors such as the direct cost (e.g. diabetes treatment and treatment of complication), indirect cost (loss of work days, loss of expected lifetime earning) have to be taken into account. A number of costing evaluations have been conducted in Malaysian localities. For example, a cost analysis conducted by Ibrahim, Aljunid and Ismail (2010) in a teaching hospital in a northern state in Malaysia, found that average annual outpatient treatment cost was RM1861.35 per patient with the minimum cost of RM654 per patient with a maximum cost of RM5579.13 per patient. The cost was attributed to medication cost, cost of laboratory tests, the cost of annual visits to the clinic and cost of medical personnel. Rohana (2007) conducted a similar cost evaluation in the northeast state of Kelantan. Data obtained from 300 diabetic patients was analysed to ascertain the cost of diabetes care. This analysis found that the expense for one patient in the hospital with a medical specialist is approximately RM1127.91. The expense for one patient in hospital without a medical specialist is approximately RM 802.15.

In Malaysia, approximately fifty percent (50%) of end stage renal disease is caused by diabetes (Lim et al., 2008). Hooi et al. (2005) estimated a mean cost of RM169 per dialysis session. Each End stage renal patient requires approximately 156 dialysis sessions per year. Hence, dialysis treatment for each patient would be approximately RM26871 per year. In 2012, the diabetic nephropathy cost was estimated to be approximately RM68,789,760 solely for dialysis treatment. This estimate did not factor in the cost of medication for dialysis patients.

Cost analysis studies have investigated the healthcare provider cost for diabetic foot treatment. Amin et al. (2009) examined treatment data of 54 patients and concluded that the average cost for daily diabetic foot treatment per patient was RM634.57. In a separate study, Ramdhan (2014) reported that the cost of treating diabetic foot infection in a tertiary hospital in Malaysia for 182 patients was USD 11,000. This cost did not take into account all indirect costs associated with diabetic foot infection, such as follow-up care as an outpatient, rehabilitation and indirect costs (emotional suffering, reduced productivity), which are estimated to be high.

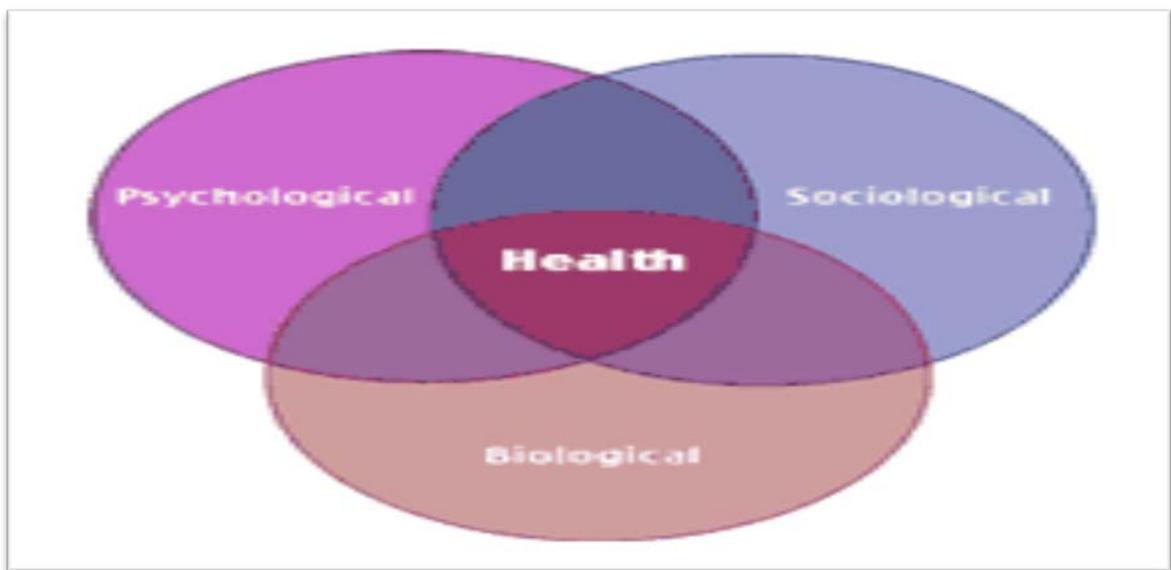
Li, Zhang, Barker, Chowdhury and Zhang (2010) estimated the global healthcare expenditure on diabetes for 2010 and 2030 for 193 countries. The estimate was derived based on the country's age–sex specific diabetes prevalence and population estimates, per capita health expenditures, and health expenditure ratios per person with and without diabetes. Data on population estimates and health was obtained from WHO. In addition, the health expenditure ratios were estimated based on utilization and cost data of a large health plan in the U.S. Diabetes expenditure for the year 2030 was projected by considering future changes in demographics and urbanization. Based on this analysis, it was estimated that in 2010 Malaysia would spend between 600,407,000 USD to 1,005,095,000 USD. It was further estimated that this cost could increase to between 1,073,139,000USD and 1,828,693,000USD by 2030.

## **1.5 Application of theories and models to diabetes management**

Diabetes is a long term condition that requires self-care and health behaviour modification (e.g. dietary changes, increased physical activity). Failure to manage diabetes well puts the individual at high risk of developing diabetes-related complications. Over the years, researchers have applied and tested the utility of behaviour theories and models to gain insight into factors that affects diabetes-related health behaviour.

### **1.5.1 Biopsychosocial model of health (Engel, 1977)**

This perspective holds to the idea that biological, psychological, and sociological processes are integrally and interactively involved in physical health and illness (Suls & Rothman, 2004). This model was proposed by Engel (1978) who claimed that all three levels of this model (biological, psychological, and social) must be taken into account in every health care task. The biopsychosocial model of health is depicted in **Figure 2** below:



**Figure 2:Biopsychosocial Model of Health (Engel, 1977)**

Numerous researchers have applied the biopsychosocial model to explore diabetes-related health behaviour (e.g. Schwartz, Coulson, Toovy, Lyons, & Flaherty, 1991; Peyrot & Peyrot & Rubin, 1999). Peyrot & Rubin (1999) conducted a study with a total of 118 subjects (57 participants with Type 1 diabetes and, 61 participants with Type 2 diabetes) to examine the psychosocial factors that facilitates and deters diabetes management. The dependent variable in this study was the blood glucose level of participants. To obtain data

on psychosocial factors, a questionnaire containing several measures of psychosocial variables and background factors was administered. The researchers found that stable psychosocial resources (i.e., education, being married, and positive coping styles) were associated with better glycemic control, while psychosocial factors such as stress were associated with poor glycemic control.

Various psychosocial factors have been shown to contribute towards optimal self-care practices among diabetic patients. Studies have demonstrated that psychological factors such as self-efficacy (Nakahara et al., 2006) and sociological factors such as good social support (Akimoto et al., 2004) contribute to optimal care. In contrast, biological factors such as depressive state (Lerman et al., 2004) impedes diabetes self-management.

### **1.5.2 Health Belief Model**

The Health Belief Model (Becker, 1974) postulates that a behaviour can best be understood if beliefs about health are clear. The model predicts that individuals will act to protect or promote their health if they believe that:

- they are susceptible to a condition or problem
- the consequences of the condition are severe
- the recommended actions to deal with the problem are beneficial
- the benefits of taking action outweigh the costs or barriers

The Health Belief model has been used within diabetes research since 1980s. For example Alogna (1980) used this model to investigate the impact of health belief and compliance to weight reduction and blood glucose control among non-insulin diabetics. Only one aspect of the Health belief model, namely perceived severity of illness, was examined to assess its impact on compliant behaviour. The study findings indicated that patients who perceived diabetes to be a severe condition were more compliant to weight reduction and blood glucose control compared to patients who viewed diabetes as a less severe condition. Cerkoney & Hart (1980) investigated all the aspects of the health belief model, but found only perceived severity yielded significant to a diabetic regime compliance.

Researchers internationally have applied health belief model to investigate diabetes management (Bond, Aiken, & Somerville, 1992; Ratanasuwan, Indharapakdi, Promrerak, Komolviphat, & Thanamai, 2005). For example, Baghianimoghadam and colleagues (2011) examined the utility of the Health Belief Model (HBM) in understanding and predicting the intention of diabetic patients in the prevention of their foot lesions and amputation. These researchers found that patients in this study had low perceived susceptibility of risk in lesions and amputations. The outcome of this study also revealed that those with primary school education had better foot care, cues to action and perceived susceptibility compared with guidance school, high school and university graduates. However, these researchers explained that this interpreted should be interpreted with caution as the sample size of school, high school and university graduates was not adequately represented in this study.

In a separate study, Piri (2010) examined the effects of education intervention based on HBM model on diet obedience in type 2 diabetic patients. These researchers found that the education based on HBM significantly increased patients perceived susceptibility, perceived severity and perceived barriers which contributed to the increase in practice diet obedience. In a study based in Ethiopia, Ayele, Tesfa, Abebe, Tilahun & Girma, (2012) investigated health belief and self-care behaviours and found that patients who were more educated, middle income, had high perceived severity of diabetes and less perceived barrier to self care were more likely to take diabetes self care. These researchers suggested that to increase the self care behavior, diabetes messages should focus on severity of diabetes and how to overcome barriers for self care by segmenting the audiences based on income and educational status with increasing the frequency and reach of message on diabetes.

Despite vast application, results obtained from studies are inconsistent. For example, Brownlee-Duffeck et al. (1987) found that patients who scored highly on benefit and vulnerability component of Health Belief Model were more likely to adhere to diabetes care regimen. Other researchers found that perceived severity contributed positively towards diabetes-related health behaviours among adults and adolescents (Cerkoney & Hart, 1980; Harris & Linn, 1985).

Many researchers have also used the Health Belief Model among young diabetes patients. For example Wdowik, Kendall, Harris and Auld (2001) applied the extended Health Belief Model to predict self-care management among adolescent diabetic patients. The extended Health belief model consists of two additional constructs which are cue for action and self-efficacy. Cue to action is a stimulus needed to trigger health-related behaviour change. This trigger could be factors such as health conditions, illness of family members, media advertisement or advice from health care professionals. Self-efficacy is one's own belief/perception of their ability to carry out the health-related behaviour. Among adolescent patients, diabetes management is greatly influenced by the cost and benefit component of the health belief model (Schafer, Glasgow, McCaul, & Dreher, 1983).

In the 1980's, the majority of research utilising the Health Belief Model investigated demographic factors that contributed towards specific health beliefs. Further to that, investigations were also conducted to assess whether beliefs enhanced or impeded health behaviour compliance. In recent years, this model has been used in the design of interventions for diabetic patients. For example, Hamuleh et al. (2010) assessed patients' health beliefs and found that literacy was associated with knowledge of diabetes, which consequently had an impact on health beliefs and diabetes management. Having established this, the researchers went on to implement an educational intervention to address diabetes knowledge. The findings of this experimental study indicated that the educational programme had a positive impact on diabetes knowledge and altered health belief and adherence behaviour.

### **1.5.3 Theory of Planned Behaviour**

The Theory of planned behaviour (TPB) (Ajzen, 1991) is an extension of The Theory of Reasoned Action, proposed by Fishbein & Ajzen (1975, 1980). According to the TPB, a person's behaviour intention contributes towards the execution of certain behaviour. Behavioural intention is influenced by three factors (attitude towards behaviour, subjective norm and behavioural control). Attitude towards the behaviour refers to beliefs about the outcome (i.e. success or failure in adhering to a particular behaviour) and evaluation of the outcome (i.e. positive and negative impact of adhering to a particular behaviour). The

second factor to influence behavioural intention is subjective norm which consists of beliefs about important others' attitude to the behaviour and motivation to comply with others. The third factor, behavioural control, is influenced by internal control factors (i.e. motivation, desire) and external control factors (i.e. advertisement and health promotion campaign). Unlike the other two factors, behavioural control can contribute directly to the behaviour without eliciting behavioural intention.

Shankar, Conner and Bodansky (2007) investigated the utility of the TPB in predicting maintenance of a frequently repeated behaviour, namely self-monitoring, in patients with Type 1 diabetes. In this study, the researchers administered a questionnaire that assessed components of the TPB to sixty-four adult patients with Type 1 diabetes. Diabetes HbA1c self-monitoring measure were also obtained. The results of the study indicate that the model explained 46% of the variance in intention and 57% of the variance in self-monitoring behaviour. Thus, this model provides a useful framework for understanding self-monitoring behaviour. Further to these, perceived difficulty and past behaviour were found to be the most significant predictors of the intention to self-monitor.

Three Canadian studies examined the utility of the TPB to predict exercise behaviour among diabetic patients. Plotnikoff, Trinh, Courneya, Karunamuni and Sigal (2009) investigated its application in predicting aerobic physical activity and resistance training among 244 adults with type 2 diabetes. Baseline data and 3-month follow-up assessments were conducted. The findings indicated that the TPB explained 10% and 8% of the variance respectively for aerobic exercise and resistance training and accounted for 39% and 45% of the variance respectively for aerobic exercise and resistance training intentions.

Plotnikoff, Lippke, Courneya, Birkett and Sigal (2010) investigated the application of the TPB to explain physical activity in individuals with Type 1 and Type 2 diabetes. They conducted a 6-month study to assess social cognitive component of the TPB at baseline and 6 months later. In addition, exercising behaviour was assessed using a questionnaire. This large population-based study of 2311 individuals found that the TPB explained >40% of

the variance in intentions for both diabetes groups. The construct of the TPB that contributed the most towards this variance was attitude towards the behaviour.

In the third study, Boudreau & Godin (2009) utilized a cross-sectional research design with a total of 501 individuals with type 2 diabetes residing in the province of Quebec. Multiple hierarchical regression analyses indicated that TPB variables explained 60% of the variance in intention. Based on these findings, it was suggested that exercise intervention aimed at Type 2 diabetes patients should address aspects of the TPB. For example, interventions should develop strategies to overcome physical activity barriers which could contribute to improved perceived behavioural control. Furthermore, it was proposed that interventions should help patients develop a sense of moral obligation to engage in regular physical activity and identify positive outcomes related to regular physical activity to impact upon subjective norms and attitude towards behaviour. In a separate study, conducted by Davis (2008) at Central Queensland University, two constructs of the TPB (i.e. subjective norm and perceived behavioural control) and past exercise behaviour were found to be significant contributors to predicting exercise intention. Those who most positively perceived that they had control over their exercise behaviour formed stronger intentions to engage in exercise.

#### **1.5.4 Transtheoretical Model of Change**

The Transtheoretical Model of Change (TTM) (Prochaska & DiClemente, 1986; Prochaska, DiClemente, & Norcross, 1992) has been used vastly within diabetes management and in the design of interventions for diabetes patients. This model proposes that behaviour change occurs in stages, namely pre-contemplation, contemplation, preparation, action and maintenance. The stages indicate the readiness of an individual to implement health-related behaviour change. Various self-report tools have been generated to investigate the patient's readiness for change based on the principals of the TTM.

Vallis et al. (2003) investigated the psychosocial factors, demographic, eating-related behaviour and health care utilization of diabetic patients (Type 1 & Type 2) in different stages of the TTM. These researchers conducted a RCT consisting of 1,029 individuals

with type 1 or type 2 diabetes. The treatment groups received an intervention that focused on healthy eating, glucose self-testing, and smoking cessation. The intervention consisted of reading material on stage based behaviour change information and stage-matched feedback. Patients were monitored quarterly and stage-matched phone counselling was provided. The control group received treatment as usual. Various instruments were utilised to facilitate data collection, including dietary intake using the National Cancer Institute Block Food Frequency questionnaire, Diabetes Family Behaviours Checklist, Interpersonal Support Evaluation List). The results of this trial supported the efficacy of staged interventions compared to treatment as usual. Furthermore, the researchers also found that the stage of readiness to adopt a healthy, low-fat diet was influenced by a number of factors. The main findings indicated that those in the action stages displayed healthier eating. In addition, participants in the action stage were more likely to be female and have a better quality of life and healthier eating habits. The study also found that social support was highest amongst those in the contemplation stage and lowest amongst those in the action stage.

The Diabetes Stages of Change (DiSC) study conducted by Jones et al., (2003) utilised randomised controlled trial methodology to compare the impact of stage- based intervention on greater readiness to change, greater increases in self-care, and improved diabetes control among patients with Type 1 and Type 2 diabetes. Participants in this study were separated into three groups. Group 1 received the staged intervention and were provided with free blood glucose testing strips. Group 2 received the intervention but did not receive the free testing strips. Group 3 received usual care. The findings of this study indicated that 43.4% of patients from group 1 and 30.5% from group 2 moved to the action stage. Similar findings were observed with regards to healthy eating and smoking cessation. More participants from the treatment group moved to the action or maintenance stage. The findings indicate that this intervention has the potential of positively impacting upon the health of broad populations with diabetes. Patients who moved to the action stage of the self-care monitoring and healthy eating displayed significantly lower blood glucose levels.

In a small scale study, Peterson & Hughes (2002) investigated readiness to change and clinical success (lower HbA1c levels) in a diabetes education program. In this study, fifty patients referred to a diabetes education centre with HbA1c levels of more than 9.0% were asked four questions prior to participating in the diabetes education program to assess patients' readiness to change. The intervention aimed to lower HbA1c levels. Patients had the choice to choose an individual, group based, hotline based or telephone based intervention. The intervention lasted for three months. The results of this study indicated that patients in the preparation and action stages achieved a significantly larger reduction in haemoglobin HbA1c levels in a shorter time than patients in the combined pre contemplation-contemplation stage. This clinical improvement persisted for at least 12 months. The TTM also proved to be effective in an exercise intervention for diabetic patients (Kim, Hwang, & Yoo, 2004).

### **1.5.5 Illness Self-regulation Model**

Leventhal and Diefenbach's model of illness self-regulation (1991) postulates that patients' perception of identity (perceptions of the label and symptoms of the illness), timeline (perceptions of the length of the illness), cure/ control (perceptions of the curability or controllability of the illness), consequences (perceptions of the consequences of the illness) and cause (perceptions of the cause of the illness) influence the way patients manage and cope with their illness. This model has been used to help understand people's adaptation and coping for many illnesses, including non-epileptic seizures (Green, Payne, & Barnitt, 2004), rheumatoid arthritis, chronic, obstructive pulmonary disease, psoriasis (Pimm & Weinman, 1998; Scharlo et al., 1998), atrial fibrillation (Steed & Newman, 1999), chronic fatigue syndrome (Heijmans, 1998) and cancer (Hunte, Grunfeld, & Ramirez, 2003).

There is a body of research that has specifically examined the relationship between illness representations and diabetes management. For example, Watkins et al., (2000) conducted an analysis of a mailed survey completed by 296 adult diabetics aged between 20–90 years old to investigate relationships among illness self-regulation, diabetes-specific health behaviours, and quality of life. The findings suggest that cognitive representation such as understanding and perceived control significantly predicted engagement in diabetes-

specific health behaviours and positive perceptions of quality of life. The findings also suggested that dietary adherence may negatively affect quality of life by increasing the level of perceived diabetes-related burden. Based on these findings, the researchers concluded that strengthening individuals' cognitive representations of diabetes cannot have the full desired positive effect on self-management behaviour and quality of life unless the burden associated with self-management is reduced. Watkins et al. (2000) acknowledged that the cross-sectional nature of the data does not allow causal inferences to be made.

In a separate study, Edgar & Skinner (2003) used the illness perception questionnaire to study the ability of coping acts to mediate the relationships between illness representations and emotional well-being in adolescents with diabetes. The study consisted of seventy adolescents with Type 1 Diabetes aged between 11 and 18 years. Participants also completed a well-being questionnaire and Kidcope (Spirito, Stark, & Williams, 1988) which is a brief screening measure of coping strategies for children and adolescents. The outcome of this research indicated that coping did not mediate the association between illness representations and emotional well-being. Furthermore, it was found that perceived impact of diabetes contributed to the negative emotional well-being among this sample of adolescents.

Broadbent, Donkin and Stroh (2011) investigated diabetic patients' perceptions of illness and treatments, and explored the relationships between adherence to self management practices and blood glucose control. The cross-sectional study was conducted in New Zealand and consisted of forty-nine Type 1 diabetic patients and one hundred and eight Type 2 diabetic patients. An illness perception questionnaire was completed which included item measuring adherence and blood glucose control. Medication adherence was associated with lower perceived consequences of diabetes, higher personal control, lower distress, and fewer symptoms. In a separate study conducted in New Zealand, Paddison, Alpass and Stephens (2010) used the Common Sense Model of Illness Self-regulation (Leventhal, Meyer, & Nerenz, 1980; Leventhal et al., 1984) to understand diabetes-related distress. The findings of this study indicated that diabetes-related distress was prevalent among patients who perceived diabetes to have serious consequences and faced difficulties

in 'making sense' of diabetes. Distress was also high with patients who believed that their diabetes symptoms come and go in cycles.

Rassart et al. (2014) investigated personality and illness adaptation in adults with Type 1 Diabetes. In this study, the 5-factor personality trait questionnaire/measure (McCrae & Costa, 1999) was used to investigate the impact of personality on illness adaptation. The five factors of personalities outlined by McCrae & Costa (1999) were extraversion, agreeableness, conscientiousness, neuroticism, and openness to experience. Participants consisted of 368 patients with Type 1 diabetes aged between 18-35 years old. Participants completed questionnaires to measure personality, diabetes-related problems, illness perceptions, and illness coping. Correlational analysis indicated that Extraversion and Agreeableness were positively related to perceived personal control and negatively related to perceived consequences. In addition, agreeableness negatively correlated to avoidant coping and diabetes-related problems. Neuroticism was positively associated with perceived consequences, avoidant coping and diabetes-related problems and negatively associated with perceived personal control. Conscientiousness was negatively related to avoidant coping and passive resignation. Openness was positively related to perceived personal control and negatively related to perceived consequences and diabetes related problems. The study also examined the connection between personality and diabetes-related problems. Outcomes indicated that agreeableness and conscientiousness negatively predicted diabetes-related problems. Furthermore, neuroticism positively predicted diabetes-related problems. Extraversion and Openness trait did not yield significance. The findings clearly indicated that personality plays a very crucial role in illness adaptation, which subsequently has an impact of diabetes management.

Illness perception was investigated qualitatively by Yilmaz-Aslan, Brzoska, Bluhm, Aslan and Razum (2014) using a population of Turkish migrants residing in Germany. This study utilized one-to-one interview methodology to elicit data from 24 male Turkish migrants. The results indicated that many Turkish migrants are well aware of the chronicity of diabetes. However, Turkish migrant men showed a denying and lenient attitude toward the course of diabetes. This could be attributed to the perception of diabetes as an illness that

lacks seriousness. These researchers explained that the perception of diabetes as an illness that lacks seriousness could also be caused by lack of awareness of diabetes and social norms in the Turkish migrant community regarding masculinity and gender roles. This study also demonstrated that emotional representations such as fear and despair played an important role in the illness perceptions of Turkish migrants with diabetes.

Recent empirical research indicated that illness perceptions contribute towards poor emotional health. For example, Nsereko, Musisi and Holtzman (2014) investigated illness perceptions, communication and depression in relation to self-care behaviour among Type 2 diabetes patients in a hospital in Kigali, Rwanda. This cross-sectional study found that participants held timeline perception that type 2 diabetes would last for their entire life. Participants also perceived the disease as a chronic but controllable condition as the serious consequences of diabetes is preventable using a number of preventive measures. The study found a significant negative correlation between time cyclical (i.e. symptoms comes and go in cycles), depressive symptoms and self-care behaviour. Time cyclical measures patients' perception of their symptoms comes and go in cycles. Patients who were depressed and perceived cyclical changes of type 2 diabetes were less involved in self-care behaviour. The study also examined whether illness perceptions (personal control) mediated the relationships between depression and self-care behaviour. However, the analysis did not yield significance.

The results on the relationship between illness perception and depression have not been consistent. In a randomized control trial conducted by Khunti et al. (2013) 824 individuals with type 2 diabetes received either a structured group education programme for six hours delivered in the community by two trained health care professional educators or usual care. Three-year follow-up data showed that patients in the intervention group had higher scores, reflecting that they had a greater understanding of their illness and its seriousness and a better perception of the duration of their diabetes and their ability to affect the course of their disease. However an improvement in depressive symptoms was not observed. Hudson, Bundy, Coventry and Dickens (2014) systematically explored the relationship between cognitive illness representations and poor emotional health and their combined

association with diabetes self-care. Nine cross-sectional studies were included in this review. The review findings indicated that cognitive illness representation did contribute to poor emotional health. Pessimistic cognitive illness representations were associated with poorer emotional health.

Over the years, researchers have investigated the application of Leventhal's Self-Regulation Model with various diabetes population, such as Chinese immigrants (Jayne & Rankin., 2004), populations of an African origin (Abubakari et al., 2012), Turkish patients (Brzoska, Yilmaz-Aslan, Sultanoglu, Sultanoglu, & Razum, 2012), Type 2 Diabetes patients from Toga (Barnes et al., 2004), insulin dependent diabetes patients (Griva, Myers, & Newman, 2000), adolescents with diabetes mellitus (Law, Kelly, Huey, & Summerbell, 2002) and Type 1 diabetic patients (Gois et al., 2010). Jayne & Rankin. (2004) adopted qualitative methodology to investigate illness self-regulation among Chinese immigrants with Type 2 diabetes in the US. The findings indicated that patients had a lack of understanding on the chronicity of diabetes and used various maladaptive coping strategies such as wishful thinking, belief in powerful others, keeping diabetes a secret, and avoiding social situations. These findings asserted the importance of educational interventions targeted at this vulnerable group of patients.

Bean, Cundy and Petrie (2007) demonstrated that there were ethnic differences in illness perceptions and diabetes self-care. The study was conducted in New Zealand and assessed differences between Europeans, South Asians and Pacific Islanders. It found that Pacific Islanders accurately perceived that diabetes had greater consequences than did Europeans and South Asians. In relevance to timeline perception, Europeans had significantly longer timeline perceptions than both South Asians and Pacific Islanders. Pacific Islanders were more affected emotionally by their diabetes than were South Asians and Europeans.

Previous research has demonstrated that illness representation has an impact on diabetes treatment adherence (Mann, Ponieman, Leventhal, & Halm, 2009; Griva, Myers, & Newman, 2000; Hampson, Glasgow, & Foster, 1995) and self-management of diabetes (Bean et al., 2007). Research with adult diabetes patients found that patients' perceived seriousness of diabetes predicted physical activity engagement and dietary adherence

(Skinner, Hampson, & Fife-Schaw, 2002). Lawson, Bundy, Lyne and Harvey (2004) found that patients who perceived diabetes to be controllable attended clinics more often than patients who did not perceive their illness to be controllable. White & O'Dowd (2001) found that compared to patients in good control ( $HbA1c \leq 7$ ), those in poor control ( $HbA1c \geq 8.5$ ) had a stronger perception that their illness was caused by hereditary factors, reported suffering from more diabetes-related symptoms, perceived diabetes as having significantly greater impact on their lives, and reported more negative emotions in relation to their illness (cited in Keogh et al., 2007). These findings illustrate the importance of patients' personal beliefs about their illness and treatment in their self-management of diabetes.

Illness perception studies have also been conducted among physicians. For example, Theunissen, de Ridder, Bensing and Rutten (2003) found that positive feeling of support was experienced by patients when clinicians discussed illness representation. Sultan, Attali, Gilberg, Zenasni and Hartemann (2011) conducted a cross-sectional study to investigate physicians' understanding of patients' personal representations of their diabetes. This study utilized 14 clinicians and 78 patients from France. Given the important role of illness representation in diabetes care, these researchers expressed the importance of physicians having a precise picture of the patients' views based on their ability to detect and attribute beliefs and feelings of their patients' illness self-perception. The findings indicate that the accuracy of clinicians' judgement of the patients' views was more predictive of self-care behaviours. Clinicians had a more accurate understanding of patients' belief concerning the timeline of the illness (chronicity) and treatment control. The researchers emphasised the need for clinicians to have an accurate understanding of patients' illness representation to facilitate effective communication. This understanding would also help clinicians to create an informed action plan of diabetes management that is suitable for individual patients. In a separate study, Gaston, Cottrell and Fullen (2012) found that caregivers' illness perception was also very important. They examined how adolescent-caregiver dyad illness representations relate to adolescents' reported diabetes self-management. The findings indicate that there was a wide range in both adolescents' and caregivers' views regarding the consequences of diabetes. However, caregivers tended to view both the impact and threat of diabetes to their child's health, to be greater than did adolescents. Adolescents and

caregivers believed that diabetes treatment was important in controlling diabetes and preventing future health complications. Caregivers also tended to hold these beliefs more strongly than adolescents. Caregivers' control/cure prevention and consequences/impact representations were most significantly related to adolescents' dietary self-management.

### **Problem statement**

Research on diabetes in Malaysia has mainly adapted a biomedical and epidemiological approach. Thus far, research in Malaysia has failed to assess patients' personal beliefs about their illness.

### **Study Aims**

This study aims to employ a mixed- methods approach that triangulates findings from two data collection methods to gain a coherent insight into illness beliefs among Malaysian Type 2 diabetes patients using a psychological approach grounded in self-regulatory theory. The present study aims to address the identified gap in the current literature, namely, an understanding of the psychological processes involved in managing diabetes. The findings from this research will provide a platform for the establishment of future successful educational and behavioural interventions aimed at diabetic patients in Malaysia. These interventions would aim to promote effective self management of diabetes.

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**Chapter 2:**  
**Understanding the illness self-regulatory experience of type 2 diabetes patients in Malaysia: A qualitative study**

This study applied Leventhal's Self-Regulation Model (Leventhal, Meyer, & Nerenz, 1980; Leventhal et al., 1984) to investigate the factors affecting diabetes management in type 2 diabetes patients in Malaysia. Leventhal and colleagues proposed that patients' cognitive and emotional representation of illness have an influence on coping responses. This study is crucial as diabetes management research in Malaysia has rarely adopted a patient-centred approach. Furthermore, the application of theoretical frameworks within diabetes research is also rare.

This study employed a qualitative research methodology to explore: (1) the cognitive representations of illness among patients suffering from type 2 diabetes in Malaysia, (2) the emotional representations of illness among patients suffering from type 2 diabetes in Malaysia, and (3) the management/coping styles adopted by patients suffering from type 2 diabetes in Malaysia.

## **2.1 Methodology**

### **2.1.1 Recruitment Procedures**

Ethical approval for this research was obtained from the Senate Ethics Committee of City University and the Malaysian Health Ministry Ethical Approval Committee prior to data collection. Participants were recruited from the Prince Court Medical Centre, Malaysia, which is a private multi-specialty hospital offering a wide range of medical services. Patients pay to receive medical treatment from this hospital. This research was conducted at the Endocrinology (Diabetes Service) clinic of the Prince Court Medical Centre.

Potential participants were initially approached opportunistically at this hospital by the Consultant Endocrinologist. At this stage, patients were also provided with verbal and written information on this research. Participants were given time (minimum of 1 day) to decide if they were willing to participate in the research. If patients were willing to participate in the research, the lead researcher (JK) was informed, and arrangements were made for data collection.

On the day of data collection, patients were given the opportunity to seek any clarification on the research from the lead researcher. Participants' written consent was obtained prior to their participation using a consent form. Verbal and written debriefing was provided after their participation.

### **2.1.2 Ethical Approval**

This research conformed to the British Psychological Society (BPS) Code of Ethics and Conduct (2009). Ethical approval for this research was obtained prior data collection. Ethical approval was obtained from the Senate Ethics Committee of City University (4<sup>th</sup> June 2014) and the Malaysian Health Ministry Ethical Approval Committee (2<sup>nd</sup> June 2014). In accordance with the Data Protection Act (1998), all data obtained will be stored in a locked cabinet, which is located within the Prince Court Medical Centre, Malaysia, and a password-protected computer. This data was only accessible by the main researcher and research supervisors.

### **2.1.2 Participants**

One-to-one interviews were conducted with participants. The year of diagnosis ranged from 1 year plus to more than 40 years. Participants recruited in this study fulfilled all of the inclusion criteria below:

- Adults aged above 18 years
- Have been medically diagnosed with type 2 diabetes
- Date of diagnosis was minimum of 1 year prior to the date of interview
- Fluent English conversational ability
- Ability to provide written informed consent

The exclusion criteria for this research are stated below:

- Patients aged below 18 years
- Patients with type 1 diabetes
- Patients with gestational diabetes
- Patients with less than 1 year diagnosis

- Patients with poor English conversational and comprehension skills
- Patients who could not provide informed consent
- Patients who could not answer the questionnaire independently due to disability, other co-morbidities and an unstable medical condition

In total seven in-depth interviews were conducted before it was felt theoretical saturation had been reached. Theoretical saturation refers to the end point in the qualitative data collection and analysis process, when further data collection and analysis cease to generate any new or distinctive categories, high level concepts, or substantive codes (Rowan & Huston, 1995). Three subsequent individual in-depth interviews were scheduled to address possible inconsistencies and gaps in the early codes and to confirm theoretical saturation. Two participants were females and eight participants were males. **Table 2** below provides the demographic details (e.g. Age, gender, occupation) of each participant who took part in this study.

<b>Table 2: Participant Demographic Detail</b>								
Participant No	Age	Gender	Duration of Diabetes	Last Recorded blood sugar level	Occupation	Ethnicity	Education	Marital Status
1	54	Male	2 years	11.5	Managerial	Malay	Masters	Married
2	48	Male	20 years	4.0	Businessmen	Malay	None	Married
3	41	Male	1 year	9.9	Professional	Indian	Diploma	Married
4	30	Female	3 years	8.8	Professional	Malay	Degree	Married
5	85+	Male	40 years	6.5	Retired	Indian	Degree	Married
6	47	Male	7 years	8.00	Professional	Indian	Masters	Married
7	65	Male	36 years	6	Businessman	Indian	Masters	Married
8	40	Male	10 years	19	Businessman	Indian	Diploma	Single
9	43	Female	23 years	14	Restaurant Owner	Chinese	SPM (O Level)	Married
10	54	Male	20 years	6	Airline Crew	Chinese	Degree	Married

### **2.1.3 Materials**

#### **Consent form (Appendix 1)**

This form was used to obtain written consent from patients prior to their participation in the research.

### **Information sheet (Appendix 2)**

This sheet contained all information regarding the research, including the nature of the research, procedure and intended use of research findings. Patients were provided with this form prior to their participation in the research.

### **Demographic questionnaire (Appendix 3)**

This questionnaire requested patients' demographic details, such as age, gender, years of diagnosis, last recorded HbA1c level, occupation, ethnicity, educational status, and marital status.

### **Semi-structured interview template (Appendix 4)**

This template was created and used for the interviews. Some of the questions explored include patients' experience of diabetes, patients' emotional reaction towards the illness, patients' cognitions of the illness, and coping strategies adopted.

### **Debriefing form (Appendix 5)**

This form was given to participants after their research participation. Participants were given in-depth information about the purpose of the research. This form also signposted participants to relevant organisations that could provide further information on diabetes.

## **2.1.5 Procedure**

Data was obtained by conducting semi-structured one-to-one interviews with participants. Each interview lasted approximately 20–25 minutes. Inpatients were interviewed in their wards. Outpatients were interviewed in a consultation room in the Diabetes & Endocrine clinic in the Prince Court Medical Centre. Interviews were conducted between June 2014 and August 2014. All interviews were voice-recorded and transcribed verbatim. Participants' written consent was obtained prior to their participation. Participants were also administered a brief demographic questionnaire prior to the interview. A debriefing

form and verbal debrief were provided after their participation. An interview schedule (**Appendix 4**) guided the semi-structured interview. According to Pope et al. (2002), the flexible nature of semi-structured interviews encourages participants to talk about issues that are most important to them. In accordance with the Data Protection Act (1998), all data obtained will be stored in a locked cabinet, which is located within the Prince Court Medical Centre, Malaysia, and a password-protected computer. This data was only accessible by the main researcher and research supervisors.

#### **2.1.6 Use of Grounded Theory**

Grounded theory is a qualitative methodology that aims to identify categories within data and link those categories in order to establish a theory that provides an explanation/insight to understand the phenomenon under investigation. Grounded theory facilitates the move from a description of what is happening to an understanding of the process by which it is happening (Corbin and Strauss, 2008; Strauss and Corbin, 1994). As illness perception among diabetic patients has not been previously explored, a grounded theory methodology was employed as this methodology provides strategies to build theories in areas previously unexplored or underexplored areas. Furthermore, the theory generated from this research would be grounded in the data and would be suitable for understanding this population. Grounded theory has been used for qualitative exploration of experiences of chronic illnesses (Charmaz, 1990).

The social constructionist approach of Chamaz (2000, 2003, and 2006) was adopted. This approach emphasised that the theories do not emerge from the data, but are constructed by the researcher; thus, the theory produced constitutes one particular reading of the data rather than the whole truth about the data.

This study adopted abbreviated grounded theory - an abbreviated version was selected. Such an approach is necessary as it is anticipated that due to the nature of the study, it would be difficult to obtain sufficient numbers of participants, as required for a full grounded theory investigation. The abbreviated grounded theory applied the same principles as a full-version grounded theory (i.e. the process of coding and constant

comparative analysis); however, theoretical sensitivity and theoretical saturation were only implemented within the text analysed (Willig, 2013).

### **2.1.7 Reflexivity**

In accordance with the principles of constructionist grounded theory, it is crucial for the grounded theorist to acknowledge their own philosophical and conceptual background and be insightful of the impact of their background on the interaction with participants. The main researcher of this study (JK) is a 31 year-old Malaysian Indian woman. When carrying out this research, the main researcher was in her final year of a doctorate in Health Psychology, and the study was her doctoral thesis. She has no personal experience of diabetes and has never worked in diabetic setting.

When interviewing patients, measures were taken to gain as much information from participants without any barriers. Measures were also taken to ensure that participants do not see the researcher as an authority figure as this could be a barrier to patients opening-up regarding their diabetic experience. This could also possibly lead to social desirability bias. During the interview, the main researcher explicitly told the participants that she does not work for the hospital and is only gathering the data for research purposes. The main researcher also dressed in a semi-casual manner to break any potential barriers that could arise from formal dressing. The age of the researcher was a facilitator for in-depth data gathering. As most of the research participants were younger than the researcher, the patients gave more details as they were really keen to help the researcher with her research.

The ethnic background of the researcher enable instant rapport with patients. During the interview, patients were at ease in discussing their diabetic experience and Malaysian cultural factors that impacted their management. The gender of the researcher was not an issue in dealing with male participants. However reflectively, male patients would have concealed intimate details of their disease and impact (e.g. sexual dysfunction) to the female researcher.

During data analysis, the researcher was aware that her own experiences might have an impact on how the experiences of patients were interpreted. Hence the themes generated were scrutinised numerous times to ensure that they are grounded in the data.

### **2.1.8 Analysis and Coding**

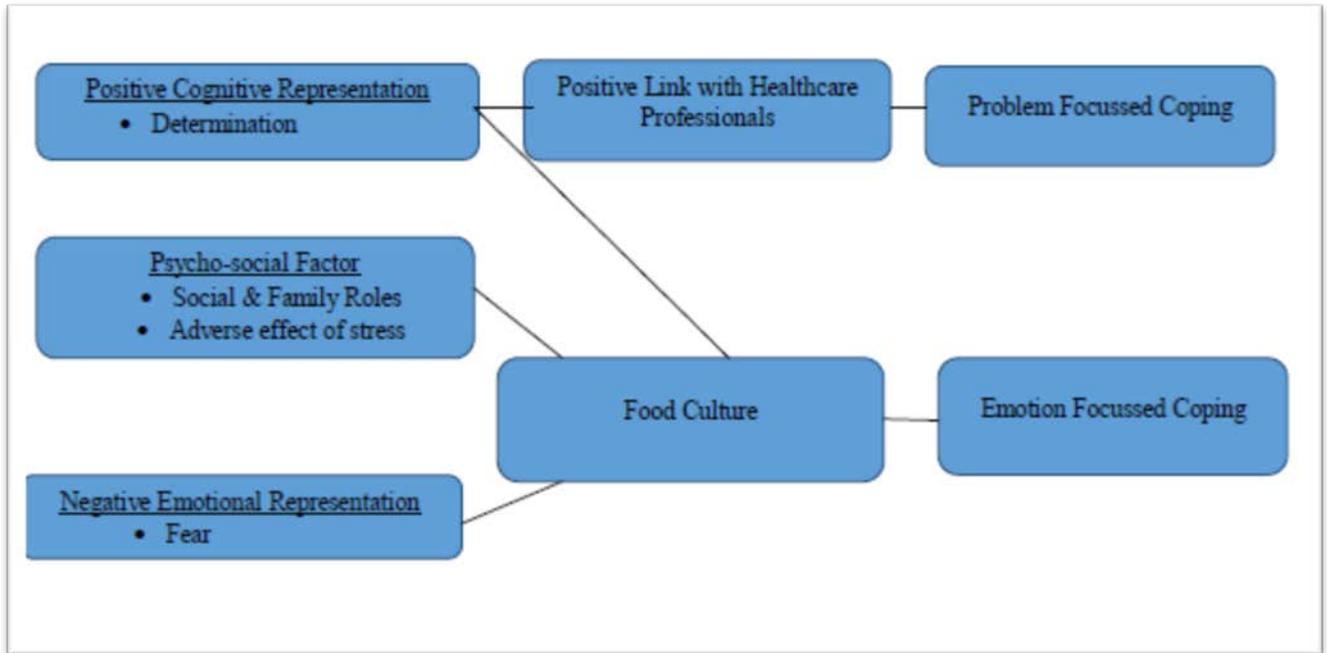
The data was initially open-coded. Open coding is a process of going through each line of the transcripts and capturing the meaning. Conforming to the guidelines provided by Glaser (1998), during initial coding the coder constantly reflected upon and questioned what was actually happening in the data and the main concerns being faced by the participants.

Once the initial open coding was complete, similar codes were grouped together and given a conceptual definition. These core categories were then linked together to build a conceptual model.

Adhering to the recommendation of Charmaz (2006), conceptual memos about the initial codes and focused codes were developed. These memos were used to record thoughts on the meaning of the codes generated.

## **2.2 Results**

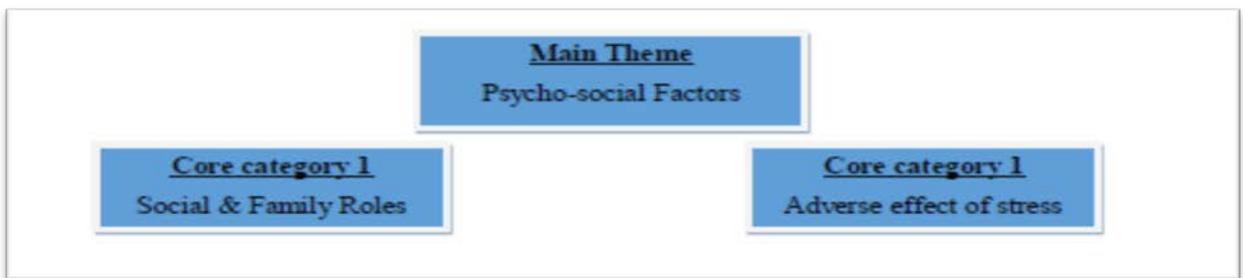
From the data an interpretative theory of Illness Self-Regulation was developed, which comprised: (i) psychosocial factors; (ii) positive cognitive representation; (iii) positive links with healthcare professionals; (iv) problem-focused coping; (v) negative emotional representation; (vi) food culture; and (vii) emotion-based coping. A visual representation of category relationships is provided in **Figure 3**.



**Figure 3: Illness Representation theory**

**Psychosocial factors**

All participants expressed the negative impact of psychosocial factors on their diabetes management. These psychosocial factors contributed towards negative cognitive representation and negative emotional representation. This main category has two core sub-categories: (i) social and family roles, and (ii) adverse effects of stress. This is visually represented in **Figure 4** below:



**Figure 4: Psycho-social factors**

### **Social and family roles**

One of the main themes generated from this qualitative research concerned social and family roles. Participants expressed that their family members, mainly their spouses, do not understand their illness and management needs. Therefore, they have a negative influence on diabetes management. Moreover, participants also expressed that the social roles also negatively impact upon diabetes management, as when they attend social functions and gatherings they want to conform to societal norms.

During the interview all participants discussed that their spouses did not have a great understanding of diabetes management and diet restrictions. Although participants reported having the intention to make behavioural modifications that are crucial for diabetes management, they reported that their spouse continued to prepare and serve food that the patients deemed to be tempting. As a result, participants reported often giving in to such temptation. Furthermore, some participants revealed that their immediate family members are aware of the diagnosis, but unaware of the serious complications that the patient is experiencing.

Participants expressed that various life roles, such as societal roles, conflict with their diabetes management. For example, some participants expressed that when they attend social functions, it is difficult for them to adhere to the diabetic diet restrictions. Participants also expressed that having diabetes has impacted negatively on their social life. For example, participants explained that they had to alter their social engagements due to the behavioural and physical constraints of diabetes.

*“Especially my wife, she likes to cook. I believe she is one of the best chefs in my family. So a lot of food, I simply like to eat. So many things and dishes, curry and the Malay type of dishes, the Indian curry dishes... I love food because I always eat at home. I very seldom eat outside, because my wife always prepares the meals. So I know I like it.”*

**(Participant 1)**

*“I’m very strict on diet. But my wife scolds me on why I don’t eat rice or eat a little bit only... because I have to take care of my health. Even though I am old, how long (more) I will live... I don’t know, so I have to keep my health.”*

**(Participant 5)**

*“Like yesterday, we had a family gathering. My aunties all came... so we ate mutton, chicken, the prawn, and all that you know. You know that you can’t consume so much. Believe me for that... but after so long, I broke my diet.”*

**(Participant 8)**

### **Adverse effects of stress**

During the interview all participants expressed that they are constantly under various forms of stress, such as financial and work pressure, which adversely affects their diabetes management. Participants expressed that despite numerous attempts to control the blood sugar level by adhering to medication and eating healthily, it continues to be uncontrollable due to stressful life events.

*“Like I said, even if I control my diet, and I’m under medication, it still won’t improve my diabetes because of the stress factor.”*

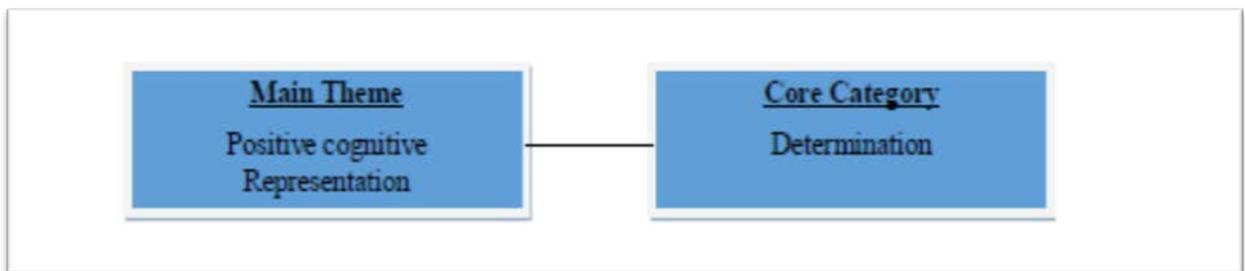
**(Participant 9)**

*“I can manage my disease to a certain extent, if I do exercise, if I can manage my stress, if I can manage my diet. Stress, I’ve always tried to manage, that is regular, but sometimes you just can’t avoid.”*

**(Participant 6)**

### **Positive cognitive representation**

Some patients had positive cognitive representation of their illness. Within this main theme, determination was a core theme. This is visually represented in **Figure 5** below:



**Figure 5: Positive Cognitive Representation**

Within the determination core category, patients expressed that they knew diabetes had no cure and were determined to control their disease in an effective manner. Patients discussed that determination is a key feature to successful diabetes management. Patients expressed that they took positive steps to manage their illness, such as adopting a healthy lifestyle.

*“You can live a normal life if you are disciplined in food intake, medicine, regular exercises — you can lead a normal life. So try to accept the fact that I’m a diabetic who can lead a disciplined life, with a due care not to overdo things or don’t take anything for granted.”*

**(Participant 7)**

*“It depends on me, on my determination on how to control. You can have your food, but you have to be active to avoid those high sugar content foods.”*

**(Participant 1)**

### **Positive relationship with healthcare professionals**

Within this theme, patients discussed the positive impact of having a good relationship with their healthcare professionals (e.g. endocrinologist, dietician). Participants expressed that their doctor had helped them to gain a better understanding of diabetes and management. With the wealth of information provided by their doctor, participants reported that this had helped them to feel more able/better equipped to take an active and effective role in their diabetes management.

*“When I was admitted in the hospital about 7–8 years back, the dietician came to me with the doctor. So she’s the one who said, ‘Ok, these are the things that you must take. These are the things you need. Ok, so this is the healthiest food for your sake. Let’s say that if you really think that you want to do things faster yourself, this is the approach’.”*

**(Participant 8)**

*“Every alternate month I visit the doctor. They give me two months of pills for diabetes. So when they check my pressure, everything is alright. So the last time I asked why my reading is always 6–7, whether there is any way you can bring it down. So he said that he would give me another dose. Half dose. We tried it for a few weeks. So I have been doing it. For the last 2 years, so far, what I know is that it helps me. It controls it up to a certain level.”*

**(Participant 10)**

### **Problem-focused coping**

This theme explores the problem-focused strategies that have been adopted by patients. Problem-focused coping strategies involve patients being aware that they are able to affect the course of the illness and then taking active measures to maintain and manage their illness.

*“They gave me a write-down book, so I write in it and say various things... so I stop the carbohydrate drinks and take warm water and normal water...so I’ve been doing all these things and I’ve been improving.”*

**(Participant 2)**

*“I have some leaflets and some articles supplied by dieticians and I may make reference to it to prepare healthy foods.”*

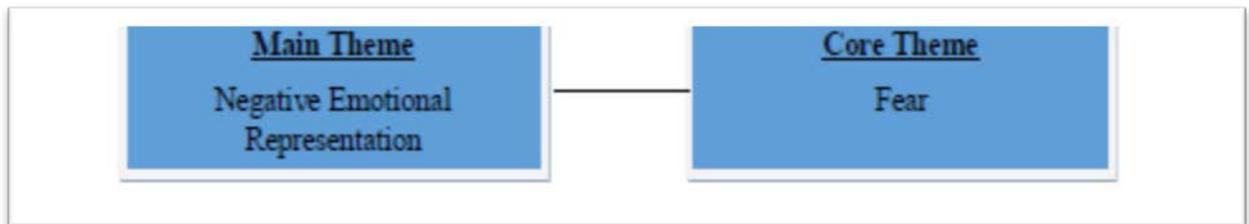
**(Participant 1)**

*“I do regular medical check-ups, every 6 months once. And they have given me a good routine and I have been taking a variety of tablets.”*

**(Participant 7)**

### **Negative emotional representation**

Patients expressed negative emotional representation of diabetes. Within this main theme, fear was a core theme. This is visually represented in **Figure 6** below:



**Figure 6: Negative Emotional Representation**

Within this theme, patients expressed various fears associated with diabetes. Firstly, patients expressed fears that their diabetes symptoms would worsen with time. Therefore, they would face a bleak future as well as various forms of diabetes-related co-morbidities. Moreover, patients also expressed fears that their future generation, e.g. their children, would be diagnosed with diabetes and would suffer the same fate as them.

*“Think it will get worse with time. I think when your body gets older you will need a lot of supplements and things like that. So I think it will get worse.”*

**(Participant 10)**

*“I have confirmed diabetes. I have high blood tension and I’m worried about my heart and also the renal failure. And renal failure is interrelated with this... one is the fear that it will escalate to other illness.”*

**(Participant 1)**

*“And my children I have to warn them, because this can be genetic. So things like that.”*

**(Participant 10)**

### **Food culture**

Malaysia is a country with a variety of food choices. The food options in Malaysia are reflective of the country’s multi-ethnic variations. Furthermore, there is also growth of the fast-food industry. Within this theme, patients expressed how the food culture within Malaysia adversely affects their determination and diabetes management. Patients noted that, although there is a determination to adopt a healthy lifestyle, the food culture creates various temptations and contributes towards the lack of adherence.

*“Being Asian, we eat a lot of rice. Most diabetics are Malays. Why, because they eat nasi lemak (Malay rice dish). And the thing is, we eat 24 hours a day. That kind of lifestyle is bad. You know, if I go to midnight I eat rice for supper. To me, you have to educate the people. Maybe from childhood, explaining that all this is bad for your health.”*

**(Participant 10)**

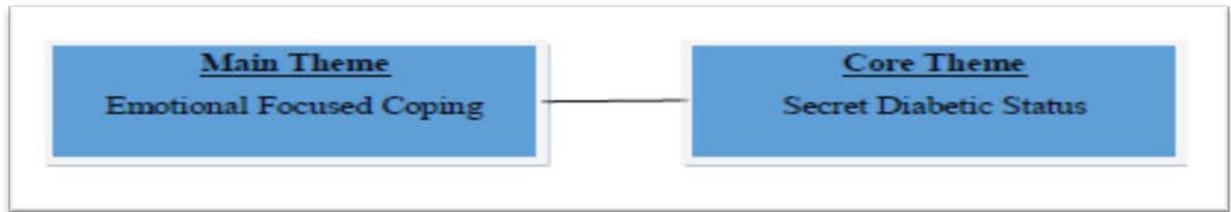
*“Any Malaysian food that we eat, there is sugar content in it. I’m married to an African. You go to Africa and there is no sugar in their food at all. I think even in the UK or America... there is hardly any sugar in their food, in their normal daily food. And second is being overweight. Most kids and people in Malaysia are obese, so if the government can do something about it, e.g. the way of sugar intake and too many sweet things being given to kids, and stuff like that, maybe we can reduce it.”*

**(Participant 9)**

### **Emotional coping styles**

Some patients, specifically those ones who expressed poor family/social support, tended to adopt an emotional coping style. Patients adopting emotion-focused coping aim to lessen emotional distress caused by the disease by using strategies such as avoidance, minimisation, distancing, and finding positive value in negative events. Patients in this

study mainly adopted one emotional coping style: keeping their diabetic status a secret. This is visually represented in **Figure 7** below:



**Figure 7: Emotional Focused Coping**

Patients kept their illness a secret from friends and colleagues. Some patients even kept their illness a secret from family members. The reason for secrecy was mainly due to the fear of stigmatisation. Patients also revealed that when others know that they are diabetic, they tend to provide unsolicited advice on issues relevant to diabetes management and treatment. Patients also revealed that some people deem them to be attention seekers for revealing their illness.

*“With my friends... I was very secretive about this diabetes thing. I don’t think I shared things with friends, except for very close friends.”*

***(Participant 4)***

*“Most of my friends don’t know I am diabetic. I have not told them.”*

***(Participant 10)***

*“Once you are a serious diabetic patient, like my father, so I know but I can't tell people, people don't understand. Most of the time, if you tell people they think you want to get the sympathy most of the time. Not only to my children, not only to my wife, even my own mother, even my own sister. Nobody understands the diabetic patient; they only know how to talk about management. They only know to complain about how you eat wrongly. You do this and you do that... but they don't understand what diabetes patients worry about.”*

***(Participant 2)***

## **2.3 Discussion**

The aim of this study was to investigate: (1) the cognitive representations of illness among patients suffering from type 2 diabetes in Malaysia, (2) the emotional representations of illness among patients suffering from type 2 diabetes in Malaysia, and (3) the management/coping styles adopted by patients suffering from type 2 diabetes in Malaysia. Findings from this study provided evidence of personal experiences of type 2 diabetes patients in Malaysia. The abbreviated grounded theory analysis revealed three core themes and seven sub-themes. All of the themes will now be discussed.

Consistent with the findings of this research, many other researchers have found that the spouse of diabetic patients plays an important role in their diabetes management and care. Glasgow and Toobert (1998) found that diabetes-related support from family and healthcare providers can improve regimen adherence. Trief et al. (2003) conducted a qualitative research consisting of seventy-four participants (patients and spouses) with diabetes. They found that spousal support is crucial, specifically in planning appropriate meals and to remind, motivate, and cajole patients to exert necessary self-control. Crucially, these researchers highlighted that it is important for the spouse to be well educated about diabetes, its successful management, and potential pitfalls.

Stephens, Rook, Franks, Khan and Iida (2010) assessed spouses' use of warnings and encouragement (reported by spouses and patients), as well as patients' reports of dietary adherence. The findings from this research suggested that spousal warning and encouragement were associated with patients' adherence to the recommended diabetic diet, with warnings being associated with poorer adherence and encouragement associated with better adherence.

In a separate study, Stephens et al. (2013) analysed end-of-day diaries of patients and their spouses to investigate the form of spouses' diet-related involvement (support, persuasion, pressure) that contributed to daily dietary adherence and diabetes-specific distress. The findings of this study indicated that pressure and persuasion from a spouse were associated with a decline in dietary adherence and an increase in their worries and concerns about

diabetes. Support from spouses increased dietary adherence and was associated with a decline in their worries and concerns about diabetes.

These researchers clearly demonstrated that patients with chronic illness react negatively, even to mild forms of control. Stephens et al. (2013) also found that the perception of individual and shared responsibility of diabetes care has an important impact on the influence of spouses. Patients who perceived that diabetes care was their individual responsibility were not influenced by spouses' diet-related involvement. Franks et al. (2012) found that almost 100% of spouses in this study reported having provided some type of diet-related support to their partners with diabetes in the past month. Moreover, the majority of participants in this study indicated that they had frequently shared meals together with their diabetic partner in the past month. Frequently sharing meals was associated with less diabetes distress among patients.

These findings illustrate the importance of addressing spousal support of diabetic patients. Spousal support could be evaluated using self-report measures. Various scales have been developed to assess spouse support. Examples of these scales include the Diabetes-Specific Family Behaviour Scale (Waller et al., 1986), the Diabetes Family Responsibility Questionnaire (Anderson, Auslander, Jung, Miller, & Santiago, 1990) and the Diabetes Family Support Questionnaire (Schafer, McCaul, & Glasgow, 1986). More crucially, spouses should be educated on diabetes lifestyle alteration. A diabetes education programme aimed at spouses will help them to provide effective and appropriate support to the diabetes patients, which will positively impact upon disease management.

Patients in this study expressed that they had problems in conforming to diabetes regimes as their social commitments and engagements conflict with their diabetes dietary constrictions. Other studies in Malaysia have found similar results. In a study conducted by Sharoni and Wu (2012), patients claimed that they were less confident about complying with their healthy-eating plans because of various outside influences, e.g. attending wedding feasts and visiting relatives' houses. This situation was further exacerbated by school holidays and festive seasons such as the Hajj celebration (Muslim celebration),

Christmas, and Chinese New Year, as most food served in Malaysia on such occasions is based on rice or glutinous rice, which are rich in carbohydrates and calories.

Patients' social circumstances do seem to have a negative impact on diabetes management. Researchers have explored whether new social interactions with other diabetic patients in the form of social networking sites would be beneficial to diabetic patients. With the importance placed on social interactions, researchers have been investigating the utility of online social networking sites to assist diabetes management. Greene, Choudhry, Kilabuk and Shrank (2011) used an innovative qualitative research design to evaluate the content of communication in Facebook communities dedicated to diabetes. These researchers identified the 15 largest Facebook groups focused on diabetes management, and analysed the content of the "wall posts" using a thematic coding scheme. The findings of this study indicated that patients with diabetes, family members, and their friends use Facebook to share personal clinical information, request disease-specific guidance and feedback, and receive emotional support.

Toma and Hancock (2014) systematically reviewed the current evidence surrounding the role of online social networking services in diabetes care. However, this reviewed focused on the use of social networking sites to enhance the interaction between diabetes patients and their healthcare providers. This review included 34 studies with a pooled dataset of 4977 patients, of whom 2550 were randomised to SNS intervention and 2427 to the control. The findings of this review clearly indicated that social network services among patients and healthcare providers beneficially reduced HbA1c when compared to controls. Furthermore, patients who obtained online social networking intervention showed significant improvement in blood pressure and total cholesterol. A subgroup analysis revealed that type 2 diabetes patients had a much greater reduction in HbA1c than those with type 1 diabetes.

The majority of patients reported that they had kept their diabetes status a secret. This is not uncommon. A survey conducted by Diabetes UK (2011) found that 39 per cent of women kept their diabetes a secret in comparison to 28 per cent of men. Furthermore, 48

per cent of people aged 17–21 were most likely to keep their diabetes a secret. The same survey found that approximately 1 million diabetes patients had kept their illness a secret. Worryingly, a secret diabetes status affects management in an adverse way. For example, patients confided that they had missed insulin injections or delayed testing their blood glucose to avoid drawing attention to themselves. In a separate study, Yilmaz-Aslan, Brzoska, Bluhm, Aslan, & Razum (2014) found that Turkish migrants residing in Germany tended to deny or not divulge their diabetes. This was specifically common in men as the illness was seen as a threat to the Turkish migrant community regarding masculinity and gender roles. Jayne and Rankin (2001) also found that diabetic Chinese immigrants with type 2 diabetes often kept the illness a secret from their employers.

There are various reasons as to why diabetes patients do not reveal their illness to family, friends and employers. Although the factors contributing to this secretive nature have not been explored in Malaysia, studies from neighbouring countries could shed light on this issue. For example, Tak-Ying Shiu (2003) found that diabetes patients in Hong Kong faced various social stigma that led them to keep their illness a secret. For example, patients' self-administration of insulin in public places has been viewed by the public with contempt and with a possible association with intravenous drug users. In this qualitative study, patients also revealed that they were viewed as having diabetes due to overindulgence in food. Patients also felt that their jobs would be at risk if their disease was made known to colleagues or supervisors.

DeCoster and Cummings (2005) suggested that there are various forms of coping with diabetes. Patients who keep their illness a secret are using an emotional problem-focused approach. A further approach that has been used by patients is a problem-focused approach (i.e. adopting an active role to manage the illness). A problem-focused approach has been proven to be more effective in diabetes self-management.

Based on the findings of the current research, it is clear that some patients adopted emotion-focused coping and maintained their diabetes status as a secret. It is very important for healthcare professionals to evaluate patients' coping styles and whether their diabetes status is a secret from significant people in their life. This is important because this

indicates that interventions provided to these patients will need to be tailored to their coping styles, as these patients could still be struggling with self-management if they are in a non-supportive family or work environment. Furthermore, patients' self-management could be compromised a great deal when they omit blood glucose self-monitoring, whereby delaying some injections. Patients could also be adopting what is deemed the normal diet of food to fit in with the non-diabetic majority.

### **Adverse effects of stress**

Stress is a factor that patients consistently discussed during the one-to-one interviews. In this study, patients expressed that their stress level is adversely affecting their diabetes management. Nozaki et al. (2009) investigated the relation between psychosocial variables and the glycaemic control of patients with type 2 diabetes. These researchers utilised various forms of self-assessment tools in their research. One of the independent variables investigated was diabetes-related distress, which was measured using the Problem Areas in Diabetes Scale (PAID). The results of this study indicated that diabetes-related distress adversely altered glucose control in people with type 2 diabetes.

Past researchers have clearly proven that psychological stress is detrimental to glycaemic control among diabetes patients (Surwit et al., 2002). Surwit, Richard and Bauman (2004) explained their book entitled *The Mind-Body Diabetes Revolution* that corresponding to the General Adaptation Syndrome model of stress of Hans Selye (1907–1982), psychological stress activates the fight-or-flight response which releases stored glucose or fat into the bloodstream. Diabetes patients do not have enough insulin to balance the glucose or fat which is released due to stress, hence the blood glucose going high.

There is an immediate need for psychological intervention targeted at reducing the stress levels of diabetic patients. Rosenzweig et al. (2007) piloted a mindfulness-based stress reduction intervention with 14 patients with type 2 diabetes. The mindfulness-based stress reduction intervention consisted of mindfulness meditation, which is a practice of self-regulating attention that lowers reactivity to stress triggers. Post-intervention measures indicated that patients did not make any behavioural changes such as diet and exercise.

However, the results of this pilot study supported the hypothesis that mindfulness-based stress reduction training is associated with improved glycaemic regulation in type 2 diabetes. These researchers claimed that mindfulness training appeared to interrupt or down-regulate an individual's psychological reactivity to stress triggers, which may, in turn, mitigate a physiological stress response, thereby improving glycaemic regulation. In a separate study, Surwit et al. (2002) used a randomised control design to investigate the impact of a stress management technique with diabetic patients. The stress management technique utilised in this study was progressive muscle relaxation. In this study, patients with type 2 diabetes were randomised to undergo a five-session group diabetes education programme with or without stress management training. This longitudinal study evaluated patients' outcome over a one-year period. The outcome of this study revealed that stress management training was associated with a small (0.5%) but significant reduction in HbA1c.

McGinnis, Cox, McGrady and Growler-Dowling (2005) used relaxation and biofeedback-assisted relaxation with type 2 diabetes patients to examine the impact on blood glucose and HbA1c. Patients with type 2 diabetes were randomised to either 10 sessions of biofeedback (electromyography and thermal) and relaxation or three sessions of education. The results of this research revealed that biofeedback and relaxation were associated with significant decreases in average blood glucose (HbA1c) and muscle tension compared with the control group. A follow-up measurement obtained 3 months post-intervention revealed that the treatment group continued to demonstrate lower blood glucose (HbA1c).

Regardless of the form of interventions, it is clear that stress management intervention does help diabetes patients to manage their blood glucose level. Therefore, stress management intervention is crucial and has been proven to have clinically significant benefits for patients with type 2 diabetes.

### **Diabetes-related fear**

Patients in this study expressed that they have various diabetes-related fears and worries. Other researchers have also found that diabetes-related fears and worries are prevalent

among diabetes patients. Similar to the findings of this research, Samuel-Hodge et al. (2000) found that African American women with type 2 diabetes were worried and fearful about being sick or “suffering” from diabetes. Participants in this study shared that their fears and worries stemmed from observing family members or friends who suffered due to diabetes. For example, patients feared having an amputation of limbs due to diabetes. Studies have also found that diabetes-related worries are more prevalent among women, which is caused by patients' perception of their inability to control diabetes (Undén et al., 2008). In a recent study, Wilkinson, Randhawa and Singh (2013) conducted a qualitative investigation with White European and South Asian patients with a new diagnosis of diabetes in order to gain understanding on the worries faced by diabetes patients. This research also aimed to identify whether cultural variations exist in the types of worries faced by patients of different ethnicities. In this study, 47 patients were interviewed (28 South Asian and 19 White European). The findings of this study indicated that, in contrast to the shock, upset and disappointment, which were the most common early reactions reported, some participants described how they coped with the diagnosis by not worrying, by being resigned to the diagnosis, or by not thinking about it.

The DAWN (Diabetes Attitudes, Wishes and Needs) study conducted by Peyrot et al. (2005) conducted a cross-national study to investigate psychosocial problems and barriers to improved diabetes management. This study was conducted in 13 countries in Asia, Australia, Europe and North America. In this study, patients and care providers were interviewed by using either face-to-face interviewing or telephone interviewing. The outcome of this study indicated that diabetes-related worries were common among patients, and providers generally recognised these worries. This study also found that many diabetes care providers (e.g. primary care physicians, diabetes specialist physicians and nurses) believed that psychological problems were associated with worse outcomes.

### **Food culture**

Patients indicated that the Malaysian food culture prevents them from having optimal control of diabetes. Patients also indicated that the food culture also contributed to the high

prevalence of diabetes in Malaysia. Malaysia is a country with 24-hour availability of food, e.g. the hawker stalls in Malaysia operate for 24 hours a day.

Tee (2013) attributes the rise in non-communicable diseases to an unhealthy diet and lifestyle. Some patients were aware that they have diabetes because of their lifestyles and overindulging dietary habits. Moreover, patients in this study also indicated that food control was hard for various reasons, e.g. the lack of knowledge and the extra effort needed to prepare diabetic meals. Patients in this study explained that they consumed normal foods like the rest of their family members who did not have diabetes.

Khor (2012) conducted a review on food availability and the rising obesity prevalence in Malaysia and found numerous worrying trends in the food consumption patterns of Malaysians. Firstly, women who had high glycaemic index diets and ate more food staples, such as bread, noodles and rice, also had an increased risk. Secondly, Malaysians also consume white rice on a daily basis. White rice ranks high on the glycaemic index, which means that it can cause a sudden spike in blood sugar levels (Mann, 2012).

### **Relationship with Healthcare Professionals (HCPs)**

In this study, patients revealed that their relationship with healthcare professionals helped them to manage their illness efficiently. Diabetic patients do have consistent contact with healthcare professionals. A population-based study in Denmark by Dalsgaard and colleagues (2012) found that persons with diabetes had nearly five additional consultations with their general practitioner during the first year after their diagnosis.

Doctor–patient interaction with regard to diabetes management and care has been investigated in past researchers. For example, Rose, Harris, Ho and Jayasinghe, (2009) investigated the interaction between patient self-efficacy and GP communication through explaining diabetes self-management in a disadvantaged region of Sydney, Australia. These researchers utilised a cross-sectional survey design to assess patients’ self-reported beliefs and behaviours about diabetes self-management. One hundred and five patients completed various self-reported measures, such as the Summary of Diabetes Self-Care

Activities Scale (SDSCA), the Diabetes Self-Efficacy Scale (DSES), and the General Practice Assessment Questionnaire (GPAQ). The findings of this study indicated a significant interaction between diabetes self-efficacy and GP communication in blood glucose testing; high ratings of GP communication enhanced self-monitoring of blood glucose when patient self-efficacy was high, but impeded self-monitoring of blood glucose when self-efficacy was low. This study clearly identified that diabetic patients experienced various psychosocial barriers. However, there is a huge concern about whether HCPs are equipped with the skills and ability to deal with patients' psychosocial issues.

Mosely, Aslam and Speight (2010) conducted the first qualitative study to explore HCPs' perceptions of communication with their diabetes patients about psychosocial concerns in the UK. In this study, 18 HCPs completed semi-structured interviews that explored three factors: (1) participants' understanding and experience of psychosocial issues, (2) their levels of confidence and comfort in dealing with psychosocial issues and the importance they place on addressing psychosocial issues during consultations, and (3) their perceptions of barriers to addressing psychosocial concerns during consultations. Findings of this study indicated that HCPs were apprehensive about some of the psychosocial issues raised by their patients during consultations, including the impact of the initial diagnosis, discussion of diabetes-related issues, cultural differences, and general emotional distress relating to diabetes. HCPs expressed and identified that they should adopt a patient-focused approach during the consultation. They identified the need for knowledge and information about how to deal with specific psychosocial issues.

### **Study Limitations**

There are various strengths and weaknesses in this study. Firstly, due to the qualitative nature of this study, the generalisability of the findings is limited. Another weakness of this study was the sampling of participants. As this sample of participants was recruited from a private hospital in Malaysia, the majority of patients are from an affluent background. It is questionable whether these findings would be applicable to other diabetic patients from a non-affluent background. Furthermore, only patients who were able to communicate in English were recruited for this study. It is highly possible that this group of

participants have also obtained some form of formal education which has contributed to their English conversational ability. It is highly likely that diabetic illness perception of non-English-speaking patients could be different. Similarly, patients with no formal education could be perceiving diabetes in a different way in comparison with patients with formal education. This study only included patients who have been diagnosed for more than 1 year. Newly diagnosed patients could have a different illness perception for these group of patients.

This study utilised abbreviated grounded theory as an analytical methodology rather than the full grounded theory. Therefore, theoretical sampling was not used. A full grounded theory study could be beneficial in the future as it would provide an opportunity for in-depth scrutiny into this topic. Thus, the study needs to be replicated with patients from other backgrounds to investigate whether these findings will be replicated. Replication should specifically focus on patients from government hospitals as they are less affluent and could be facing other issues which were undiscovered by this research. Furthermore, similar studies should also be conducted with non-English-speaking patients and patients with no formal education. Future studies should also aim to include patients who are newly diagnosed.

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### **Appendix 1: Consent Form**



#### **Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia**

I confirm that I have read and understood the information sheet for the above study and have had an opportunity to ask questions.

I understand the responses I give will be treated as confidential, my contact details will always remain separate from the data and I will only be recognised by my participant number.

I understand that in the event that the findings of this research is published, my identity will remain anonymous

I understand that interview will be recorded, and all information provided will be treated as confidential and would only be accessible to lead researcher and research supervisors.

I understand that participation in this study is entirely voluntary and refusal to take part involves no penalty and I may withdraw from the study at any point.

I understand that standardized debriefing will take at the end of this study. The debriefing will include the purpose of the study so that I can recognize my contribution to the research.

**By signing this form I am stating that I am over 18 years of age, and that I understand the above information and consent to participate in this study being conducted by a Doctorate in Health Psychology student from City University, London.**

**Participant Number:** \_\_\_\_\_ *(to be filled by researcher)*

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Contact Details of Lead Research:

**Jana Kanapathy (Lead Researcher)**

*Trainee Health Psychologist*

E-mail: \_\_\_\_\_

**Appendix 2: Information sheet**



### **Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia**

My name is Jana Kanapathy. I am a Doctorate in Health Psychology student at City University London. I would like to invite you to participate in research that I am carrying out. Before you make a decision about participating, please read the information sheet and understand why the research is being done and what it will involve.

Ask me if there is anything that is not clear or if you would like more information.

#### **What is the purpose of the study?**

The aim of the study is to explore your experience of having Type 2 diabetes. The results from the discussion will help us to understand your personal experience of having this condition. This study aims to gain understanding on how diabetes affects people in Malaysia. The insight gained will help develop better services for diabetes patients.

#### **Why have I been invited?**

You are being invited to participate in the study because you fit the inclusion criteria of this study, which are stated below:

- Aged above 18
- Have been medically diagnosed with Type 2 diabetes

- Date of diagnosis minimum 1 year prior the date of interview
- Able to converse in English
- Able to provide consent to participating in this research

**Do I have to take part?**

Taking part is entirely voluntary. If you decide to take part you are still free to withdraw at any time and without giving a reason. Withdrawal from this research would not affect treatment/access or use of services within this hospital.

**What will happen if I take part?**

If you decide to take part in this study you will be required to take part in a one-to-one discussion with me. The discussion will typically take 40-45 minutes and will remain strictly anonymous. The discussion will consist of open ended questions. Interviews will be recorded so that I can write up what we have discussed for the purposes of the research. Interviews will take place at a time convenient to you and will be conducted in University Malaya Hospital.

**What are the possible disadvantages and risks of taking part?**

There is NO potential disadvantage or harm in taking part in this study

**What are the possible benefits of taking part?**

There are indirect benefits to participating in this study. This research would be a crucial first step to gain understanding on how diabetes patients in Malaysia deal with their illness. It is expected that this work will emphasize the importance of addressing diabetic patients' illness perceptions. Further to these, the findings of this research would also have potential influence on health promotion and intervention design for these patients

**What will happen when the research study stops?**

If this research study stops, all raw data will be destroyed and all electronic files will be deleted

**Will my taking part in the study be kept confidential?**

If you consent in taking part in the study, all the information which is collected about you and from you will be kept strictly confidential. The information under no circumstances will be passed on to anybody. You will not be identifiable in any report produced. Your audio recording will be destroyed after it has been written up. A copy of the findings of this research will be available to research participants upon request.

**What will happen to results of the research study?**

The findings from the discussion will be written up as part of my Doctorate thesis. I also aim to present the findings in diabetes related conferences. The findings may also be published in research journals. Your identity will remain anonymous.

**What will happen if I don't want to carry on with the study?**

All participants are free to withdraw from the study without an explanation or penalty at any time.

**What if there is a problem?**

If there is a problem or complain on this research, your local point of contact would be

**Dr. Shamin Ramasamy**

Consultant Endocrinologist

E-mail: [shamin.ramasamy@princecourt.com](mailto:shamin.ramasamy@princecourt.com)

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone [REDACTED]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: **Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia.**

You could also write to the Secretary at:

[REDACTED]  
Secretary to Senate Research Ethics Committee  
Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB  
Email: [REDACTED]

**Who has reviewed the study?**

This study has been approved by City University London *Senate* Research Ethics Committee and University Malaya Ethics Committee.

**Further information and contact details**

If you would like to take part then please contact:

**Jana Kanapathy (Lead Researcher)**

*Trainee Health Psychologist*

E-mail: [REDACTED]

If you have any questions or queries regarding the research please contact Jana Kanapathy as above or:

**Dr Vanessa Bogle (Research Supervisor)**

*Chartered Health Psychologist (City University, London)*

E-mail: [REDACTED]

**Thank you for taking the time to read this information sheet.**

**Appendix 3: Demographic questionnaire**



**CITY UNIVERSITY  
LONDON**

Participant number: \_\_\_\_\_ *(to be filled by researcher)*

**How old are you?**

\_\_\_\_\_

**Please state your  
gender**

<input type="checkbox"/>	Male
<input type="checkbox"/>	Female

**Duration of diabetes:**

\_\_\_\_\_

**Please state your last recorded blood sugar level:**

\_\_\_\_\_

**Please state your occupation**

<input type="checkbox"/>	Student
<input type="checkbox"/>	Manual
<input type="checkbox"/>	Routine non-Manual
<input type="checkbox"/>	Managerial
<input type="checkbox"/>	Other _____

<input type="checkbox"/>	Professional
<input type="checkbox"/>	Medical/Nursing
<input type="checkbox"/>	Retired/semi-retired
<input type="checkbox"/>	Unemployed
<input type="checkbox"/>	

**Please state your ethnicity**

<input type="checkbox"/>	Malay
<input type="checkbox"/>	Indian
<input type="checkbox"/>	Chinese
<input type="checkbox"/>	Other (please state: _____)

**Please state your education level**

<input type="checkbox"/>	None	<input type="checkbox"/>	PhD
<input type="checkbox"/>	SPM	<input type="checkbox"/>	Other
<input type="checkbox"/>	Diploma	<input type="checkbox"/>	Please state: _____
<input type="checkbox"/>	Degree		
<input type="checkbox"/>	Masters		

**Please state your marital status**

<input type="checkbox"/>	Single
<input type="checkbox"/>	In a relationship
<input type="checkbox"/>	Married
<input type="checkbox"/>	Divorced
<input type="checkbox"/>	Widowed

**Appendix 4: Semi-structured interview template**



**Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia**

Hello, my name is Jana Kanaphy and I am a trainee health psychologist. I'm currently doing my Doctorate in Health Psychology at City University London. I am here today to ask you about your experience of having Type 2 Diabetes. This is not a test; there are no right and wrong answers. (Mention tape recorder/confidentiality/right to withdraw).

**Can you tell me about yourself and about your diagnosis of diabetes?**

- When were you diagnosed
- Initial reaction (feelings, emotions, thoughts)
- Concerns

**Emotional representations:**

1. What are your feelings associated with having diabetes
2. Could you explain if have any worries and/or anxiety about diabetes
3. Could you explain if you have been fearful or afraid of having diabetes? What contributes to this fear?

**Timeline**

1. What are your views on the duration of your illness  
(**Prompts:** permanent, temporary)
2. In your view, do you believe your symptoms will improve with time

**Consequences:**

1. What is your view about the seriousness of diabetes
2. In what way, if any, has diabetes impacted on your life??
  - i. (**Prompt:** medically, psychologically (emotions/feelings), socially)
3. In your view, does your illness affect the way others see you?
4. Can you tell me about any financial constraints that resulted from having diabetes
  - i. (**Prompts:** medical treatment cost, medication)
5. What impact has your illness had on those close to you? (**Prompt:** family, friends)

**Personal control:**

1. Do you think that it is within your ability to control your diabetes symptoms
2. What measures have you taken to control your diabetes symptoms
3. Do you believe that the course of your illness depends on you

**Treatment control items**

1. What kind of treatment are you currently receiving for diabetes
2. What are your views on this treatment  
(**Prompt:** effective, ineffective, negative effect. Positive effect)

**Illness coherence**

1. Tell me about your understanding of diabetes.
  - i. (**Prompt:** good understanding, poor understanding)
2. Do you find any aspects of diabetes puzzling, mysterious?
  - i. (**Prompt:** What aspects)

**Timeline cyclical**

1. Tell me about the pattern of your diabetes symptoms  
(**Prompt:** does the symptoms come and go, predictable /unpredictable, what influences this change?)

### **Causes of diabetes**

1. In your view what caused your diabetes  
(**Prompt:** behavioural factor, hereditary, stress/anxiety, luck)

### **Appendix 5: Debriefing form**



### **Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia**

Thank you for taking your valuable time out to take part in this research. Your contribution is very much appreciated. The aim of this study is to investigate the thoughts and emotions attributed to diabetes among diabetic patients in Malaysia and the management/coping styles adapted by patients.

The findings from the discussion will be written up as part of my Doctorate thesis. I also aim to present the findings in diabetes related conferences. The findings may also be published in research journals. Your identity will remain anonymous.

It was estimated that by 2030, 2.48 million Malaysians will be affected by diabetes. Diabetes prevalence rate in Malaysia has risen much faster than expected. Thus far, diabetes researches in Malaysia have failed to assess patients' personal beliefs about their illness.

The present study would be addressing the identified gap in the current literature, namely, an understanding of the psychological processes involved in managing diabetes. The findings from this research would also provide a platform for the establishment of future successful educational and behavioural interventions aimed at diabetes patients in Malaysia.

If you would like to discuss any issues further, please consult the lead researcher, who will direct you to the appropriate services. If you would like further information on diabetes then please contact any of the service below:

<b>Malaysian Diabetes Association</b> No. 2, Lorong 11/4E, 46200 Petaling Jaya Selangor Darul Ehsan  <b>Tel:</b> 03-79574062 <b>Fax:</b> 03-79604514 <b>Email:</b> <a href="mailto:info@diabetes.org.my">info@diabetes.org.my</a>	<b>National Diabetes Institute (NADI)</b>  No. 1, Jalan SS 3/50, University Garden, 47300 Petaling Jaya, Selangor, Malaysia  Telephone : 03-78761676 / 78761677 Fax : 03-78761679  E-mail : <a href="mailto:enquiry@nadidiabetes.com.my">enquiry@nadidiabetes.com.my</a> Website : <a href="http://www.diabetesmalaysia.com.my">www.diabetesmalaysia.com.my</a>
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If you have further questions or concerns about this study please contact:

**Jana Kanapathy (Lead Researcher)**

*Trainee Health Psychologist*

Contact Number: [REDACTED]

E-mail: [REDACTED]

**Dr Vanessa Bogle (Research Supervisor)**

*Chartered Health Psychologist*

E-mail: [REDACTED]

We declare that the information provided above is in accordance to the best of our knowledge.

**Thank you for your participation in this study**

## **Chapter 3:**

### **Using an Illness Perception Questionnaire-Revised (IPQ-R) to predict self-monitoring practices and medication adherence in type 2 diabetes patients in Malaysia: A quantitative study**

Regular self-care practices, such as eating a healthy diet, exercising, and regular glucose monitoring, are crucial in diabetes management (Glasgow et al., 2002; Norris, Lau, Smith, Schmid, & Engelgau, 2002). Various studies on diabetic patients in Malaysia have found poor medication adherence and suboptimal self-care practices (Mastura, Chew, Lee, Cheong, & Ghazali, 2011; Mustafa, 1998; Mafauzy, 2005; Mafauzy, 2006). Research thus far has failed to investigate the factors that contribute towards poor self-care practices among diabetic patients in Malaysia. As previously stated, the Illness Perception model has been successful in predicting diabetes self-care practices such as dietary compliance, medication adherence, and physical activity (e.g. Broadbent, Donkin, & Stroh, 2011; Rassart et al., 2014). The aim of this study is to investigate the relationships between patients' illness perceptions and their adherence to self-care regimens. As Malaysia is a

country with diverse ethnicity, the secondary aim of this study is to determine whether there are cultural differences in the way in which patients with type 2 diabetes from different ethnic groups conceptualise their illness and treatment.

## **3.1 Methodology**

### **3.1.1 Study Design**

This study utilised a cross-sectional design.

### **3.1.2 Recruitment Procedures**

Ethical approval for this research was obtained from the Senate Ethics Committee of City University and the Malaysian Health Ministry Ethical Approval Committee prior to data collection. Participants were recruited from the Prince Court Medical Centre, Malaysia, which is a private multi-specialty hospital offering a wide range of medical services. Patients pay to receive medical treatment from this hospital. This research was conducted at the Endocrinology (Diabetes Service) clinic of the Prince Court Medical Centre.

Potential participants were initially approached opportunistically at this hospital by the Consultant Endocrinologist. At this stage, patients were also provided with verbal and written information on this research. Participants were given time (minimum of 1 day) to decide if they were willing to participate in the research. If patients were willing to participate in the research, the lead researcher (JK) was informed, and arrangements were made for data collection.

On the day of data collection, patients were given the opportunity to seek any clarification on the research from the lead researcher. Participants' written consent was obtained prior to their participation using a consent form. Verbal and written debriefing was provided after their participation.

### **3.1.3 Participants**

Participants recruited in this study fulfilled all of the inclusion criteria below:

- Adults aged above 18 years

- Have been medically diagnosed with type 2 diabetes
- Date of diagnosis was minimum of 1 year prior to the date of interview
- Fluent English conversational ability
- Ability to provide written informed consent

The exclusion criteria for this research are stated below:

- Patients aged below 18 years
- Patients with type 1 diabetes
- Patients with gestational diabetes
- Patients with less than 1 year diagnosis
- Patients with poor English conversational and comprehension skills
- Patients who could not provide informed consent
- Patients who could not answer the questionnaire independently due to disability, other comorbidities and an unstable medical condition

### **3.1.4 Materials**

#### **Demographic questionnaire (Appendix 1)**

This questionnaire requested patients' demographic details, such as age, gender, years of diagnosis, last recorded HbA1c level, occupation, ethnicity, educational status, and marital status.

#### **Consent form (Appendix 2)**

This form was used to obtain written consent from patients prior to their participation in the research.

#### **IPQ-R diabetes questionnaire (Appendix 3)**

Participants' illness perception was measured using the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996), which is a validated quantitative assessment of the five components of illness representation. The illness perception questionnaire measures identity (perceptions of the label and symptoms of the illness), timeline (perceptions of the length of the illness), cure/control (perceptions of the curability or controllability of the illness), consequences

(perceptions of the consequences of the illness), and cause (perceptions of the cause of the illness).

#### **Summary of diabetes self-care activities (Appendix 4)**

Participants' self-care behaviour was measured using the Self-Care Inventory-Revised (SCI-R), which is a self-rated questionnaire which was devised and validated by La Greca, Swales, Klemp and Madigan (1988). The SCI-R is a brief yet reliable and valid self-report measure of diabetes self-management that is useful for both research and practice (Toobert, Hampson, & Glasgow, 2000). This questionnaire has 14 items on a 5-point Likert scale that reflects how well the subjects followed recommendations for self-care during the past month (i.e. 1 = "never" to 5 = "always").

#### **Information sheet (Appendix 5)**

This sheet contained all information regarding the research, including the nature of the research, procedure and intended use of research findings. Patients were provided with this form prior to their participation in the research.

#### **Debriefing form (Appendix 6)**

This form was given to participants after their research participation. Participants were given in-depth information about the purpose of the research. This form also signposted participants to relevant organisations that could provide further information on diabetes.

### **3.1.5 Analysis**

Data were analysed using SPSS version 22.0. Various analyses, such as descriptive analysis and Pearson correlations, were conducted. Group differences were examined by a Kruskal–Wallis H test.

## **3.2 Results**

A total of 305 patients with type 2 diabetes completed the questionnaire. One hundred and fifty participants were female (49%), and 155 participants were male (51%). Descriptive analysis revealed that thirty-one percent (31%) of participants were professionals and twenty-six percent (26%) held a managerial position. Twenty percent (20%) of participants reported that they had another occupational background, and ten percent (10%) were retired. Two percent (2%) were students, and another two percent (2%) were from a medical background. Finally, five percent (5%) were manual workers.

Forty-two percent (42%) of participants were Malays, twenty-one percent (21%) were Indians, and a further twenty-one percent (21%) were Chinese. Sixteen percent (16%) of participants classified themselves as being from 'another' ethnic background. Further analysis revealed that these participants were migrants who have Malaysian citizenship originating from various ethnic backgrounds. Descriptive analysis of participants' educational background revealed that more than twenty-seven percent (27%) of the participants had post-graduate qualifications (e.g. Master's and Ph.D.). Thirty-three percent (33%) of participants had a degree, and twenty percent (20%) had a diploma. Seven percent (7%) of participants did not have any formal education. In terms of marital status, the majority of participants were married (74%) and twenty percent (20%) were single. **Table 3** below displays participants' demographic details with corresponding percentages.

The diagnosis duration of participants ranged from 1 year to a maximum of 30 years. The mean duration for this sample of participants was six years. The last reported blood sugar reading ranged from 4.00 HbA1c to 16.40 HbA1c. The mean reading of HbA1c was 6.3. Forty-seven percent (47%) of participants reported the desired HbA1c of  $\leq 7$ .

<b>Table 3: Demographic Details Of Patients</b>	
<b>Gender</b>	<b>Percentage</b>
Males	49%
Females	51%
<b>Occupation</b>	
Professionals	31%
Managerial	26%
Medical	2%
Retired	10%
Unemployed	3%
Student	2%
Manual	5%
Other	20%
<b>Education</b>	
None	7%
SPM (O Level/GCSE equivalent)	12%
Diploma	20%
Degree	33%
Master's	26%
PhD	1%
Other	1%
<b>Ethnicity</b>	
Malay	42%

Indian	21%
Chinese	21%
Other	16%
<b>Marital Status</b>	
Married	74%
Single	20%
In a relationship	2%
Divorced	2%
Other	2%

### **3.2.1 Self-Care Practices**

The Self-Care Inventory-Revised (SCI-R) was used to assess patients' self-care practices. Mean calculation revealed that the self-care practice with the highest mean was taking the correct dose of diabetic pills and insulin. Seventy-two percent (72%) of participants rated that they 'usually or always' take the correct dose of diabetes pills and insulin. Seventy percent (70%) of participants also reported that they 'usually or always' take their pills and insulin at the correct time. More than half of the sample participants (59%) reported that they 'usually or always' check their blood glucose with the use of a monitor. One of the self-care practices with the lowest mean score was adjusting the insulin dosage based on glucose values, food and exercise. Twenty-five percent (25%) of participants reported that they never or rarely adjust their insulin dosage. Furthermore, thirty percent (30%) of participants reported that they sometimes adjust their dosage. A further self-care practice with a low mean score was carrying quick-acting sugar to treat a low blood sugar level. Only thirty-six percent (36%) of participants reported that they 'usually or always' carry quick-acting sugar to treat low blood glucose.

The outcome of the Self-Care Inventory-Revised was subjected to descriptive analysis. The mean and standard deviation of self-care practice items are presented in **Table 4** below.

<b>Table 4: Mean and Standard Deviation of Self-Care Items</b>		
	<b>Mean</b>	<b>SD</b>
1. Check blood glucose with monitor	3.67	1.05
2. Record blood glucose results	3.59	1.03
3. Take the correct dose of diabetes pills or insulin	3.77	1.47
4. Take diabetes pills or insulin at the right time	3.70	1.39

5. Eat the correct food portions	3.37	1.01
6. Eat meals/snacks on time	3.34	1.08
7. Keep food records	2.60	1.09
8. Read food labels	2.90	1.22
9. Treat low blood glucose with just the recommended amount of carbohydrates	2.65	1.39
10. Carry quick-acting sugar to treat low blood glucose	2.63	1.36
11. Exercise	3.18	1.06
12. If on insulin: Adjust insulin dosage based on glucose values, food, and exercise	2.26	1.63

**Table 5** below presents the percentages of responses for each item of the Self-Care Inventory-Revised (SCI-R).

<b>Table 5: Percentages of Responses of Self-Care Items</b>						
	<b>Missing</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Usually</b>	<b>Always</b>
1. Check blood glucose with monitor	1%	2%	7%	31%	36%	23%
2. Record blood glucose results	1%	2%	7%	36%	34%	20%
3. Take the correct dose of diabetes pills or insulin	0%	10%	3%	15%	34%	38%
4. Take diabetes pills or insulin at the right time	0%	8%	7%	15%	39%	31%
5. Eat the correct food portions	0%	3%	8%	44%	33%	12%
6. Eat meals/snacks on time	0%	3%	13%	41%	28%	15%
7. Keep food records	0%	13%	39%	30%	10%	8%
8. Read food labels	0%	12%	25%	31%	20%	12%
9. Treat low blood glucose with just the recommended amount of carbohydrates	13%	5%	21%	30%	26%	5%
10. Carry quick-acting sugar to treat low blood	7%	16%	20%	31%	16%	10%

glucose						
11.Exercise	1%	2%	20%	46%	16%	15%
12.If on insulin: Adjust insulin dosage based on glucose values, food, and exercise	23%	13%	12%	28%	16%	8%

The influence of demographic variables on total self-care practices was investigated using a Kruskal–Wallis H test, as assumptions for parametric testing were not met, specifically the homogeneity of variance. A Kruskal–Wallis H test showed that there was a statistically significant difference in self-care scores between different age groups:  $\chi^2 (1) = 9.53, p = 0.02$ . Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. The post-hoc analysis revealed statistically significant differences between patients aged 41–50 (mean rank = 160.98) ( $p = .001$ ) and patients aged 21–40 (mean rank = 127.46) ( $p = .001$ ). This indicates that patients aged 41–50 scored higher on self-care measures than patients aged 21–40.

Statistically significant differences in self-care scores between gender were also found:  $\chi^2 (1) = 23.81, p = 0.01$ . The mean rank self-care score was 175.41 for females and 132.68 for males. This indicates that female patients scored higher than male patients on the self-care measures.

A Kruskal–Wallis H test showed that there was a statistically significant difference in self-care scores between the different durations of diabetes:  $\chi^2 (1) = 4.73, p = 0.03$ . Post-hoc analysis revealed statistically significant differences between self-care scores of patients experiencing diabetes from 1–7 years (mean rank = 145.62) ( $p = .001$ ) and patients experiencing diabetes from 8–15 years (mean rank = 178.58) ( $p = .001$ ). This indicates that patients experiencing diabetes from 1–7 years scored poorer than patients experiencing diabetes from 8–15 years on the self-care measure.

Statistically significant differences in self-care scores between the different occupational groups ( $\chi^2 (1) = 24.11, p = 0.01$ ) were found. Post-hoc analysis revealed statistically significant differences between self-care scores of retired participants (mean rank = 198.00) ( $p = .001$ ) and students (mean rank = 73.00) ( $p = .001$ ). Post-hoc analysis also revealed

statistically significant differences between self-care scores of unemployed patients (mean rank = 223.00) and students ( $p = .001$ ). This indicates that students performed poorer than retired and unemployed patients on self-rating measures.

### **3.2.2 IPQ-R Diabetes Questionnaire**

The outcome of the IPQ-R Diabetes questionnaire was subjected to descriptive analysis. The mean and standard deviation of IPQ-R Diabetes questionnaire subscales are presented in **Table 6** below:

<b>Table 6: Mean and Standard Deviation of IPQ-R</b>			
	Mean	SD	Range
Consequences Subscale	18.03	3.68	10–25
Personal Control Subscale	22.25	3.77	14–30
Treatment Control Subscale	18.82	2.58	14–25
Illness Cohesion Subscale	17.57	3.22	10–25
Time Cyclical Subscale	12.23	2.79	1–16
Emotional Representation Subscale	18.47	3.67	7–26
Timeline Subscale	20.14	7.84	11–73

A Pearson product–moment correlation coefficient was computed to assess the relationship between the self-care total score and the Illness Perception subscales. There was a strong negative correlation between the self-care total score and consequences subscale [ $r(303) = -0.30, p < 0.01$ ], personal control subscale [ $r(303) = -0.17, p < 0.01$ ], treatment control subscale [ $r(303) = -0.18, p < 0.01$ ] and emotional representation subscale [ $r(303) = -0.26, p < 0.01$ ]. There was a significant negative correlation between the self-care total score and illness cohesion subscale [ $r(303) = -0.14, p < 0.05$ ]. There was also a significant negative correlation between the self-care total score and identity subscale [ $r(303) = -0.15, p < 0.01$ ].

There was no significant correlation between the self-care total score and time cyclical and timeline subscales. Increases in scores of the consequences, personal control, treatment control, illness cohesion and emotional representation subscales were correlated with decreases in the self-care total score. The relationships between the illness representation subscale and self-care behaviour are presented in **Table 7** below:

**Table 7: Relationships Between Illness Representation Subscale and Self-Care Behaviour (n = 305)**

	Consequences Subscale	Personal Control Subscale	Treatment Control Subscale	Illness Cohesion Subscale	Time Cyclical Subscale	Emotional Representation Subscale	Timeline Subscale	Identity Subscale
Self-Care Total Score	-0.30	-0.17	-0.18	-0.14	Not significant	-0.26	Not significant	-0.15

Moreover, a Pearson product–moment correlation coefficient was computed to assess the relationship between the individual items of self-care and the Illness Perception subscales.

The findings are presented in **Table 8** below:

**Table 8: Relationships Between Illness Representation Subscale and Individual Self-Care Items (n = 305)**

	Consequences Subscale	Personal Control Subscale	Treatment Control Subscale	Illness Cohesion Subscale	Time Cyclical Subscale	Emotional Representation Subscale	Timeline Subscale	Identity Subscale
1. Check blood glucose with monitor	-0.31**	NS	NS	NS	NS	-0.29**	-0.15**	-0.22**
2. Record blood glucose results	-0.24**	0.13*	NS	NS	NS	-0.17**	-0.16**	-0.18**
3. Take the correct dose of diabetes pills or insulin	NS	NS	0.15*	NS	NS	NS	0.15*	NS
4. Take diabetes pills or insulin at the right time	NS	NS	NS	NS	NS	NS	NS	NS
5. Eat the correct food portions	-0.46**	NS	NS	NS	NS	-0.26**	NS	NS
6. Eat meals/snacks on	-0.41**	-0.24**	-0.16**	NS	-0.18**	-0.31**	NS	-0.18*

time								
7. Keep food records	-0.25**	-0.45**	-0.39**	-0.23**	NS	NS	NS	-0.27**
8. Read food labels	-0.31**	-0.13*	-0.18**	NS	NS	-0.18**	-0.32**	NS
9. Treat low blood glucose with just the recommended amount of carbohydrates	NS	-0.14*	-0.26**	-0.28**	0.11*	-0.18**	NS	NS
10. Carry quick-acting sugar to treat low blood glucose	NS	-0.19**	-0.22**	-0.23**	0.22**	-0.23**	NS	NS
11. Exercise	-0.47**	-0.14*	NS	NS	NS	-0.27**	NS	-0.15**
12. If on insulin: Adjust insulin dosage based on glucose values, food, and exercise	0.19**	-0.19**	-0.33**	-0.26**	0.29**	NS	0.21**	0.14*

A Pearson product–moment correlation coefficient was computed to assess the relationship between checking blood glucose with a monitor and Illness Perception subscales. This analysis revealed a negative correlation between checking blood glucose with a monitor and the consequences subscale [ $r(303) = -0.31, p < 0.01$ ], emotional representation subscale [ $r(303) = -0.29, p < 0.01$ ], timeline subscale [ $r(303) = -0.15, p < 0.01$ ] and identity subscale [ $r(303) = -0.22, p < 0.01$ ]. This indicates that increases in scores of the consequences, emotional representation, timeline and identity subscales were correlated with a decrease in checking blood glucose with a monitor. There was a negative correlation between recording blood glucose results and the consequences subscale [ $r(303) = -0.24, p < 0.01$ ], emotional representation subscale [ $r(303) = -0.17, p < 0.01$ ], timeline subscale [ $r(303) = -0.16, p < 0.01$ ] and identity subscale [ $r(303) = -0.18, p < 0.01$ ]. This indicates that increases in scores of the consequences, emotional representation, timeline and identity subscales were correlated with a decrease in recording blood glucose results.

There was a positive correlation between taking the correct dose of diabetic pills or insulin and the treatment subscale [ $r(303) = 0.15, p < 0.05$ ] and timeline subscale [ $r(303) = 0.15, p < 0.05$ ]. This indicates that increases in scores of the treatment and timeline subscales were correlated with an increase in taking the correct dose of diabetic pills or insulin. Furthermore, there was also a negative correlation between eating the correct food portions

and the consequences subscale [ $r(303) = -0.46, p < 0.05$ ] and emotional representation subscale [ $r(303) = -0.21, p < 0.05$ ]. This indicates that increases in scores of the consequences and emotional representation subscales were correlated with a decrease in eating the correct food portions.

Eating meals/snacks on time was negatively correlated with the consequences subscale [ $r(303) = -0.41, p < 0.05$ ], personal control subscale [ $r(303) = -0.24, p < 0.05$ ], treatment control subscale [ $r(303) = -0.16, p < 0.05$ ], time cyclical subscale [ $r(303) = -0.18, p < 0.05$ ], emotional representation subscale [ $r(303) = -0.31, p < 0.05$ ] and identity subscale [ $r(303) = -0.13, p < 0.05$ ]. This indicates that an increase in scores of consequences, personal control, treatment control, time cyclical, emotional representation and identity subscales correlated with a decrease in eating meals/snacks on time. A strong negative correlation was found between keeping food records and the consequences subscale [ $r(303) = -0.25, p < 0.01$ ], personal control subscale [ $r(303) = -0.45, p < 0.01$ ], treatment control subscale [ $r(303) = -0.39, p < 0.05$ ], and illness cohesion subscale [ $r(303) = -0.23, p < 0.05$ ]. This indicates that increases in scores of the consequences, personal control, treatment control and illness cohesion subscales were correlated with a decrease in keeping food records.

There was a negative correlation between keeping food records and the consequences subscale [ $r(303) = -0.25, p < 0.05$ ], personal control subscale [ $r(303) = -0.45, p < 0.05$ ], treatment control subscale [ $r(303) = -0.39, p < 0.05$ ], illness cohesion subscale [ $r(303) = -0.23, p < 0.05$ ] and identity subscale [ $r(303) = -0.27, p < 0.05$ ]. This indicates that increases in scores of the consequences, personal control, treatment control, illness cohesion and identity subscales were correlated with a decrease in keeping food records.

There was a negative correlation between reading food labels and the consequences subscale [ $r(303) = -0.31, p < 0.05$ ], personal control subscale [ $r(303) = -0.13, p < 0.05$ ], treatment control subscale [ $r(303) = -0.18, p < 0.05$ ], emotional representation subscale [ $r(303) = -0.18, p < 0.05$ ] and timeline subscale [ $r(303) = -0.32, p < 0.05$ ]. This indicates that increases in scores of consequences, personal control, treatment control, emotional

representation and timeline subscales were correlated with a decrease in reading food labels.

Treating low blood glucose with the recommended amount of carbohydrates correlated negatively with personal control [ $r(303) = -0.14, p < 0.05$ ], treatment control [ $r(303) = -0.26, p < 0.05$ ], illness cohesion [ $r(303) = -0.28, p < 0.05$ ] and emotional representation subscales [ $r(303) = -0.18, p < 0.05$ ]. This self-care item also positively correlated with the time cyclical subscale [ $r(303) = 0.11, p < 0.05$ ]. This indicates that increases in scores of the personal control, treatment control, illness cohesion and emotional representation subscales were correlated with a decrease in treating low blood glucose with the recommended amount of carbohydrates. However, the increase in scores of the time cyclical subscale correlated with an increase in treating low blood glucose with the recommended amount of carbohydrates.

There was a negative correlation between carrying quick-acting sugar to treat low blood glucose and personal control [ $r(303) = -0.19, p < 0.05$ ], treatment control [ $r(303) = -0.22, p < 0.05$ ], illness cohesion [ $r(303) = -0.23, p < 0.05$ ] and emotional representation subscales [ $r(303) = -0.23, p < 0.05$ ]. This indicates that increases in scores of the personal control, treatment control, illness cohesion and emotional representation subscales were correlated with a decrease in carrying quick-acting sugar to treat low blood glucose. However, there was a positive correlation between this self-care item and the time cyclical subscale [ $r(303) = 0.22, p < 0.05$ ]. This indicates that increases in scores of the time cyclical subscale correlated with an increase in carrying quick-acting sugar to treat low blood glucose.

Self-rated exercising behaviour was negatively correlated with consequences [ $r(303) = -0.47, < 0.01$ ], personal control [ $r(303) = -0.14, p < 0.01$ ], emotional representation [ $r(303) = -0.27, p < 0.01$ ] and identity subscales [ $r(303) = -0.15, p < 0.01$ ]. This indicates that a high score on consequences, personal control, emotional representation and identity subscales correlated with a decrease in exercising behaviour.

Adjusting the insulin dosage based on glucose values, food, and exercise was positively correlated with consequences [ $r(303) = 0.19, p < 0.01$ ], time cyclical [ $r(303) = 0.29, p < 0.01$ ], timeline and identity subscales [ $r(303) = 0.14, p < 0.01$ ]. However, this self-care item negatively correlated with personal control [ $r(303) = -0.19, p < 0.01$ ], treatment control [ $r(303) = -0.33, p < 0.01$ ] and illness cohesion subscales [ $r(303) = -0.26, p < 0.01$ ]. This indicates that an increase in consequences, time cyclical, timeline and identity subscale scores will correlate with an increase in adjusting the insulin dosage based on glucose values, food, and exercise. However, an increase in personal control, treatment control and illness cohesion subscale scores will correlate with a decrease in adjusting the insulin dosage based on glucose values, food, and exercise.

### **3.2.3 IPQ-R Diabetes Subscales**

#### **3.2.3.1 Timeline Subscale**

The timeline subscale measures the perceptions of the length of the illness. A high score on this subscale indicates perceptions that the illness will last a long time. A low score on this scale indicates perceptions that the illness will last a short time.

The influence of demographic variables on the timeline subscale of the Illness Perception Questionnaire-Revised was investigated using a Kruskal–Wallis H test, as assumptions for parametric testing were not met, specifically the homogeneity of variance. A Kruskal–Wallis H test showed that there was a statistically significant difference in timeline scores between different age groups:  $\chi^2(1) = 11.22, p = 0.02$ . Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. The post-hoc analysis revealed statistically significant differences in timeline scores between patients aged below 20 (mean rank = 93.50) and patients aged 41–50 years above the mean rank (mean

rank = 174.33) ( $p = 0.003$ ). Patients aged 41 and above scored higher on the timeline scale than patients aged 21–40 (mean rank = 114.29) ( $p = 0.003$ ). The oldest age group of patients, aged 51–65, scored significantly higher (mean rank = 147.61) ( $p = 0.03$ ) on the timeline scale than patients aged 41–50.

A statistically significant difference in timeline scores between the different durations of the diabetes group was also found:  $\chi^2 (1) = 6.21, p = 0.01$ . Post-hoc analysis revealed statistically significant differences in timeline scores between patients diagnosed more than 16 years (mean rank = 174.33) and patients diagnosed from 1–7 years (mean rank = 93.50) and 8–15 years (mean rank = 127.08) ( $p = 0.001$ ). This indicates that patients diagnosed for more than 16 years scored higher than other patients on the timeline subscale.

A Kruskal–Wallis H test showed that there was a statistically significant difference in timeline scores between the different ethnic groups:  $\chi^2 (1) = 22.03, p = 0.01$ . Post-hoc analysis revealed statistically significant differences in timeline scores between Malay patients (mean rank = 168.76) and Chinese patients (mean rank = 127.08) ( $p = 0.001$ ). There was also a significant difference between timeline scores of Malay patients and other ethnic group patients (mean = 122.60) ( $p = 0.001$ ). This indicates that Malay patients scored higher on the timeline subscale than Chinese and other ethnic group patients.

A statistically significant difference in timeline scores between the different marital statuses ( $\chi^2 (1) = 4.41, p = 0.01$ ) was obtained. Post-hoc analysis revealed statistically significant differences in timeline scores between divorced patients (mean rank = 239.50) and single patients (mean rank = 142.00), married patients (mean rank = 147.39) and patients who are in a relationship (mean rank = 93.50) ( $p = 0.001$ ). This indicates that divorced patients scored much higher on the timeline subscale than patients who are single, married or in a relationship. A statistically significant difference in timeline scores between different education groups was also observed:  $\chi^2 (1) = 5.95, p = 0.01$ . Patients with no education (mean rank =

239.00) and another educational background (mean rank = 239.00) scored significantly higher on the timeline subscale than patients with a diploma (mean rank = 146.41), PhD (mean rank = 93.50), Master's (mean rank = 131.79), degree (mean rank = 144.42) or SPM (GCSE equivalent) (mean rank = 117.75) ( $p = 0.001-0.03$ ).

A Kruskal–Wallis H test showed that there was a statistically significant difference in timeline scores between the different HbA1c level groups:  $\chi^2 (1) = 16.69$ ,  $p = 0.01$ . Patients with an HbA1c from 8–10 scored lower (mean rank = 81.17) on the timeline subscale than patients with an HbA1c  $\leq 7$  (mean rank = 98.63) ( $p = 0.03$ ).

### **3.2.3.2 Emotional Representation Subscale**

The emotional representation subscale measures the emotional reactions to illness. A high score on this subscale indicates a high emotional reaction to illness. A low score on this subscale indicates a low emotional reaction to illness.

The influence of demographic variables on the emotional representation subscale of the Illness Perception Questionnaire-Revised was investigated using a Kruskal–Wallis H test. The Kruskal–Wallis H test showed that there was a statistically significant difference in emotional representation between the different marital status groups:  $\chi^2 (1) = 6.96$ ,  $p = 0.01$ . Post-hoc analysis did not yield any significance.

### **3.2.3.3 Treatment Control Subscale**

The treatment control subscale measures identity perceptions of the curability or controllability of the illness. A high score on this subscale indicates high perceptions of curability and controllability of the illness. A low score on this subscale indicates low perceptions of curability and controllability of illness.

The influence of demographic variables on the treatment control subscale of the Illness Perception Questionnaire-Revised was investigated using a Kruskal–Wallis

H test. The Kruskal–Wallis H test showed that there was a statistically significant difference in treatment control scores between the different age groups:  $\chi^2 (1) = 4.73, p = 0.01$ . Post-hoc analysis did not yield any significance.

A Kruskal–Wallis H test showed that there was a statistically significant difference in treatment control scores of patients with different durations of diabetes:  $\chi^2 (1) = 6.07, p = 0.01$ . Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. Post-hoc analysis revealed statistically significant differences in treatment control scores of patients diagnosed from 8–15 years (mean rank = 124.15) and patients diagnosed from 1–7 years (mean rank = 159.90) ( $p = 0.03$ ). Furthermore, patients with more than 16 years of diagnosis (mean rank = 167.17) ( $p = 0.03$ ) scored higher than patients diagnosed from 8–15 years. There was a statistically significant difference in treatment control scores between the different occupational groups:  $\chi^2 (1) = 22.12, p = 0.01$ . Post-hoc analysis revealed that unemployed patients (mean rank = 65.50) scored lower than manual (mean rank = 165.50) ( $p = 0.001$ ), managerial (mean rank = 168.62) ( $p = 0.001$ ), retired (mean rank = 165.50) ( $p = 0.01$ ), medical workers (mean rank = 215.50) ( $p = 0.03$ ), students (mean rank = 215.50) ( $p = 0.03$ ) and professionals (mean rank = 152.34) ( $p = 0.03$ ).

There was a significant difference in treatment control scores between different ethnic groups:  $\chi^2 (1) = 34.33, p = 0.01$ . Post-hoc analysis revealed that Malay patients scored higher (mean rank = 181.40) than Chinese (mean rank = 124.15) ( $p = 0.001$ ), Indian (mean rank = 147.62) ( $p = 0.02$ ) and those from other ethnic groups (mean rank = 126.50) ( $p = 0.001$ ).

#### **3.2.3.4 Time Cyclical Subscale**

The time cyclical subscale measures beliefs about the predictability or cyclic nature of illness. A high score on this subscale indicates beliefs in a high predictability or cyclic nature of illness. A low score indicates beliefs in a low predictability or cyclic nature of illness.

The influence of demographic variables on the time cyclical subscale of the Illness Perception Questionnaire-Revised was investigated using a Kruskal–Wallis H test. The test showed that there was a statistically significant difference in time cyclical subscale score patients with different durations of diabetes:  $\chi^2(1) = 6.76, p = 0.01$ . Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. The post-hoc analysis revealed statistically significant differences in time cyclical scores of patients diagnosed with diabetes from 8–15 years (mean rank = 176.85) and patients diagnosed from 1–7 years (mean rank = 144.73) ( $p = 0.01$ ). This indicates that patients diagnosed with diabetes from 8–15 years scored higher on the time cyclical subscale.

A Kruskal–Wallis H test showed that there was a statistically significant difference in time cyclical subscale scores between the different marital status groups:  $\chi^2(1) = 3.96, p = 0.01$ . Post-hoc analysis did not yield any significance. There was a significant difference in time cyclical scores between different educational groups:  $\chi^2(1) = 24.79, p = 0.01$ . The post-hoc analysis revealed statistically significant differences in scores of SPM qualified patients (mean rank = 213.71) and patients with another qualification (mean rank = 83.00) ( $p = 0.01$ ), no qualification (mean rank = 198.00) ( $p = 0.001$ ), a degree (mean rank = 144.00) ( $p = 0.001$ ), Master's (mean rank = 140.19) ( $p = 0.001$ ) and PhD (mean rank = 83.00) ( $p = 0.01$ ).

### **3.2.3.5 Consequences Subscale**

The consequences subscale measures perceptions of the consequences of the illness. A high score indicates a perception of high consequences. A low score indicates a perception of low consequences.

The influence of demographic variables on the consequences subscale of the Illness Perception Questionnaire-Revised was investigated using a Kruskal–Wallis H test. The test showed that there was a statistically significant difference in consequences subscale scores between the different HbA1c groups:  $\chi^2(1) = 6.93, p = 0.01$ .

Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. The post-hoc analysis revealed statistically significant differences in consequences subscale scores between patients with an HbA1c level above 11 (mean range = 45.50) and patients with an HbA1c level less than 7 (mean range = 97.75) ( $p = 0.001$ ) and patients with an HbA1c level from 8–10 (mean range = 102.50) ( $p = 0.001$ ).

There was also a significant difference in consequences subscale scores of different occupational groups:  $\chi^2 (1) = 10.29, p = 0.01$ . Post-hoc analysis revealed statistically significant differences in consequences subscale scores between students (mean range = 83.00) and manual workers (mean range = 183.00) ( $p = 0.04$ ). Moreover, retired patients scored lower (mean range = 108.00) than managers (mean range = 158.00) ( $p = 0.05$ ), professionals (mean range = 169.84) ( $p = 0.05$ ), manual workers (mean range = 183.00) ( $p = 0.04$ ) and medical workers (mean range = 233.00) ( $p = 0.01$ ).

#### **3.2.3.6 Personal Control Subscale**

The personal control subscale measures perceptions of the controllability of the illness. A high score in this subscale indicates a high perception of controllability and a low score indicates a low perception of controllability.

The influence of demographic variables on the personal control subscale of the Illness Perception Questionnaire-Revised was investigated using a Kruskal–Wallis H test. This test showed that there was a statistically significant difference in personal control subscale scores between the different ethnic groups:  $\chi^2 (1) = 12.12, p = 0.01$ . Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. The post-hoc analysis revealed statistically significant differences in personal control subscale scores of Malay patients (mean range = 171.70) and Chinese patients (mean range = 126.65)

( $p = 0.001$ ). This indicates that Malay patients scored higher than Chinese patients on the personal control subscale.

There was a statistically significant difference in personal control subscale scores between different marital status groups:  $\chi^2 (1) = 15.80, p = 0.01$ . Post-hoc analysis revealed that single patients scored significantly higher (mean range = 195.08) than married (mean range = 145.95) ( $p = 0.001$ ), divorced (mean range = 68.00) ( $p = 0.003$ ) and patients in a relationship (mean range = 68.00) ( $p = 0.003$ ).

### **3.2.3.7 Identity Subscale**

The identity subscale measures patient's rating of the number of symptoms that the patient sees as part of the illness. A high score on this subscale indicate that patients perceive that a high number of symptoms are part of the illness.

The Illness Perception Questionnaire lists 14 symptoms that could have been experienced by patients. These items represent the identity subscale. The questionnaire also requested patients to rate if they thought the symptoms were caused by diabetes. Fifty-three percent (53%) of patients reported that they experienced weight loss and fifty-four percent (54%) rated that these symptoms were caused by diabetes. More than half of the participants (59%) also reported that they experienced fatigue and fifty-four percent (54%) reported that this symptom was caused by their diabetes. The final symptom that was frequently reported by participants was the loss of strength. Sixty-one percent (61%) of participants reported this symptom. Moreover, fifty-four percent (54%) of participants reported that this symptom was caused by their diabetes.

The influence of demographic variables on the identity subscale of the Illness Perception Questionnaire-Revised was investigated using a Kruskal–Wallis H test. The test showed that there was a statistically significant difference in identity subscale scores between the different occupational groups:  $\chi^2 (1) = 20.26, p = 0.01$ . Pairwise comparisons were performed using Dunn's (1964) procedure with a

Bonferroni correction for multiple comparisons. Post-hoc analysis indicated that managers (mean range = 179) scored significantly higher on this subscale than professionals (mean range = 143.87) ( $p = 0.03$ ), the 'other' employment group (mean range = 121.50) ( $p = 0.001$ ) and unemployed participants (mean range = 96.50) ( $p = 0.01$ ). Furthermore, students scored higher (mean range = 246.00) than medical staff (mean range = 96.50) ( $p = 0.02$ ), unemployed (mean range = 96.50) ( $p = 0.04$ ) and the 'other' occupational group (mean range = 121.50) ( $p = 0.01$ ). There was a significant difference in identity subscale scores between different HbA1c groups:  $\chi^2(1) = 16.17, p = 0.01$ . Post-hoc analysis indicated that participants with an HbA1c from 8–10 scored lower (mean range = 85.67) than participants with an HbA1c  $\leq 7$  (mean range = 104.35) ( $p = 0.02$ ).

A Kruskal–Wallis H test showed that there was a statistically significant difference in identity subscale scores between the different educational groups:  $\chi^2(1) = 10.02, p = 0.01$ . Post-hoc analysis indicated that participants with a PhD (mean range = 249) ( $p = 0.001$ ) and other educational qualification (mean range = 249) ( $p = 0.001$ ) scored significantly higher than patients with an SPM qualification.

### 3.3 Discussion

This study was conducted to investigate the relationships between patients' illness perceptions and their adherence to self-care regimens. The secondary aim of this study was to determine whether there are cultural differences in the way in which type 2 diabetic patients from different ethnic groups conceptualise their illness and treatment.

Findings from this study indicate that less than fifty percent (50%) of patients had the desired HbA1c  $< 7$ . These findings are consistent with other research findings in Malaysia which have consistently demonstrated that patients have difficulties in meeting their HbA1c target (Mastura et al., 2011; Rampal et al., 2009). However, in comparison with other research findings (e.g. Wong and Rahimah, 2004; Mafauzy, 2006), the rate of patients who were compliant with the recommended HbA1c level is higher in this study.

This study found that female patients scored higher than male patients on self-care practices. Research has proven that there is a variation in the measures that males and females take to manage diabetes (Legato et al., 2006). The lack of self-care among males could possibly be attributed to the male gender roles. Malaysia is a country that still adopts traditional gender roles. According to Liburd, Namageyo-Funa and Jack (2007), men desire conforming to the traditional masculine characteristics of autonomy and dominance, and stoicism may hinder self-care, glycaemic control, and observance of treatment. The findings of this study also indicated that younger patients have poorer self-care scores than older participants. According to Tan and Magarey (2008), a possible explanation for this could be that older patients have been diagnosed for a longer period and, thus, have better comprehension and strategies for diabetes management.

This is the first study in Malaysia that has utilised the Illness Perception Questionnaire among a diabetic population. Therefore, the findings from this research can serve as a basis for the further application of the model in research and practice. The Illness Perception Questionnaire is very helpful in understanding patients' appraisal of type 2 diabetes. Bean, Cundy and Petrie (2007) demonstrated that illness representation has an impact on diabetes treatment adherence and self-management of diabetes. Similarly, the current research adds to the vast number of established findings on the importance of studying and understanding illness representation of diabetes patients.

Some findings of this research contradict previous findings of similar research. For example, Watkins et al., (2000) found that perceived control significantly predicted engagement in diabetes-specific health behaviours. In a separate study, Broadbent, Donkin and Stroh (2011) found that medication adherence was associated with higher personal control. However, the findings of the current study indicate that treatment control and self-care were negatively correlated.

Previous research has demonstrated that patients' perceived seriousness/consequences of diabetes predicted physical activity engagement and dietary adherence (Skinner, Hampson,

and Fife-Schaw, 2002; Skinner et al., 2002). The findings of the current study found that patients' perception of the seriousness/consequences of diabetes was negatively correlated with self-care practices. However, these findings are consistent with the findings of Broadbent, Donkin, and Stroh (2011) who found that a higher level of self-care adherence was associated with lower perceived consequences control.

Nsereko et al., (2013) found a significant negative correlation between time cyclical and self-care behaviour. Patients who perceived cyclical changes of type 2 diabetes were less involved in self-care behaviour. In this study, no significance was found between the time cyclical subscale and overall self-care score. However, similar to the findings of Nsereko and colleagues (2014), an investigation on individual items of self-care indicated that the time cyclical subscale was negatively correlated with eating meals and snacks on time, treating low blood glucose with the recommended level of carbohydrates, carrying quick-acting sugar, and adjusting insulin usage.

Consistent with the findings of Bean et al., (2007), the current study has demonstrated that there were ethnic differences in illness perceptions and diabetes self-care. The findings of this study indicate that Malay patients had a higher score than other ethnic groups on personal control, treatment control and timeline subscales.

The findings of this research shed important insight into patients' illness perception. Nevertheless, this study does have some limitations. One of the major limitations of this study is that the sample was recruited from a private Malaysian hospital. Therefore, patients are from higher socio-economic backgrounds and, thus, are more likely to be more educated than the typical Malaysian population. This could affect the generalisability of these findings. Another factor that could also affect generalisability is the potential for selection bias. This study could be biased due to population/sampling bias. Other forms of selection bias could have also affected the findings, such as volunteer bias (due to the convenience sampling) and bias arising from our exclusion criteria. Therefore, the generalisability of the findings is limited. Therefore, future studies are needed to explore whether the current results are representative of the entire population of Malaysia with diabetes. Future studies should be conducted within Malaysian government hospitals.

Measures should also be taken to replicate this study within rural areas in Malaysia. Future research should also work on translating the Illness Perception Questionnaire to the Malaysian language (Malay). This step is crucial as patients accessing the government hospitals in Malaysia may not be comfortable with the usage of the English-medium questionnaire. The data obtained from the Malay version of the questionnaire should be subjected to parametric testing in order to test the reliability and validity. Having a valid Illness Perception Questionnaire translated and validated in Malay could be very important for diabetes healthcare providers who intend to use this scale in assessing patients' perception of diabetes.

A further limitation of this study is the usage of self-reported measures. It could be very beneficial in the future to obtain objective measures of HbA1c. The data obtained through self-report measures could be contaminated by social desirable bias. This is a bias in the tendency for participants to respond to questions in a way that presents them as good, or adherent to recommendations. In this study, it is highly possible that patients reported higher levels of self-care due to this bias. To reduce the possibility of social desirable reporting, the questionnaire was administered by the lead researcher and not by the Consultant Endocrinologist. However, the very fact that the study was conducted within the hospital vicinity could have increased the chances of social desirable bias.

The cross-sectional nature of this study also hinders the ability to ascertain the direction of the relationship between illness perception and self-care behaviour. For example, it can be expected that patients' illness perceptions shape their self-care behaviours. However, the success or failure in self-care behaviour could, in turn, shape patients' illness perceptions. Thus, a longitudinal study could be utilised in future to investigate the direction of the relationship between illness perception and self-care behaviour.

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**Appendix 1: Demographic questionnaire**



**CITY UNIVERSITY  
LONDON**

Participant number: \_\_\_\_\_ *(to be filled by researcher)*

**How old are you?**

**Please state your  
gender**

**Duration of diabetes:**

\_\_\_\_\_

\_\_\_\_\_

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<input type="checkbox"/>	Male
<input type="checkbox"/>	Female

**Please state your last recorded blood sugar level:**

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**Please state your occupation**

<input type="checkbox"/>	Student	<input type="checkbox"/>	Professional
<input type="checkbox"/>	Manual	<input type="checkbox"/>	Medical/Nursing
<input type="checkbox"/>	Routine non-Manual	<input type="checkbox"/>	Retired/semi-retired
<input type="checkbox"/>	Managerial	<input type="checkbox"/>	Unemployed
<input type="checkbox"/>	Other _____		

**Please state your ethnicity**

<input type="checkbox"/>	Malay
<input type="checkbox"/>	Indian
<input type="checkbox"/>	Chinese
<input type="checkbox"/>	Other (please state: _____)

**Please state your education level**

<input type="checkbox"/>	None	<input type="checkbox"/>	PhD
<input type="checkbox"/>	SPM	<input type="checkbox"/>	Other
<input type="checkbox"/>	Diploma	Please state: _____	
<input type="checkbox"/>	Degree		
<input type="checkbox"/>	Masters		

**Please state your marital status**

<input type="checkbox"/>	Single
<input type="checkbox"/>	In a relationship
<input type="checkbox"/>	Married
<input type="checkbox"/>	Divorced
<input type="checkbox"/>	Widowed

**Appendix 2: Consent form**



**Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia**

I confirm that I have read and understood the information sheet for the above study and have had an opportunity to ask questions.



## YOUR VIEWS ABOUT YOUR DIABETES

Listed below are a number of symptoms that you may or may not have experienced since your diabetes. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your diabetes, and whether you believe that these symptoms are related to your diabetes.

	I have experienced this symptom since my diabetes			This symptom is related to my diabetes	
	Yes	No	_____	Yes	No
Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Breathlessness	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No

We are interested in your own personal views of how you now see your current diabetes.

Please indicate how much you agree or disagree with the following statements about your diabetes by ticking the appropriate box.

VIEWS ABOUT YOUR DIABETES		STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
P1	My diabetes will last a short time					
P2	My diabetes is likely to be permanent rather than temporary					
P3	My diabetes will last for a long time					

	<b>VIEWS ABOUT YOUR DIABETES</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
IP4	This diabetes will pass quickly					
IP5	I expect to have this diabetes for the rest of my life					
IP6	My diabetes is a serious condition					
IP7	My diabetes has major consequences on my life					
IP8	My diabetes does not have much effect on my life					
IP9	My diabetes strongly affects the way others see me					
IP10	My diabetes has serious financial consequences					
IP11	My diabetes causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my diabetes gets better or worse					
IP14	The course of my diabetes depends on me					
IP15	Nothing I do will affect my diabetes					
IP16	I have the power to influence my diabetes					
IP17	My actions will have no affect on the outcome of my diabetes					
IP18	My diabetes will improve in time					
IP19	There is very little that can be done to improve my diabetes					
IP20	My treatment will be effective in curing my diabetes					
IP21	The negative effects of my diabetes can be prevented (avoided) by my treatment					
IP22	My treatment can control my diabetes					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My diabetes is a mystery to me					

IP26	I don't understand my diabetes					
IP27	My diabetes doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my diabetes change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My diabetes is very unpredictable					
IP32	I go through cycles in which my diabetes gets better and worse.					
IP33	I get depressed when I think about my diabetes					
IP34	When I think about my diabetes I get upset					
IP35	My diabetes makes me feel angry					
IP36	My diabetes does not worry me					
IP37	Having this diabetes makes me feel anxious					
IP38	My diabetes makes me feel afraid					

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## CAUSES OF MY DIABETES

We are interested in what you consider may have been the cause of your diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your diabetes. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11*	Overwork					
C12*	My emotional state e.g. feeling down, lonely, anxious, empty					
C13*	Ageing					
C14*	Alcohol					
C15*	Smoking					
C16*	Accident or injury					
C17*	My personality					
C18*	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR diabetes. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

**Appendix 4: Summary of diabetes self-care activities**

**Self Care Inventory-Revised Version (SCI-R)**

This survey measures what you actually do, not what you are advised to do. How have you followed your diabetes treatment plan in the past 1-2 months?

	Never	Rarely	Sometimes	Usually	Always	
1. Check blood glucose with monitor	1	2	3	4	5	
2. Record blood glucose results	1	2	3	4	5	
3. Take the correct dose of diabetes pills or insulin	1	2	3	4	5	Not taking diabetes pills or insulin
4. Take diabetes pills or insulin at the right time	1	2	3	4	5	Not taking diabetes pills or insulin
5. Eat the correct food portions	1	2	3	4	5	
6. Eat meals/snacks on time	1	2	3	4	5	
7. Keep food records	1	2	3	4	5	
8. Read food labels	1	2	3	4	5	
9. Treat low blood glucose with just the recommended amount of carbohydrate	1	2	3	4	5	Never had low blood glucose
10. Carry quick acting sugar to treat low blood glucose	1	2	3	4	5	
11. Exercise	1	2	3	4	5	
12. If on insulin: Adjust insulin dosage based on glucose values, food, and exercise	1	2	3	4	5	Never had low blood glucose

**Information sheet (Appendix 5)**



**CITY UNIVERSITY  
LONDON**

## **Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia**

My name is Jana Kanapathy. I am a Doctorate in Health Psychology student at City University London. I would like to invite you to participate in research that I am carrying out. Before you make a decision about participating, please read the information sheet and understand why the research is being done and what it will involve.

Ask me if there is anything that is not clear or if you would like more information.

### **What is the purpose of the study?**

The aim of the study is to explore your experience of having Type 2 diabetes. The results from the discussion will help us to understand your personal experience of having this condition. This study aims to gain understanding on how diabetes affects people in Malaysia. The insight gained will help develop better services for diabetes patients.

### **Why have I been invited?**

You are being invited to participate in the study because you fit the inclusion criteria of this study, which are stated below:

- Aged above 18
- Have been medically diagnosed with Type 2 diabetes
- Date of diagnosis minimum 1 year prior the date of interview
- Able to converse in English
- Able to provide consent to participating in this research

### **Do I have to take part?**

Taking part is entirely voluntary. If you decide to take part you are still free to withdraw at any time and without giving a reason. Withdrawal from this research would not affect treatment/access or use of services within this hospital.

### **What will happen if I take part?**

If you decide to take part in this study you will be required to fill in 3 questionnaires which will be given to you by the researcher. It will take approximately 15 minutes to complete the questionnaire. You will not be asked to fill in any identifiable personal details.

### **What are the possible disadvantages and risks of taking part?**

There is NO potential disadvantage or harm in taking part in this study

### **What are the possible benefits of taking part?**

There are indirect benefits to participating in this study. This research would be a crucial first step to gain understanding on how diabetes patients in Malaysia deal with their illness. It is expected that this work will emphasize the importance of addressing diabetic patients' illness perceptions. Further to these, the findings of this research would also have potential influence on health promotion and intervention design for these patients.

### **What will happen when the research study stops?**

When the research study stops, all raw data will be destroyed and all electronic files will be deleted.

**Will my taking part in the study be kept confidential?**

If you consent in taking part in the study, all the information which is collected about you and from you will be kept strictly confidential. The information under no circumstances will be passed on to anybody. You will not be identified in any report produced. Your audio recording will be destroyed after it has been written up. A copy of the findings of this research will be available to research participants upon request.

**What will happen to the results of the research study?**

The findings from the discussion will be written up as part of my Doctorate thesis. I also aim to present the findings in diabetes related conferences. The findings may also be published in research journals. Your identity will remain anonymous.

**What will happen if I don't want to carry on with the study?**

All participants are free to withdraw from the study without an explanation or penalty at any time.

**What if there is a problem?**

If there is a problem or complain on this research, your local point of contact would be

[REDACTED]  
Consultant Endocrinologist  
E-mail: [REDACTED]

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: **Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia.**

You could also write to the Secretary at:

[REDACTED]  
Secretary to Senate Research Ethics Committee  
Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB  
Email: [REDACTED]

**Who has reviewed the study?**

This study has been approved by City University London Senate Research Ethics Committee and Malaysian National Medical Research Register.

**Further information and contact details**

If you would like to take part then please contact:

**Jana Kanopathy (Lead Researcher)**

*Trainee Health Psychologist*

E-mail: [REDACTED]

If you have any questions or queries regarding the research, please contact Jana Kanopathy as above or:

**Dr Vanessa Bogle (Research Supervisor)**

*Chartered Health Psychologist (City University, London)*

E-mail: [REDACTED]

**Thank you for taking the time to read this information sheet.**

**Appendix 6: Debriefing form**



## Understanding the illness self-regulatory experience of Type 2 Diabetes patients in Malaysia

Thank you for taking your valuable time out to take part in this research. Your contribution is very much appreciated. The aim of this study is to investigate the thoughts and emotions attributed to diabetes among diabetic patients in Malaysia and the management/coping styles adapted by patients.

The findings from the discussion will be written up as part of my Doctorate thesis. I also aim to present the findings in diabetes related conferences. The findings may also be published in research journals. Your identity will remain anonymous.

It was estimated that by 2030, 2.48 million Malaysians will be affected by diabetes. The diabetes prevalence rate in Malaysia has risen much faster than expected.

Thus far, diabetes researches in Malaysia have failed to assess patients' personal beliefs about their illness. The present study would be addressing the identified gap in the current literature, namely, an understanding of the psychological processes involved in managing diabetes. The findings from this research would also provide a platform for the establishment of future successful educational and behavioural interventions aimed at diabetes patients in Malaysia.

If you would like to discuss any issues further, please consult the lead researcher, who will direct you to the appropriate services. If you would like further information on diabetes, then please contact any of the services below:

<p><b>Malaysian Diabetes Association</b> No. 2, Lorong 11/4E, 46200 Petaling Jaya Selangor Darul Ehsan</p> <p><b>Tel:</b> 03-79574062 <b>Fax:</b> 03-79604514 <b>Email:</b> <a href="mailto:info@diabetes.org.my">info@diabetes.org.my</a></p>	<p><b>National Diabetes Institute (NADI)</b> No. 1, Jalan SS 3/50, University Garden, 47300 Petaling Jaya, Selangor, Malaysia</p> <p>Telephone : 03-78761676 / 78761677 Fax : 03-78761679 E-mail : <a href="mailto:enquiry@nadiabetes.com.my">enquiry@nadiabetes.com.my</a> Website : <a href="http://www.diabetesmalaysia.com.my">www.diabetesmalaysia.com.my</a></p>
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If you have further questions or concerns about this study please contact:

**Jana Kanopathy (Lead Researcher)**

*Trainee Health Psychologist*

Contact Number: [REDACTED]

E-mail: [REDACTED]

**Dr Vanessa Bogle (Research Supervisor)**

*Chartered Health Psychologist*

E-mail: [REDACTED]

We declare that the information provided above is in accordance to the best of our knowledge.

**Thank you for your participation in this study.**

## **Chapter 4: Implications for Clinical Practice**

### **4.1 Restatement of the Problem**

Research on diabetes in Malaysia has mainly adopted a biomedical and epidemiological approach. Thus far, research in Malaysia has failed to assess patients' personal beliefs about their illness. This study employed a mixed methodology approach, which triangulates findings from two data collection methods, to gain a coherent insight into illness beliefs among Malaysian type 2 diabetes patients using a psychological approach grounded in self-regulatory theory.

### **4.2 Major Findings**

The qualitative study investigated the following: (1) the cognitive representations of illness among patients living with type 2 diabetes in Malaysia, (2) the emotional representations of illness among patients living with type 2 diabetes in Malaysia, and (3) the management/coping styles adopted by patients living with type 2 diabetes in Malaysia.

This study found that patients adopted positive cognitive representation, such as determination. The findings also suggest that patients viewed their relationship with their healthcare provider positively, which supported disease management. Patients with determination and good health provider support adopted problem based coping. Some patients had negative emotional representations towards diabetes, such as fear. In addition, patients' management of diabetes was affected by various psycho-social factors, such as the lack of understanding of family and stress. All patients expressed that Malaysian food culture had a negative impact of diabetes management. This study also revealed that some patients adopted emotional focused coping, specifically by keeping their diabetic status a secret.

The quantitative study was conducted to investigate the relationships between patients' illness perceptions and their adherence to self-care regimens. There was a strong negative correlation between the self-care total score and consequences subscale, personal control subscale, treatment control subscale and emotional representation subscale. There was a

significant negative correlation between the self-care total score and illness cohesion subscale. There was also a significant negative correlation between the self-care total score and identity subscale. This study also found that there was a difference in the ways in which different ethnic groups conceptualise their illness.

#### **4.3 Diabetes Prevention and Management in Malaysia**

As the epidemic of diabetes continues to worsen, developing and implementing an extensive and comprehensive preventive strategy is critical. According to Schwarz (2011), one of the most effective ways of managing diabetes is to prevent its development in the first place. Various prevention studies have demonstrated favourable findings. Many prevention studies have focused on weight loss and management. Thus far, the Malaysian Health Ministry has proposed plans for screening for diabetes within governmental health clinics and hospitals. According to this guideline, Malaysians above the age of 30 should be screened annually for diabetes. The guidelines also clearly indicate individuals with high risk of developing diabetes, such as individuals who have symptoms suggestive of diabetes (tiredness, lethargy, polyuria), adults who are overweight, or who have impaired glucose tolerance (IGT) or impaired fasting glucose (IFG) on previous testing, a first-degree relative with diabetes, or those who are physically inactive. Although this guideline clearly suggests ways of screening and detecting diabetes, the role of detection and screening remains mainly with the governmental health sector. Therefore, the screening and prevention initiatives should be a responsibility of both private and governmental healthcare and NGOs.

Researchers have explored the efficacy and cost-effectiveness of screening for diabetes in unconventional places such as pharmacy and optometry practices. For example, Howse (2010) proposed that implementing a diabetes screening strategy in half of optometric practices in England would have the potential to identify up to 150,000 new cases of diabetes and pre-diabetes a year. On the other hand, Hersberger, Botomino, Mancini and Bruppacher (2006) found that a national pharmacy-based screening campaign could be highly beneficial in identifying patients with high risk of developing diabetes and in providing an opportunity to initiate targeted counselling regarding a therapeutic lifestyle

change. According to Boltri et al. (2007), identifying patients at high risk does not always require huge investment. These researchers piloted a study that tested the impact of a diabetes risk assessment completed by patients without nursing assistance. In this study, patients filled in the American Diabetes Association Risk Assessment questionnaire and patients at high risk were screened for diabetes. The outcome of this study indicated that a simple patient-based risk assessment used in the outpatient setting might represent a simple, economical method for discovering previously undiagnosed type 2 diabetes.

Malaysia is a country that could have a high prevalence of impaired glucose tolerance. Thus, early detection of this condition could help to prevent the diagnosis of diabetes. Various trials have demonstrated that interventions targeted at pre-diabetic patients have favourable outcomes. For example, Wong et al. (2013) conducted a randomised controlled trial to determine the efficacy of delivering a short-message service (SMS) in order to provide diabetes-related information on reducing the risk of developing diabetes in Chinese professional drivers with pre-diabetes. Patients in this study were randomised either to receive an SMS group-receiving message comprising knowledge and lifestyle modification on diabetes or to a control group with usual care. This small-scale trial found that fewer subjects developed diabetes at 12 months in the intervention group than in the control group. Lindström et al. (2003) conducted the Finnish Diabetes Prevention Study and revealed that lifestyle intervention was beneficial to patients, and weight loss improvements were maintained up to 3 years post-intervention. Similarly, the US Diabetes Prevention Program aimed at discovering whether modest weight loss through dietary changes and increased physical activity or treatment with the oral diabetes drug metformin (Glucophage) could prevent or delay the onset of type 2 diabetes in study participants. Participants in the intervention group achieved a 58% relative risk reduction in the incidence of diabetes over the course of the study (mean of 2.8 years). Furthermore, Perreault et al. (2014) provided empirical evidence that intensive lifestyle modification demonstrated a 56% lower risk of diabetes 10 years from randomisation among those who were able to achieve normal glucose regulation. According to the WHO (2003), lifestyle intervention and metformin prescription for patients with IFG have been proven to be cost-

effective (and were both judged to be cost-effective) and have delayed the transition from IGT to diabetes.

A roll-out of a National Health Check Programme, such as the NHS Health Check, could be highly beneficial. Moreover, it is essential to develop a culturally sensitive diabetic prevention programme. This programme would need to be piloted, evaluated and modified on a constant basis in order to improve and maintain its efficiency and impact.

One of the biggest challenges faced by Malaysia is the dichotomous public–private system of health care services. Having a dual healthcare system prevents collaboration to establish best-practice models. The Malaysian Health Ministry (MOH) offers a range of services, including health promotion, disease prevention, and curative and rehabilitative care delivered through clinics and hospitals, while special institutions provide long-term care. The dual healthcare system has its pros and cons. The Malaysian Health Minister Dato' Liow in 2004 explained that the private sector is playing an important role in easing the healthcare burden. However, he reiterated that the government and private sectors should work together as the doctors are trained for the nation, irrespective of whether they work for the government or privately.

Various publications, such as the United Nations Development Programme (UNDP) Human Development Report (2006) and the World Health Report (2006), highlight that the Malaysian government spends some 6.9% of its total expenditure on health care but has managed to achieve quite laudable health outcomes. Life expectancy at birth has risen from 55.8 years and 58.2 years for men and women in 1957 to 71.8 years and 76.3 years in 2006, respectively. However, the dual healthcare system also has its cons. The 10th Malaysian Health Plan (2011–2015) highlights that the existing healthcare delivery system has been far from efficient and there has been tremendous wastage of resources within the public and private sectors. The existence of the dual system of care contributes to the misdistribution of resources. This has led to duplication of services and, to a certain extent, underutilisation of high-end, expensive technology.

Due to the dual healthcare system, many steps that are being taken by other countries could not be successfully applied in Malaysia. For example, Cunningham (2013) explained that one of the steps being taken by NHS Scotland to curb the prevalence of diabetes was to create nationwide research and development programmes that integrate electronic patient records with biological and health system data. An integrated patient record system would ensure nationwide quality-assured provision of diabetes care. Furthermore, the electronic patient record system would also facilitate epidemiological investigation, drug safety studies, enhanced efficiency of clinical trials through automated follow-up of clinical events and treatment response, and large-scale genetic, pharmacogenetic and family-based studies essential for stratified diabetes medicine. This step is crucial to establish best-practice models of diabetes prevention and care.

In Malaysia, MOH established the National Diabetes Registry in 2009. The Diabetes Registry was established to further strengthen Non-Communicable Disease surveillance in Malaysia, specifically for monitoring the quality of care among patients living with diabetes and managed in MOH healthcare facilities. An effective register would help to identify patients with poor diabetes control and patients who are at risk of complications. Most importantly, it will also identify patients who are newly diagnosed. This will enable health providers to provide the much needed guidance in helping these patients with management issues. The MOH realises the importance of research and data and its contribution to facilitating a better understanding of the improvements needed. However, establishing a system that incorporates information from the whole population of Malaysia is challenging due to the dual healthcare system. Malaysian national data does not include data from private sector services, partly because the private sector is not publicly funded, and data sharing is not established.

The current Diabetes Registry only has details obtained from the Ministry of Health hospitals, and since this registry was only established in 2009, there are still various issues being faced. For example, the data currently does not capture hospital admissions and diagnosis related to inpatient treatment. Furthermore, data verification is also not in place.

Data verification is crucial to ensure that the data entered in the registry reflects that which is captured in the medical records.

However, one of the major issues with the current database is that it does not encapsulate data from private hospitals and, thus, does not provide a holistic picture of the burden of diabetes in this country. There is currently arbitrary turf protectionist access to information from private healthcare institutions. Therefore, information exchange should be made more efficient through the use of a unified system of health information portability mechanisms. The Malaysian healthcare system should work towards a better partnership and collaboration of services, wherein the best of each system can be harnessed for the healthcare betterment of citizens.

To establish a better integration between the private and public sector, Malaysia is taking active initiatives to establish an information and communications technology (ICT) system which would be an important enabler in resolving health issues when there is system-wide and organisational commitment and investment. It is crucial that this system is transparent towards integrating services and improving information sharing. However, there are various hurdles, such as the huge investment required in infrastructure, the lack of informatics expertise, and the need to make informatics relevant to local needs and capacities.

Secondly, there is an immediate need for the Malaysian Health Ministry to conduct a comprehensive diabetes service provision analysis. This analysis would have to gather information on the overall availability of different facility-based health services in the country and their readiness to provide those services. Among other things, this service provision analysis would need to obtain details on the types of interventions/services available within the country, the nature of interventions and services, and populations accessing the services. In Malaysia, currently, there are various services provided by various organisations to prevent and manage diabetes. Despite having a wide range of services, there is a lack of integration.

Conducting a service provision analysis would enable the identification of services that are available to diabetes patients in Malaysia, the nature of such service elements, where they exist, the discipline/professional group of those providing the service, and more. This activity would help to establish what works and what does not. It will also assist in the process of identifying gaps in service provision. Service provision analysis would also help with cost savings, as it would possibly prevent the replication of the same services.

A steering group consisting of key stakeholders, including the clinicians, commissioners, diabetic nurses, psychologists, and service users, is needed to help with the diabetic service provision analysis. This steering group would work on bringing together the diverse stakeholders involved in the commissioning and delivery of local diabetes services, including people with diabetes.

Various methodologies can be employed to obtain data on current service provision. Organisations which undertake service mapping analysis have often adopted a quantitative methodology due to its convenience in data collection. For example, Diabetes UK (2008) adopted a survey approach to gathering information on the availability of psychological care for people with diabetes in the UK. This survey had a response rate of 58% and successfully identified gaps in service provision. The outcome of this intervention would provide an intervention map that clearly describes the key high-level actions or interventions available in Malaysia.

#### **4.3.1 Patient Education**

The Malaysian Clinical Practice Guidelines (2009) emphasise the importance of diabetes education. They have proposed an approach similar to that taken by many Western countries, such as the UK, Canada and Australia, wherein patients in Malaysia should be educated on diabetes as soon as they are diagnosed. NICE Guidelines (2009) further emphasised that diabetes education should be reinforced and reviewed annually. The educational intervention should be tailored to the needs of the patients. Within a multinational context, it is challenging to establish a 'one size fits all' educational programme and expect the desired behavioural change.

Education programme designers should work on creating culturally sensitive educational programmes that could benefit patients from various different demographic backgrounds. Osborn and Fisher (2008) emphasised the importance of addressing variations in cultural values underlying motivations, preferences, and behaviours of individuals from different ethnic groups in order to improve the effectiveness of diabetes educational programmes.

Malaysia has established a Malaysian Diabetes Educators Society, which organises various forms of activity and conferences to enhance the performance of diabetes educators. However, thus far, there has been no cohesion in the delivery of these educational programmes. Moreover, research in Malaysia has also established that patients who received diabetes education appeared to have problems with comprehension and application of the education received. This research also found that the majority of patients had forgotten the educational advice received after a period, which emphasises the need for re-education on a regular basis.

Prior to the educational intervention, a thorough needs assessment of the patient is needed. The needs assessment could be designed to incorporate questions that explore the patients' health-related behaviour, such as:

- Food consumption
- Smoking behaviour
- Alcohol consumption
- Stress level
- Exercise
- Use of complementary medication

The information gathered from the patients would enable healthcare providers to tailor the education to meet the needs of the individual patient. A tailored educational approach has proven to be more successful than a generic educational model (Sun, Tsoh, Saw, Chan, & Cheng, 2012). For example, Ko, Lee, Kim, Kang and Kim (2011) found that individually tailored education for low-income adult diabetic patients in Korea produced improvement in diabetes knowledge and self-management in all categories of lifestyle, diet, exercise,

foot care, medication, and insulin therapy. Having a needs assessment questionnaire could also establish baseline data on each patient, which could eventually be used as a pre- and post-measure to ascertain the effectiveness of the educational programme.

The findings of the qualitative aspect of the current research revealed that spouses do not appear to understand the diabetic health needs of their partners, as reported by the participants. Therefore, it might be useful to provide educational training for the spouses of diabetic patients to enhance their level of knowledge on diabetes management. Malaysia is a country that still very much follows the stereotypical gender roles. For example, the wives or the women in the family still conform to stereotypical roles of preparing food for the family. Abdullah, Noor and Wok (2008) found that Malaysian Muslim women still closely adhere to their traditional cultural values, in which they are expected to be a strong mother while remaining effeminate and subservient as a wife. Thus, educating female members of the family is essential. Empirical evidence suggests that family interventions for diabetes patients have various positive outcomes (García-Huidobro, Bittner, Brahm, & Puschel, 2011). For example, Keogh et al. (2011) found that family interventions for poorly controlled type 2 diabetes are effective in improving mean A1C levels, beliefs about diabetes, psychological well-being, diet, exercise, and family support. In a separate study, Hu and colleagues (2013) found that family-based diabetes interventions for Hispanic adults and their family members showed improvement in the health of diabetic patients and their family. Patients displayed improvement in systolic blood pressure, diabetes self-efficacy, diabetes knowledge, and physical and mental components of health-related quality of life. Patients also had higher levels of intake of healthy foods, and the performance of blood glucose tests and foot inspections were reported. The family members of diabetic patients had lowered their body mass index and improved their diabetes knowledge from pre-intervention to immediately post-intervention.

#### **4.3.2 Multiple Behaviour Change Interventions**

As established, diabetes management requires various behaviour modification. Therefore, a cohesive multiple behaviour change intervention is needed and could be highly beneficial in the management of diabetes. This form of intervention has been previously conducted. For example, Toobert et al. (2007) investigated the efficiency of the Mediterranean

Lifestyle Program (MLP) which targets various health behaviours, such as consuming a “Mediterranean” diet (low in saturated fat), regular physical exercise, stress management practice, smoking cessation, and social support among postmenopausal women with type 2 diabetes. The group-based Mediterranean Lifestyle Program (MLP) produced substantial and broad benefits. Both the magnitude and the maintenance of the behavioural effects on dietary, stress management and physical activity outcomes were impressive. Moreover, patients also showed that the MLP produced enhancements in quality of life. In a separate study, Toobert et al. (2011) investigated the effectiveness of cultural adaptation of a successful multiple health behaviour change programme, ¡Viva Bien!, with Latinas. The ¡Viva Bien! programme included a 2.5-day retreat (followed by weekly meetings) and encouraged participants to: (a) follow the Mediterranean diet adapted for Latin American subcultures, (b) practise stress management techniques daily, (c) engage in 30 min of daily physical activity, (d) stop smoking, and (e) take part in support groups based on problem solving. The purpose of the retreat was to introduce each of the major components of the programme and provide time for participants to practise new skills. After the retreat, the intervention continued with 4-hour facilitator-led meetings, providing 1 hour each of instruction and practice of diet, stress management, physical activity, and support groups (1 h for each component = 4 h). Meetings were held weekly for six months, and then faded to twice monthly for six months. The ¡Viva Bien! treatment condition reduced A1c by 0.8% from the baseline to 6 months. Participants demonstrated decreased saturated fat consumption, increased physical activity and stress management practices, and increased use of socio-environmental supportive resources. Women who participated in ¡Viva Bien! improved psychosocial variables such as social support, problem solving, and self-efficacy, which have been linked to health behaviour change.

Diabetes management interventions in Malaysia could work towards establishing a culturally sensitive multiple behaviour change intervention tailored for the population.

#### **4.3.3 Ongoing Web-Based Help for Diabetes**

Patients in this study expressed that family and social roles serve as a barrier to optimal diabetic management. Therefore, it is crucial to provide patients with ongoing support. In

recent years, there has been an explosive growth of Internet users around the world and a corresponding upsurge in interest in using the Internet to deliver online public health interventions such as smoking cessation treatment. The potential advantages of Internet-based treatment are clear. From the users' perspective, online treatment programmes are convenient, and content can be accessed 24 hours a day, seven days a week, 365 days a year.

As the Internet becomes an increasingly influential source of health-related information for consumers, it is important to understand the potential public health impact of Internet-based behaviour change programmes, such as for smoking cessation (Cobb, 2005). The ability to obtain accurate medical information quickly, conveniently, and privately online presents an opportunity for better-informed decision making and greater participation in personal healthcare (Goldsmith, 2000).

Furthermore, Griffiths (2005) postulates that web-based peer support, therapeutic support and advice are excellent media for self-help. Thus, forums/blogs provide a platform for service users to use this peer support if they wish during the behaviour change.

However, prior to the implementation of computerised interventions for the diabetic population, a few crucial matters need to be addressed. The main aim of the computerised interventions is to provide 24 hours of access from anywhere desirable to patients. However, it is important to create a programme that is tailored to the needs of Malaysian patients. Once the programme is developed, it is crucial to conduct a pilot study to test the computerised intervention efficiently. For the purposes of piloting the programme, patients with computer access can be targeted. This programme would be web-based, so people can access the programme from any area with an Internet connection (e.g. internet cafe, library). However, it is crucial for patients to have a consistent clinical meeting (1-to-1, telephone or e-mail) with the healthcare provider. A clinical meeting will provide extra support for participants and ensure that the patients are conforming to the computerised intervention treatment plan.

The Malaysian Health Ministry should also devise ways to promote the computerised interventions as a choice of treatment. Collaborative work with the health promotion/public health team could be beneficial in making people aware of the computerised interventions treatment option.

#### **4.3.4 Self-Efficacy and Motivational Interviewing**

The outcome of this study indicates that even among patients with a high personal control score, their self-management score was low. These findings suggest that although patients know that they can control their illness, they are not actively taking steps to control it. This could be caused by a lack of self-efficacy to carry out the self-care practices. Bandura (1997) defines self-efficacy as the individual's belief in their ability to complete the given behavioural goals. Empirical findings provide strong evidence that self-efficacy was a significant predictor of diabetes self-care behaviours (Alaboudi, Hassali, Shafie, AlRubeaan, & Hassan, 2014). Having high diabetes-related self-efficacy has been proven to reduce stress response in terms of a reduction in 'depression, anxiety' and 'helplessness' of the patients (Kanbara et al., 2008).

This calls for psychological interventions such as counselling. According to Fowles, Shields, Barron, McQuaid and Dunbar (2014), a brief counselling session with patients can bring about the necessary behaviour change among diabetic patients. Motivational interviewing should also be incorporated into the management of diabetes. The principles of motivational interviewing have been applied to the management of various diseases.

Research investigating the applicability of motivational interviewing among diabetic patients has yielded favourable results. For example, Song, Xu and Sun (2014) conducted a meta-analysis to evaluate the effect of motivational interviewing on self-management in patients with type 2 diabetes. This meta-analysis included 10 randomised controlled trials that assessed the effects of MI on self-management and HbA1c levels in patients with type 2 diabetes. The outcome of this meta-analysis revealed that motivational interviewing was associated with improved self-management abilities among patients with type 2 diabetes, and short-term motivational interviewing of less than six months effectively decreased the HbA1c level.

A qualitative study by Dellasega, Añel-Tiangco and Gabbay (2012) found that diabetic patients receiving motivational interviewing expressed that they favoured motivational interviewing as it promoted non-judgmental accountability, which encourages patients to

take responsibility for their diabetes and to take ownership of the lifestyle changes they need to make in order to be healthy. In addition, patients in this study also expressed that motivational interviewing provided them with encouragement and empowerment to make behaviour modification. Patients also expressed that motivational interviewing promoted a positive working relationship with healthcare providers, as the typical paternalistic and rushed encounter was replaced by a collaborative, guided approach to promoting a positive behaviour change. Chen, Creedy, Lin and Wollin (2012) found that the motivational interviewing approach significantly improved patients' self-management, self-efficacy and quality of life. Motivational interviewing has also been proven to be a beneficial adjunct to behavioural obesity treatment for women with type 2 diabetes (West, DiLillo, Bursac, Gore, & Greene, 2007).

#### **4.3.5 Goal Setting**

The American Diabetes Educator Society (2006) clearly identified that goal setting is a crucial aspect of diabetes behaviour change interventions. Making big behavioural and lifestyle changes immediately after the diagnosis of diabetes may seem like a daunting task. Therefore, it is crucial to break lifestyle changes into small, manageable action steps. Goal setting helps to break down the behaviour change for efficient diabetes management into small, manageable steps. *A Guide to Implementing a Care Planning Approach to Diabetes Care* (2009), which is an NHS publication, emphasised that goal setting is crucial in diabetes management, but patients should be guided towards making SMART goals. SMART goals comprise S = Specific, M = Measurable, A = Attainable, R = Realistic, and T = Time-scaled. Furthermore, there are various other factors that should be discussed with patients to ensure the success of achieving a specific goal. Healthcare providers should discuss with patients the potential barriers to achieving the behaviour goals. This will help to ascertain whether the goal is realistic and measures should be taken to maintain progress. It is also important to determine the patient's confidence in achieving the goal. Goal setting is important because having small goals can help to motivate patients to take an active role in self-management and may reinforce that they can successfully manage their disease. Providing patients with incentives may also be beneficial. Patients and healthcare providers should also work on a plan to review the progress in a timely manner.

Goal-setting approaches have been very beneficial in diabetes self-management (Langford, Sawyer, Gioimo, Brownson, & O'Toole, 2007). For example, DeWalt et al. (2009) conducted a quasi-experimental study using a one-group pre-test and post-test design to assess the effectiveness of a goal-setting intervention, along with a self-management guide. Two hundred and fifty patients enrolled in this study were provided with an in-person counselling session designed to take approximately 15 min. The initial intervention was followed by two brief telephone counselling sessions at two and four weeks. Patients were then equipped with problem-solving and goal-setting skills. Patients then worked on setting a behavioural goal for themselves. The results of this experiment indicated that most patients chose to set goals in diet and exercise domains. Ninety-three percent of patients achieved at least one behavioural goal during the study, and seventy-three percent of patients achieved at least two behavioural goals. These researchers concluded that a brief goal-setting intervention (along with a diabetes self-management guide) helped patients to set and achieve healthy behavioural goals.

Goal settings approaches are being utilised in Asian countries have also yielded favourable results. Naik et al. (2011) utilised a randomised methodology to test the effectiveness of goal setting in diabetes group clinics. In this study, the intervention group were given education and guided towards setting realistic behaviour goals, while the control group only received educational information. The outcome of this trial indicated that patients who were guided with goal setting achieved a significantly better outcome than the control group. The finding also indicated that diabetes group clinics that include structured goal-setting approaches to self-management can significantly improve HbA1c levels post-intervention and maintain improvements for 1 year. Other studies have also documented the longitudinal impact of goal setting. Anderson, Christison-Lagay and Procter-Gray (2010) reported the effectiveness of self-management goal setting in a community health centre during a 3-year period. This research found that goals focused on medication, and healthy eating was more often successfully attained. Successful goal attainment was independently associated with achieving or maintaining an A1C value of  $\leq 7.0\%$ .

#### **4.3.6 Translating Research into Practice**

A health behaviour change is a complex process. Thus, diabetes educators in Malaysia should be well trained with knowledge and skills of facilitating behaviour change. Firstly, educators should be taught theories and models of behaviour change that could be incorporated into their consultation with diabetic patients. For example, Ruggiero (2000) explained how the usage of a transtheoretical model of change could be hugely beneficial to diabetes educators in order to assess patients' readiness to change. Having comprehensive knowledge on models and theories of behavioural change would enable educators to pick and choose the models and theories that best fit a patient's needs. Thus, tailored information and services could be provided, whereby increasing the chances of success.

Diabetes educators should also be given training on ways in which to measure stress, anxiety and depression. As the presence of stress, anxiety and depression does negatively impact on diabetes management, measures should be taken to assist patients at the first sight of these symptoms. Training and treatment for anxiety and depression may not fall under the remit of a diabetes educator. Therefore, a clear referral pathway should be established. This will enable patients to gain the necessary support and treatment from a relevant professional.

#### **4.3.7 Health Psychology in Diabetes Management**

The field of health psychology definitely has much to contribute towards preventing diabetes and disease management. Health psychologists are experts in the field of behaviour modification and would be able to design and evaluate efficient behaviour change interventions, such as physical health interventions, and healthy-eating interventions to help the community to lead a healthier life. These measures would help to prevent diabetes.

Furthermore, with patients with diabetes, a health psychologist would be able to ascertain the barriers that are preventing diabetes self-management. For example, as demonstrated in this research, it is clear that certain illness perceptions deter self-management. Other factors

could also serve as barriers, such as the lack of self-efficacy and lack of social support. A health psychologist would be able to identify and rectify these barriers as these professionals are equipped with skills to utilise theories and models and promote better self-management.

As demonstrated in qualitative research, stress is a barrier to optimal diabetes management. Patients also expressed that they are not equipped or trained to deal with stress. A health psychologist can be a valuable resource in identifying maladaptive reactions to stress and can help patients to develop more useful and effective methods of coping.

A health psychologist could potentially bring about the much needed change in patients' behaviour as these professionals are trained to adopt a patient-centred role in disease management. Thus, the traditional barriers faced in a doctor–patient relationship with communication of a treatment plan (without addressing patients' needs, expectations, and concerns) would be addressed sufficiently. This could be beneficial to patients and would possibly improve health outcomes.

Finally, the research and evaluation expertise of a health psychologist is also valuable to any form of diabetic service. A health psychologist would be able to design and create patient-centred interventions that would optimise outcomes. Moreover, a health psychologist could also provide on-going support in evaluating diabetic services in order to establish best-practice models of delivery and cost-effectiveness.

## **Conclusion**

In conclusion, this research paper assesses patients' personal beliefs about their illness. By adopting a mixed methodology approach that triangulates findings from two data collection methods, a coherent insight into illness beliefs among Malaysian type 2 diabetes patients was established. The findings of this research have potential utility in diabetes management interventions. In providing diabetic management interventions, it is crucial to identify an individual patient's specific illness perception. This would promote a better understanding of patients' illness reasoning, which, in turn, could give healthcare professionals the opportunity to individualise the diabetic management intervention/advice. Interventions

could also aim to alter patients' illness perception, which has been proven to have a positive impact on self-care practices.

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# Section C

## Professional Practice

## **Generic Professional**

### **Background of Professional Practice**

Upon completing Stage 1 Health Psychology training in June 2008, I was awarded a bursary to pursue Stage 2 Health Psychology training. This bursary was jointly funded by City University, London and NHS South West (SW) Essex. As part of the course requirement, I was employed as a Trainee Health Psychologist by NHS SW Essex. This was a new role created to accommodate Stage 2 Health Psychology trainees. Predictably, there was a lack of understanding on my job role and capabilities among fellow colleagues who worked at NHS SW Essex. To rectify this issue, I had meetings with each team leader (e.g. Smoking, Obesity) to explain my role and capabilities. One of the initial challenges faced within my role was to understand the workplace dynamics and organisational structure. However, with guidance, assistance and support of my team leader, I was able to gain in-depth understanding on these issues.

Prior to commencing my role, I expected to be involved in medical/illness services when appointed. I anticipated to be involved in various behavioural interventions targeted at smoking, obesity and alcohol consumption. In reality my role was within the public health services and involved research, design and delivery of innovative public health solutions. My role was situated within the Health Improvement & Public Health Directorate and encompassed the following:

- Advising the Primary Care Trust (PCT) on Health Psychology inspired solutions to public health problems
- Involvement in research and evaluation for the Health Improvement & Public Health Directorate

While working with NHS SW Essex, I played a crucial role in various research projects undertaken for and on behalf of the organisation. The list below provides a brief description of each project I was involved with:

- Stroke Awareness Project worth £500,000 – Commissioned by the Essex Cardiac and Stroke Network. A sample of 634 participants were given a questionnaire which assessed stroke awareness. In this team project, I designed the questionnaire, uploaded it to the electronic software (KeyPoint), which exported the final dataset to SPSS. A series of ANOVAs were used to assess the statistical validity of the differences observed. I also wrote several sections of the final report which was disseminated to key stakeholders of Essex Cardiac and Stroke Network.
- Cardiovascular Disease (CVD) Risk Assessment project worth £110,000 – Carried out a qualitative study informed by social marketing principles to investigate CVD risk assessment and service awareness amongst deprived communities in South West Essex. I played a vital role in this team project where I designed the focus group template, conducted four of the twelve focus groups and analysed the data obtained using template analysis. A process of triangulation was used between me and two colleagues to combine the entire data set, creating a final master table of themes. I wrote several sections of the final report which included recommendations for senior commissioners. As a result of this study, NHS SW Essex designed a new CVD risk assessment process and campaign.
- Smoking Audit - Collated and analysed current smoking trends in NHS SW Essex which included a dataset obtained from all GPs within the locality. SPSS statistical package was used to identify demographic and geo-demographic differences in the current smoking trends. The outcome of this analysis helped Smoking Cessation

commissioners to adapt a targeted and informed approach at reducing the rates of smoking within this locality.

- Child Bereavement Audit – Commissioned by Basildon Hospital Paediatrician, this quantitative explorative study aimed to assess the services available for bereaved parents. The outcome of this study clearly identified gaps within service provision for bereaved parents. Steps to rectify these gaps were outlined.
- Pharmacy Needs Assessment - Carried out quantitative questionnaire study to assess the role of community pharmaceutical services in improving the health of local people. The outcome of this study helped key stakeholders within NHS SW Essex to gain insight into the populations' views of pharmacy services and usage patterns. The insight gained was used to enhance pharmacy services within SW Essex.

To fulfil core competencies of Stage 2 training, I explored various opportunities to provide teaching/training to diverse populations. Teaching and training sessions were designed, delivered and successfully evaluated for three diverse populations (e.g. Healthcare Professionals, BSc Psychology students and MSc Health Psychology students) in two different countries (London and Malaysia). The topics of the teaching/training sessions included individual differences in behaviour change, Social Marketing, Research Practicalities and Stage 2 Health Psychology Training. Conducting these teaching/training sessions provided an ideal platform to gain hands-on experience in conducting teaching sessions and to tailor educational materials specifically for the target audience to enhance participants'/students' learning.

In addition, opportunities to conduct Health Psychology consultancy were also explored and undertaken. The first consultancy opportunity was provided by the Institute for Health and Human Development of University of East London. I was appointed as Consultant Researcher and assisted in evaluating Tower Hamlet PCT's Pilot Vascular Screening initiative. Within my role I carried out literature review on social marketing research

related to this project, carried out focus groups/ one-to-one interviews, thematically analysed data obtained and assisted in the final evaluation report.

### **Unit 1.1 Implement and Maintain Systems for Legal, Ethical and Professional standards in Applied Psychology**

In undertaking various research projects, it was essential for me to establish and maintain systems for security and control of information. To enhance my understanding and knowledge on this issue, I familiarised myself with various publications on Ethics and Codes of Conduct (e.g. BPS Code of Ethics and Conduct, 2009; BPS Guidelines for minimum standards of ethical approval in psychological research, 2009; BPS Ethical Principles for Conducting Research with Human Participants, 2009; Health and Care Professions Council (HPC) - Guidance on conduct and ethics for students, 2010). Further to these, I established links with the Research and Development (R&D) Centre of Essex. The R&D team reviewed project proposals, and provided guidance on potential ethical issues and the nature of approval needed for each projects. The teaching session on Ethics and Conduct, at City University, further provided a platform to seek clarification on legal, ethical and professional standards.

Within my role, I implemented a stringent process of collating, storage and retrieval of information obtained for research purposes. All materials obtained were coded using reference numbers to ensure anonymity. Materials were then stored in a securely locked NHS cabinet and password protected computer.

When recruiting participants for research projects, adequate information regarding the aims, objectives and research process were provided to participants. Participants were also allowed to seek clarification on any uncertainty they had with regards to their involvement in the research. These measures allowed participants to make an informed decision on their participation. Consent was obtained from participants prior to their participation. Debriefing was provided to each participant after their participation in research projects. My training helped me identify issues that might affect legal, ethical and professional practice. I also gained the confidence and courage to provide advice on these issues within

the NHS. For example, on a recruitment day organised by NHS SW Essex, organisers aimed to video record participants but overlooked the importance of obtaining consent for participants. I had a discussion with the organisers of the recruitment day and highlighted the importance of obtaining consent and in addition designed information and consent forms for the organisers.

### **Unit 1.2 Contribute to the Continuing Development of Oneself as a Professional Applied Psychologist**

Throughout my training, I received supervision from a work supervisor based at NHS SW Essex and a University Supervisor based at City University. I had regular meetings with both supervisors to ensure the task and duties being carried out within my job role were fulfilling the requirements of the Stage 2 training.

As this was my first post in the NHS, during my initial stages in training, I lacked confidence in carrying out the work assigned to me. To tackle this issue, I often completed the work assigned to me 2 weeks prior to the deadline and submitted draft copies to relevant individuals for feedback. All feedback received were then evaluated and used to amend the work. This strategy helped me understand my personal strengths and weaknesses and create a piece of work that was consistent with the expectations of the relevant individuals.

My lack of confidence at the beginning of the training also encouraged me to actively seek consultation and advice either from my work supervisor or university supervisor. One-to-one meetings were held in a timely manner, which provided me with an opportunity to seek consultation and advice. On a few occasions, I sought advice and consultation from external individuals. For example, when planning focus groups for the CVD project, I contacted a marketing company who had experience in organising focus groups within Essex. Through this contact, the marketing company was able to enlighten me on the timing, location and other issues related to the focus groups planning. The knowledge gained helped me in all the focus groups I conducted.

In addition, consistent team meetings were held with members of the Health Psychology team in NHS SW Essex. These meetings provided a platform to bring up dilemmas faced and decide on the best possible approach that should be undertaken. Each member of the Health Psychology team had varied strengths and weaknesses in terms of skills and expertise. This provided an ideal opportunity to learn from one another and to rectify weaknesses. For example, I had adequate quantitative analysis skills but lacked practical experience and skills in qualitative analysis. Hence, I was able to provide guidance to colleagues on quantitative analysis and gain guidance from them on qualitative analysis methodology. Working closely with two other trainee health psychologists also helped me to evaluate and systematically compare best practice models demonstrated by my colleagues and incorporate it within my own practice. For example, by observing colleagues conducting focus groups I gained new techniques and skills for facilitating my own focus groups.

I always work within the boundaries of professional practice and help individuals understand these boundaries when necessary. For example, when given a project on child bereavement, boundaries were established so that I would be able to carry out postal quantitative work but would not be able to carry out qualitative work with bereaved parents as I did not have adequate skills and training to undertake this task.

To facilitate professional development, I attended all the compulsory teaching and training sessions organised by City University and attended the BPS Health Psychology Conference (2008, 2009). Attending various different conferences helped me incorporate best practice into my own work. For example, new sources of knowledge gained during these conferences helped me to introduce and make new recommendations for services within NHS SW Essex. Throughout my training, I pursued opportunities to enhance and advance professional performance. This was done mainly by seeking and pursuing external courses to enhance my knowledge and understanding on health related behaviours and other health psychology related areas. The training courses I have attended include Smoking Cessation (stage 1 & 2), alcohol brief intervention, child obesity training (MEND), motivational interviewing, CBT and Social Marketing. Attending these courses provided me with an

ideal opportunity to also observe various training presentation methods. For example, I learned that role-plays during training helped enhance my understanding. This observational learning helped me when I was delivering teaching and training within my practice.

Within my role, I often provided advice on service development/improvement and research/evaluation. For example, NHS SW Essex was keen on establishing CCBT intervention for people with mild depression and anxiety. The assistant director of Public Health Services asked me to work on a proposal for establishing this intervention. Within this proposal I was asked to include clear advice/guidance on steps that should be taken to establish the CCBT intervention for anxiety and depression within NHS SW Essex. Prior to writing the proposal, I conducted a thorough literature review and reviewed other data on CCBT interventions for anxiety and depression (e.g. NICE guidelines). The CCBT for anxiety and depression service development proposal contained step-by-step guidance that was formulated using appropriate sources of psychological evidence and knowledge.

### **Unit 1.3 Provide Psychological Advice and Guidance to Others**

Colleagues working within the Public Health services often sought advice and guidance on research/evaluation methodologies that should be employed to investigate health related behaviour. Advice and guidance were also provided on measures that should be taken to create behavioural or intervention evaluation surveys/questionnaires. On some occasions, I also advised colleagues on steps that should be taken to conduct effective literature searches/reviews (e.g. databases that can be utilised, key words search, etc). On all occasions tailored advice was provided to fit the necessity of each individual. Measures were taken to ensure that the advice given was relevant and accurate. I provided advice that was based on up to date psychological knowledge, principles and practices.

On some occasions, advice was provided based on a piece of work that was conducted by the Health Psychology Team. For example, when providing advice to key stakeholders of NHS SW Essex on measures that should be taken to improve the uptake of cardiovascular screening, quotations obtained from relevant past research on CVD awareness were used to

enlighten stakeholders on participants' views on CVD screening. Anonymous quotations were used to protect participant confidentially.

Prior to providing advice to any individual, I often obtained guidance from my work supervisor. She reviewed documents/emails and provided me with constructive comments. For example, during the initial stages of my training, my work supervisor advised that my writing style was academically orientated. As a result, I learned to deliver my advice in a more effective way suitable to the target audience. This was done by utilising diagrams, graphs and bullets points rather than paragraph upon paragraph of text.

To evaluate the impact of the advice provided, I often contacted relevant individuals two weeks later to discuss their views on the advice provided and the next course of action. I soon realised that some individuals needed more than two weeks. I amended my approach and discussed a suitable time for me to contact relevant individuals during initial meetings.

#### **1.4 Providing feedback to Clients**

As a trainee Health Psychologist working for the NHS Public Health Services my role did not involve direct psychological work with patients/service users. However, during my training I was involved with various organisations in undertaking research/evaluation projects. Hence, I was involved in projects with primary clients (Schein, 1999) on these projects. In this regard, feedback to clients was intended to communicate the progress of the project allocated. The feedback provided to clients who were allocated health psychology related projects was given within appropriate duration and timings to ensure the smooth running of the projects. Measures were also taken to structure and organise the feedback content to meet clients' needs and understanding.

#### **Reflection**

On reflection, my placement has helped me gain understanding on a range of issues including the applicability of health psychology within public health and the application of

research skills to gain community insight/understanding. Having previously conducted research solely within the University setting, my work placement allowed me to conduct research and evaluation within a public health setting. This research experience has allowed me to gain in-depth understanding on the ethical approval procedures within the NHS. Further to this, practical experience and theoretical knowledge gained throughout this training has equipped me with essential skills to handle ethical dilemmas professionally while maintaining legal and ethical practice. Prior to joining the Stage 2 training, I was proficient in quantitative research skills and lacked practical knowledge of qualitative research skills. This training has helped enhance my quantitative research skills and gain essential experience in qualitative research skills, therefore equipping me with knowledge, skills and expertise to be a versatile Health Psychology researcher.

Throughout this training, one of the most essential attributes gained was to critically evaluate my practice as a Trainee Health Psychologist. The reflective logs helped me record my progress and evaluate future steps that should be taken to enhance my understanding on Health psychology related issues. Further to this, the logs assisted in highlighting training needs to enhance my professional development.

Working within a health psychology team with two other trainee health psychologists helped me to work collaboratively and maintain professional relationships with colleagues. Team work was an important factor within my practice and through collaborative work, the Health Psychology team was able to generate many Health psychology inspired solutions to public health issues that were being faced. Further to this, collaborative work with colleagues was also crucial when faced with practical barriers within project. As a team, we were able to work productively to develop solutions to the barriers faced.

Throughout my practice, I was proactive and hard-working. Working as part of a multi-disciplinary team, it was essential for me to be persistent in maintaining a high level of professionalism throughout my practice. Further to this, it was also important for me to gain in-depth understanding and be sensitive to workplace dynamics. Within my role, I managed to use communication skills including written and oral communication to communicate with colleagues, key stakeholders and lay members of the public.

My cognitive/intellectual skills improved dramatically throughout this training. I gained experience in conducting literature reviews and formulating recommendations towards service development and improvement within NHS SW Essex. Working within a Health Psychology team also facilitated the promotion of health psychology within the organisation. This further facilitated the application of Health Psychology theories to enhance services. While progressing through the course, my confidence increased and I was able to work autonomously on projects allocated. Using my critical thinking skills, I was able to evaluate current service provision and provide recommendations on alternative approaches that should be adapted to enhance the impact on the community.

In conclusion, Stage 2 training provided me with the opportunity to develop as a motivated and creative healthcare professional. My future career aspiration is to build upon current experiences by seeking a career within public health services in developing countries such as Malaysia or Singapore. The skills, knowledge and expertise gained through this training will enable me to provide Health Psychology inspired solutions to public health issues faced in these countries.

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### **Consultancy**

On May 2010, I was contacted by a former lecturer at City University, Dr Emeo Estacio, who requested my participation as a research consultant on an evaluation project to be conducted by The Institute for Health and Human Development at University of East London. The aim of the evaluation project was to develop specifications and deliver an evaluation of Tower Hamlet Primary Care Trust's (PCT) pilot vascular check programme.

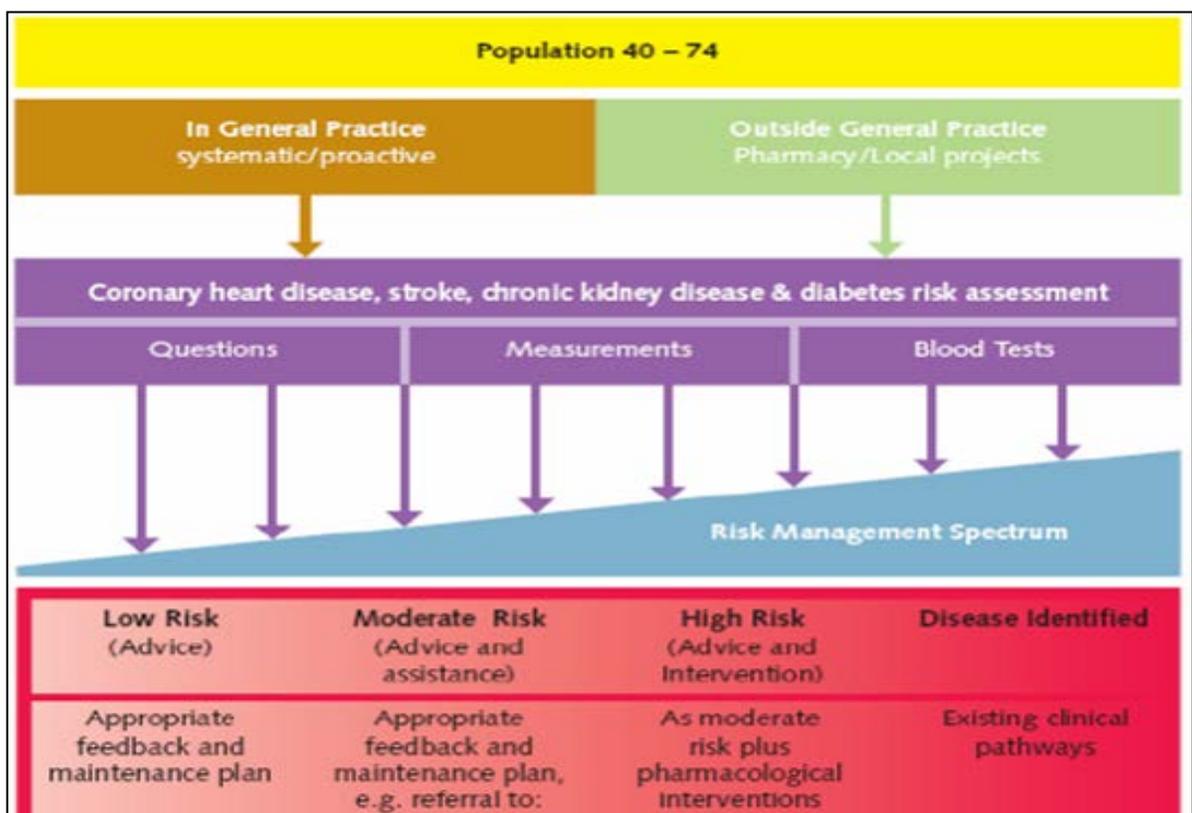
### **Background**

Cardiovascular disease (CVD) is the single largest cause of death in the UK, accounting for approximately 200,000 deaths per year. Most of these deaths result from either heart disease or strokes (NICE, 2010). UK has one of the highest death rates from coronary heart disease in the world (Poulter, 2003). CVD cost the UK economy £29.1 billion in 2004, with CVD and cerebrovascular disease accounting for 29% (£8.5 billion) and 27% (£8.0 billion)

of the total, respectively. The major cost component of CVD was health care, which accounted for 60% of the cost, followed by productivity losses due to mortality and morbidity, accounting for 23%, with the remaining 17% due to informal care-related costs (Luengo-Fernandez et al, 2006).

The national policy context of the vascular check programme is set out in the Department of Health strategy *Putting Prevention First* which brings together several related conditions - coronary heart disease (CHD), stroke, diabetes and kidney disease - under one cluster and aims to (a) identify an individual's risk of developing these conditions; (b) ensure that people understand their risk; and (c) act proactively to manage risk.

NHS Health Check (formally known as the vascular check programme and, before that, the vascular risk assessment and management programme) is a new national initiative for people in England aged between 40 and 74. The objective of the programme is to identify and assess an individual's risk of developing cardiovascular disease (CVD), namely CHD (heart attack and angina), stroke, diabetes and kidney disease; communicate the risk in a way that the individual clearly understands and manage the risk appropriately through tailored advice, clinical management, signposting or referral to other lifestyle interventions and services. It includes being recalled every 5 years for reassessment if identified as being at low risk and annually if at high risk.



### **Figure 1: Overview of NHS Health Check**

Many PCTs nationally have piloted / rolled out this screening programme. The pilot vascular check was conducted in Tower Hamlets between February and March 2009. Four GP practices participated in this pilot screening. The pilot screening utilised the QRISK2 model<sup>1</sup> to analyse patient information for all those registered with the practice between the ages of 40 and 74. Patients are ranked based on their risk factors for developing CVD. Those with the highest potential risk are then invited in for a check, which includes blood pressure, cholesterol testing, blood testing and a lifestyle questionnaire. The test is conducted by healthcare assistants (HCAs). Following the assessment, all high-risk patients will be referred to their GP, as well as given further lifestyle advice – such as referral to the PCT’s health trainers or smoking cessation groups. The Institute for Health and Human Development at the University of East London was granted the contract to evaluate the Pilot Vascular Check of Tower Hamlet in March 2009.

The purpose of this evaluation was to ascertain the effectiveness of the model of delivery implemented during the pilot phase and to determine what improvements (if any) can be made for the roll out programme after the pilot phase.

This consultancy opportunity adopted a process consultancy model (Schein, 1999) as the consultant and the client worked collaboratively to achieve the aims and objectives of the evaluation project.

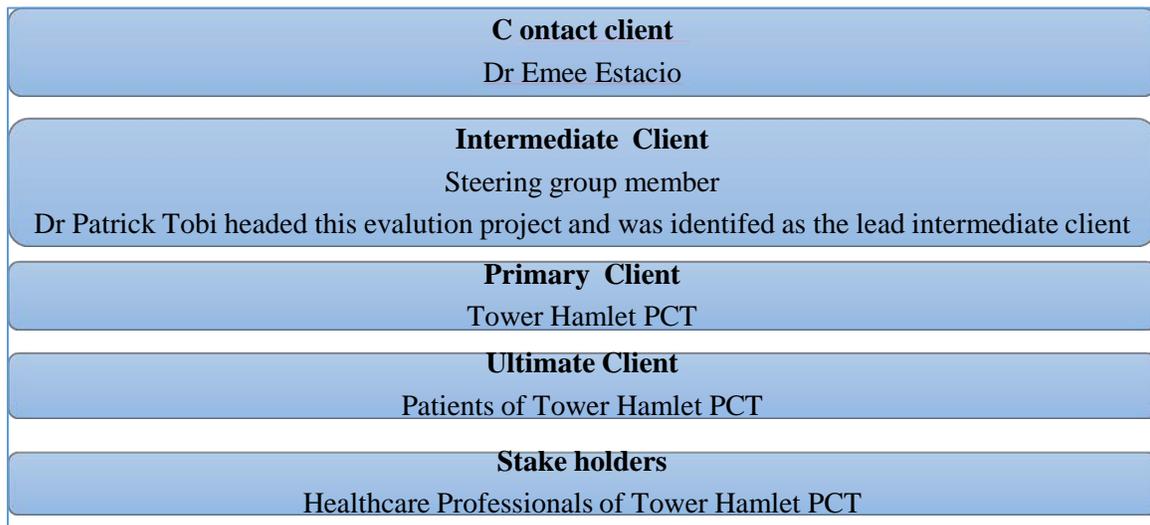
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<sup>1</sup> QRISK2 Model is only risk score specifically developed and academically validated for use in the UK, QRISK2 factors specific issues related to ethnicity into risk scoring. It also takes account of both family history and any social issues that can increase an individual’s risks. As a result, it fitted well with Tower Hamlets’ population (Cater, 2009)

### Unit 3.1 - Assessment of requests for consultancy

On 20<sup>th</sup> May 2009, I was given the Expression of Interest document that was submitted to Tower Hamlets PCT by Dr Emeo Estacio (**Appendix 1**). This document clearly outlined the nature of this evaluation. I further attended the first steering group meeting on 25<sup>th</sup> June 2009.

The steering group meeting was attended by the contact client, Dr Emeo Estacio and other members of the evaluation team. In assessing the request for consultancy, I identified the clients involved in this project based on the recommendation of Schein (1987). The outcome of this assessment is presented in **Figure 2** below:



**Figure 2: Identification of the client**

During the steering group meeting, the lead intermediate client went through the Expression of Interest document with me and voiced his expectations of the consultant. He outlined the key objectives that the client expected from the consultant, and negotiated a time frame for each objective. My scopes within the evaluation are stated below:

- Review social marketing and related literature
- Attend regular team meetings
- Carry out in-depth interviews with current and former service users to explore their experiences of the vascular check pilot
- Carry out in-depth interviews with commissioners and service delivery teams
- Thematically analyse the qualitative data to generate recommendations on how social marketing can be embedded in the roll out of the programme
- Support and contribute to the production of the final evaluation report

I was presented with a consultancy contract which was drafted by the client (**Appendix 2**). The client had prioritised needs, expectations and requirements in the contract. I clarified issues that were unclear and assessed the requirements of the lead intermediate client as being realistic and agreed to complete this piece of consultancy work for them within the time allocated. I signed the consultancy contract as a form of agreement to abide by the client's expectations, needs and requirements.

During the first steering group meeting, we also identified possible constraints facing the consultancy. Steering group members brainstormed ideas/steps to overcome the identified constraints. The two constraints identified are listed below:

- Ramadan was approaching. Hence, getting Muslim patients for the focus group was going to be challenging
- Due to the outbreak of the Swine flu, getting GPs for the evaluation was going to be difficult.

To overcome these constraints, we planned to prioritise the client engagement event and work on conducting the engagement as soon as possible to avoid any issues that would

arise from Ramadan. To overcome the issues with GP engagement, we decided to interview GP practice managers when GPs were unavailable. Steering group members expressed their agreement with the solutions proposed.

As a consultant of this project, one of the key expectations of the client was for me to review social marketing and related literatures and produce a report. One of the key documents that I had to review was a social marketing project report entitled *Improving Heart Health: Views on Vascular Screening Initiative*, which was based on social marketing work conducted within Tower Hamlet prior to the pilot vascular screening phase. In producing this report, I also reviewed various other literatures relevant to this consultancy. The findings of the literature review were presented in the form of a report to the research team on 27<sup>th</sup> July 2009. A copy of this review is attached (**Appendix 3**).

Prior to starting the consultancy project, I assessed the feasibility of the proposed consultancy by identifying materials and human resources necessary for the consultancy. Based on the assessment conducted, I did not foresee any constraints that would deter my progress during this consultancy.

### **Unit 3.2- Plan Consultancy Contract**

This consultancy project was well planned. The steering group consisted of highly experienced and skilled researchers. My consultancy contract commenced on 22<sup>nd</sup> June 2009 and lasted until 16<sup>th</sup> October 2009.

This evaluation was based on an evaluation framework that triangulates several data collection methods and different stakeholder viewpoints to build a coherent picture of the programme's inputs, process, and outputs. The defining features of the framework were:

- A *whole system approach* that generates multi-stakeholder perspectives from both service providers and users
- A *mixed methods research design* that combines qualitative and quantitative methods to collect information

- A *social marketing element* that segments service users with a view to understanding appropriate communication channels and the most effective mix of intervention approaches

It was agreed that the consultant would provide a final report describing the work carried out under the contract according to the following schedule:

- Social marketing review (27<sup>th</sup> July 2009)
- Interim report for thematic analysis (7<sup>th</sup> September 2009)
- Final report for thematic analysis (28<sup>th</sup> September 2009)
- Final evaluation report (16<sup>th</sup> October 2009)

Further to this, the gantt chart below was created with the objectives and deadlines for the entire team involved in the project.

<b>PROJECT AREAS AND TASKS</b>	Month 1				Month 2				Month 3				Month 4			
<b>Preparation &amp; Background</b>																
Project initiation meeting	█															
Agreement on project specifications, objectives, tools, deliverables and workplan	█	█														
Sign SLA	█	█														
Development of data collection tools	█	█	█	█												
Ethics application	█	█														
Partnership-building with key contacts	█	█	█	█												
Organise research team		█	█	█	█											
<b>Documentary review</b>																
Collation of relevant documents	█	█	█	█	█	█	█	█								
<b>Analysis of statistical data</b>																
Review of patient registers, data cleaning						█	█	█	█							



recorder. Hard paper copies (e.g. signed consent forms) were stored securely in a locked cabinet within UEL.

Reflectively, the working relationship established during this project, contributed to the success of this project. I learned that when working in a big project involving various different individuals, it is important to have regular meetings to establish good working relationships as it provides a ground for the consultant and client to openly discuss and resolve issues/concerns.

### **Unit 3.4 Conduct Consultancy**

My role within this consultancy required me to conduct interviews/focus groups with various individuals involved in the pilot vascular screening programme. Interviews were conducted based on the templates provided in **Appendix 4-7**. All interviews/focus groups lasted approximately 1 hour and were audio recorded. Verbatim transcriptions were created based on the recordings. Transcripts were analysed using template analysis. All information obtained were managed in accordance with the Data Protection Act (1998).

The table below summarises the number of interviews/focus groups I had conducted for this project:

<i>Participants</i>	<i>Number</i>	<i>Summary description</i>
Patients	15	Age range: 54 – 75 yrs; Gender: Men - 7, Women – 8; Ethnicity: White British –10, Bangladeshi – 3, Others – 2; Non-attendees: 4
HCA's	6	
Other practice staff	7	Practice managers, administrators, IT staff
CVD specialists	1	CVD nurse specialist

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Commissioners	2	PCT commissioning leads
Healthy lifestyle services	6	Health trainers manager, Smoking cessation advisers, Neighbourhood healthy lifestyle managers
<b>Total</b>	<b>37</b>	

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Through my previous engagement in similar projects, I realised that recruitment of Health Care Professionals (HCPs) are usually very challenging as HCPs often find it challenging to allocate time and resources to research participation. However, within this project, engagement with HCPs was relatively easy as UEL had established links with key stakeholders within Tower Hamlet PCT who played a crucial role in making the engagement phase as smooth as possible. The project was also very well organised and gave enough allowance for the HCPs to allocate time for the interview/ focus groups.

With patient engagement, one café event was planned. However the event had a poor turnout. This could be due to the lack of follow up of practice staff with patients to ensure their attendance. The evaluation period overlapped with the onset of the swine flu epidemic and preparations to tackle the problem was the priority for practice staff. Hence researchers had to come up with a contingency plan to engage with patients. Patients who attended the vascular screening programme were easier to engage with compared to patients who did not attend the programme. However, in the final stages of the project, research team members decided to conduct telephone interviews with non-engaging patients. This step was productive.

<b>Unit 3.5 Monitor the Process of Consultancy</b>
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To monitor the process of the consultancy, weekly meetings were held for the whole duration of the consultancy period. To implement quality assurance and control mechanisms, targets were set together with appropriate time frames to fulfil the objectives

of the project. These targets and time frames were circulated to all members of the steering group and agreements were obtained. Further to these, when submitting reports (e.g. social marketing report, interim report and final report of findings) to the project team members, I ensured that all draft documents were submitted 2 weeks prior the final deadline to enable relevant individuals to comment within realistic time-scales. This provided a vital platform for the client to comment on my work and it gave me the opportunity to make necessary changes to my work to ensure the client's satisfaction.

### **Unit 3.6 Evaluate the Impact of the Consultancy**

The outcomes and objectives of the consultancy project were met within the allocated time. The steering group members presented the findings of the project in the form of a report to the primary client. The lead intermediate client also presented the findings in the form of an oral presentation to key stakeholders within Tower Hamlet PCT.

Based on the findings of this evaluation project, a list of recommendations was generated to help the PCT to enhance the vascular screening programme to reach the intended target audience.

As this was my first consultancy opportunity, I created an evaluation tool to enable the lead intermediate client to evaluate my performance as a consultant within this project. The evaluation form required evaluators to rate the consultant's ability using a 4 point scale (1-strongly agree / 4-strongly disagree). There was also a non-applicable option for each item of the evaluation form. The evaluation form requested evaluators to rate the following:

- Personal Attributes of consultant (e.g. Attendance and initiative)
- Knowledge and Skills of consultant (e.g. Had adequate knowledge )
- Productivity of consultant (e.g. Provided services that matched the specifications of the contract)
- Communication of consultant (e.g. Returned phone calls and/or e-mails promptly, was a good listener)
- Interaction of consultant (e.g. Was able to work as part of a team)
- Overall Performance of consultant (e.g. Delivered work/projects on time)

The client provided favourable appraisal by strongly agreeing/agreeing with most of the statements in the evaluation form. This rating indicated that the client agreed that the consultant had good personal attributes, knowledge/skills and communication skills. Furthermore the ratings also indicated that the client agreed that the consultant was productive and interacted well with team mates during this evaluation.

### **Reflection**

This was a process consultancy opportunity. As this opportunity arose very early in my stage 2 training, a process consultancy was ideal as I could work collaboratively with the client to meet the objectives of the project. I was involved in a cardiovascular awareness study at South West (SW) Essex PCT in August 2010. Having previously worked on a similar project, I was confident in my ability to work on this consultancy project. Taking into consideration that this project employed the same methodology as the study I had completed in SW Essex (i.e. qualitative methodology), I did not face any obvious problems in fulfilling the client's expectations. It also helped me to work efficiently and maintain high standard at all times. Prior to starting my stage 2 placement, I was solely a quantitative researcher with very minimal qualitative research skills. However, in the first few months of my placement at SW Essex PCT, I had the opportunity to enhance my qualitative research and analytical skills. This experience provided me with essential skills and experience to handle this consultancy project. As being employed in a capacity of a consultant was new to me, I found that I needed to frequently step back and reflect to ensure that I was fulfilling the objectives of this project adequately.

Reflectively, my involvement in this project helped me understand the importance of project planning/management in executing a project successfully. The timeframe for this evaluation was short. However, the project was completed within the allocated timeframe due to excellent project planning/management skills utilised by the steering group members.

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## **Appendix 1: Expression of Interest Evaluation of Tower Hamlets Pilot Vascular Check Programme**

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# Evaluation of Tower Hamlets Pilot Vascular Check Programme

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## Expression of Interest to Tower Hamlets PCT

March 2009



**UEL** University of  
East London

**INSTITUTE for  
HEALTH and HUMAN DEVELOPMENT**

### 1 Summary

This expression of interest is our response to the invitation from Tower Hamlets PCT to further develop specifications and deliver an evaluation of its pilot vascular check programme. The exercise will assess the effectiveness of the pilot against a set of pre-specified areas, highlight what is working and what is not, measure user satisfaction and investigate how recommendations from a pre-pilot social marketing research project might be used to strengthen the service. Findings from the evaluation will inform how the pilot will be subsequently rolled out borough-wide to deliver

best value to all residents of Tower Hamlets. The timing of the work means that while some early outcomes may be measurable, this will be a primarily formative evaluation.

Our approach to addressing the work is based on an evaluation framework that triangulates several data collection methods and different stakeholder viewpoints to build a coherent picture of the programme's inputs, process and outputs. The defining features of the framework are:

- A *whole system approach* that generates multi-stakeholder perspectives from both service providers and users.
- A *mixed methods research design* that combines qualitative and quantitative methods to collect information.
- A *social marketing element* that segments service users with a view to understanding appropriate communication channels and the most effective mix of intervention approaches.

The work will be carried out by a team of public health, health promotion and community engagement researchers from the Institute for Health and Human Development (IHHD) at the University of East London. IHHD is a multidisciplinary organisation with extensive experience in the London region, and in particular East London, whose work focuses on the socioeconomic and cultural determinants of health and wellbeing. We provide solutions that can help individuals make lifestyle choices to promote their health and wellbeing and that of future generations.

We have an intimate appreciation of the socio-demographic and service delivery context of Tower Hamlets owing to work we have done locally including a recent evaluation of Tower Hamlets Health Trainers service. Furthermore, we will bring to this evaluation a wealth of experience and learning from the lifestyle change work we have been delivering in Well London, a Big Lottery Funded 3-year programme of investment in the most deprived communities in London around healthy eating, increased opportunities for physical activity and improved mental wellbeing.

## 2 Our understanding of the project

### 2.1 Background

The national policy context of the vascular check programme is set out in the Department of Health strategy *Putting Prevention First* which brings together several related conditions - coronary heart disease (CHD), stroke, diabetes and kidney disease - under one cluster and aims to (a) identify an individual's risk of developing these conditions; (b) ensure that people understand their risk; and (c) act proactively to manage risk.

At the London level, work by McKinsey with London's Directors of Public Health and a range of discussions with PCT chief executives and other stakeholders, has demonstrated significant support for developing a vascular prevention strategy across London. This is based on the scale of the challenge facing London and the fact that there are actions that can make a difference in both the short and longer term on mortality, morbidity and health service use and spend. As a consequence, NHS London made the programme one of its six corporate priorities for 2008/9. Known as *Healthy London*, the Vascular Strategy will screen all adults over 40 in London to assess their risk of developing any of the stated conditions.

Based on a risk algorithm individuals will be referred either for (a) medical management of established disease; (b) medical preventive treatment (anti-hypertensives, statins, etc) or (c) lifestyle change through exercise referral, obesity management, etc.

## **2.2 Local context**

In Tower Hamlets, the vascular check pilot is being delivered from GP practices and targets residents over 40 years who are not currently on CHD or Diabetes registers. It began in January 2009 and will run until March. Preparatory work included social marketing research to understand the needs of the target audience, development of an appropriate service delivery model and training of health care assistants to implement the programme. The service delivery model is based on 2 levels of screening:

- Level 1 (by all GP practices by May 31, 2009) - risk identification and ranking of patients over 40 years, and entry of their details into a risk register.
- Level 2 (piloted in 4 GP practices) - all Level 1 activities and screening of patients in order of highest risk.

## **2.3 Evaluation objectives**

This exercise will address four objectives:

- i. Ascertain the effectiveness of the programme against the following specified indicators:
  - Delivery logistics
  - Communication channels
  - Appropriateness of delivery setting
  - Capacity of delivery organisations
  - Impact on other services
  - Patient demographics
- ii. Measure service user satisfaction
- iii. Identify how recommendations from the social marketing research can be embedded in the programme
- iv. Determine programme facilitators, barriers and gaps

## **3 Key deliverables**

The work will deliver the following outputs:

- a. Mid-project progress update.
- b. In-depth interviews (or focus groups) with service users<sup>2</sup>
- c. Thematically structured descriptive and analytical report of the programme's effectiveness
- d. An itemisation with commentary of what works well, what does not, barriers and gaps in provision
- e. A summary appraisal of options for embedding social marketing recommendations into the fully rolled out programme.

## **4 Our approach**

### **4.1 Overview of methodology**

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<sup>2</sup> We have not specified a minimum number as it is not possible with qualitative interviewing to precisely identify beforehand the point of thematic saturation (i.e. when no more new themes emerge from further interviews). As a rough guide, the pre-pilot social marketing project interviewed 54 participants. We anticipate that the client may wish to specify a figure in a service level agreement.

The evaluation methodology is based on a framework that triangulates several data collection methods and different stakeholder viewpoints. The key stakeholders have been identified as public facing clinical staff, GP practice managers, Public health team, Tower Hamlets council, community groups and religious organisations e.g. local mosques. Triangulation will enable information obtained by a method or from one stakeholder to be corroborated and so strengthen confidence in the findings.

There are three core features of the framework:

- A *whole system approach* that generates multi-stakeholder perspectives from both service providers and users.
- A *mixed methods research design* that combines qualitative and quantitative methods to collect information. The following data collection methods will
- A *social marketing element* that segments service users with a view to understanding appropriate communication channels and the most effective mix of intervention approaches.

#### **4.2 Evaluation tools**

The multifaceted nature of the pilot dictates that we combine a variety of methods to obtain information. The main methods are:

- a. **Documentary review** – the following reports will be critically appraised
  - *Opinion Leader's* social marketing report, other relevant local work identified by the client, the Department of Health's national evaluation plan for the vascular checks programme, and related plans of NHS London and the North East London Cardiac and Stroke Network.
  - Tower Hamlet PCT's vascular strategy, service specifications, CEG clinical guidelines and operating procedures.
- b. **Analysis of statistical data** from the GP registers - to describe uptake rate and profile the social and demographic characteristics of users.
- c. **Non-participant observation**
  - observation of administrative and operating procedures.
  - observation of patient journey through the system.
- d. **In-depth 1-1 semi-structured interviews** (or focus groups as appropriate)
  - with admin and operational staff including all five health care assistants, GPs, practice managers and other support staff. Discussion topics will include changes in workload, ability to cope, effect on the practice, and referrals
  - with attending patients – discussion topics will include their journey through the system, how they were contacted, scheduling appointments, acceptability and satisfaction.
  - with non-attendees – to understand reasons for not attending.
  - with PCT service leads – to understand the commissioning context and gather information for an environmental analysis.
- e. **Environmental analysis** – a scan of the structural and organisational contexts in which the pilot is being implemented will be made and this will inform recommendations for rolling out the full programme. Analysis will rely on two techniques - DEPLEST (demographic, epidemiologic, political, legal/regulatory, economic, social and technological dimensions) and SWOT (strengths, weaknesses, opportunities and threats) analyses.

- DEPLEST analysis – we will use this tool to scrutinise the external context of the pilot and frame it within the bigger picture of *Healthy London* and the national programme.
- SWOT analysis – this will categorise the DEPLEST domains into opportunities or threats and map them against the internal strengths and weaknesses of the service model.

### 4.3 Objective-method matrix

The matrix below illustrates how each evaluation method relates to one or more of the objectives of the exercise.

Evaluation objective	Documentary review	Quantitative analysis	Observation	Interview or focus group	Environmental analysis
Effectiveness of delivery & communication logistics			✓	✓	
Appropriateness of delivery setting			✓	✓	
Organisational capacity	✓		✓	✓	✓
Impact on other services				✓	✓
Patient demographics		✓			
Measurement of service user satisfaction				✓	
Incorporating social marketing recommendations	✓			✓	
Service facilitators, barriers and gaps	✓	✓	✓	✓	✓

### 4.4 Analysing the information

From our experience of similar work, a practical way to link together the different pockets of information is to first analyse information *within* each method and then triangulate common themes across the different methods. A coherent report and recommendations will emerge from this thematic synthesis.

## 5 Work plan and Timescale

The Gantt chart below outlines our provisional work plan, key stages of work and timetable for delivery. The exercise will take place over 3½ months from 16<sup>th</sup> March to 30<sup>th</sup> June 2009. A definitive work plan will be agreed with the Project Steering Group once a full proposal has been accepted.

<b>Activities</b>	<b>Month 1</b>	<b>Month 2</b>	<b>Month 3</b>	<b>Month 4</b>
<b><u>Phase I: Preparation</u></b>				
SLA signed; project initiation meeting with steering group				
Revision/agreement on project specifications, objectives, tools, deliverables and work plan.				
Collation/review of policy and programme documents				
Development of data collection tools – data extraction form, interview topic guides, etc				
Identify/contact key stakeholders				
Ethics application for service user research				
<b><u>Phase II: Data collection</u></b>				
On-site visits				
1st round interviews – service providers				
Review of patient registers, data entry, cleaning and analysis				
Mid-project progress update				
2nd round interviews – service providers and users				
<b><u>Phase III: Data analysis and write up</u></b>				
Quantitative data analysis				
Environmental analysis				
Thematic synthesis				
Final report				

We have an excellent track record of delivering projects on time and on budget without compromising quality. We have experience in delivering similar work and therefore are confident that the proposed timescale above is realistic. We also have additional resources available if needed to increase staff capacity.

## 6 Proposed costs

The project will cost £40,580 to deliver. Under current legislation VAT is not applicable, however we reserve the right to add VAT to the contract value if required to do so by HM Revenue & Custom. A breakdown of resource allocation, project activities and costs is detailed below.

	Days	Rate	Total
<b>Staff</b>			
Project lead	5.0	£780	£3900
Project manager/Health policy specialist	7.0	£510	£3570
PDRF (Public health specialist)	18.0	£380	£6840
PDRF (Health promotion/Social marketing)	18.0	£410	£7380
PDRF (Statistician/data management)	18.0	£380	£6840
Research assistant (Qualitative)	21.0	£380	£7980
Administrator (data management, logistics and general administration)	21.0	£160	£3360
<b>Staff - subtotal</b>	<b>108.0</b>		<b>£39650</b>
	<b>Units</b>	<b>Rate</b>	<b>Total</b>
Travel			£350
Digital voice recorders	2	£50	£100
One-off small capital costs - stationery			£80
Phone calls			£100
Consumables, letters, postage, other printing, miscellaneous			£300
<b>Sub-total</b>			<b>£930</b>
<b>Total</b>			<b>£40580</b>

## 7 Assumptions, Risks and Risk Management

The timescale for the evaluation is short because the full scale vascular checks programme is planned to be rolled out in April. Accordingly, we have tried to be realistic about what can be delivered within the period. We assume that roll out will not be full steam from the start but phased

in which case some degree of overlap with the evaluation should not be a problem. By the time the programme reaches scale, the final evaluation report will be available to inform the process.

Given the time constraints, we expect that an inception meeting will be held with the project steering group at the earliest possible time.

Engaging with primary care professionals (particularly GPs) is time consuming and a major risk to meeting the project deadline. We therefore expect that the PCT will *actively* facilitate access to key stakeholders, GP practices and patient registers.

There are ethical issues involved when dealing with service users whether directly or through accessing confidential information about them. Immediately the proposal is approved, we will submit an application for ethics approval to the University of East London Research Ethics Committee (REC). The process of approval takes about 6- 8 weeks and we have made provision for this by scheduling aspects of the exercise that require approval for the latter stages of the work. It is pertinent to note though that the National Research Ethics Service does not classify service evaluation as research requiring ethical review by an NHS REC.

The final report submitted on 30<sup>th</sup> June 2009 will be a draft version which the PCT may subsequently circulate for comments. We will make revisions as appropriate and return a definitive report to the PCT within 4 weeks of receipt of all comments.

## **8 Capacity statement**

The Institute for Health and Human Development at the University of East London is a multidisciplinary organisation focusing on the social, economic and cultural determinants of health and wellbeing. IHHD provides solutions that can help individuals make lifestyle and consumption choices to promote their health and wellbeing and that of future generations. IHHD has extensive experience of carrying out health and wellbeing-focused research and community engagement in excluded and BME population groups in London including. Examples include the Westminster Ethnic Minorities Needs Audit for Westminster City Council (2005); Barriers to access of TB Services among Black Africans in London for the Medical Research Council (2006) Evaluation of Tower Hamlets Health Trainers (2007/08) and the Healthy Redbridge Project (2008) – a health and lifestyles borough-wide initiative. IHHD is currently leading on a £9.4m community engagement, design, brokerage and evaluation project for the London Health Commission led Big Lottery funded Well London project. IHHD is also involved in the development of the monitoring, evaluation and research work stream for the 2012 Health Legacy programme.

The evaluation team will be led by Professor Adrian Renton. Adrian Renton is a Public Health physician, Professor of Public Health and Director of the Institute for Health and Human Development at University of East London. He is a fellow of the Faculty of Public Health with a doctorate in epidemiology who has authored over 100 peer reviewed scientific publications. He has managed research programmes for the Department of Health and the Department for International Development and has received grant funding from the MRC and Wellcome Trust. He has 15 years of experience nationally and internationally in using outreach-based and participatory processes in the design, delivery and evaluation of health interventions, and extensive experience of survey

work. Adrian sits on the NHS London Leadership Group for the Vascular Checks programme and also advises the Department of Health on the national evaluation framework.

Tower Hamlets Pilot Vascular  
Screening Evaluation  
(Literature Review)

July 2009

The Department of Health (DH) published Putting Prevention First on 1st April 2008, which sets out plans for the NHS to introduce a systematic and integrated programme of vascular risk assessment and management for those aged between 40 and 74 on a five-year recall basis. Since then many PCTs nationally have piloted/ rolled out this screening programme. The pilot vascular check has been conducted in Tower Hamlets between February and March 2009. Four GP practices participated in this pilot screening. The pilot screening utilized the QRISK2 model to analyse patient information for all those registered with the practice between the ages of 40 and 74. Patients are ranked based on their risk factors. Those with the highest potential risk are then invited in for a check, which includes blood pressure, cholesterol testing, blood testing and a lifestyle questionnaire. The test is conducted by healthcare assistants (HCAs). Following assessment, all high-risk patients will be referred to their GP, as well as given further lifestyle advice – such as referral to the PCT's health trainers or smoking cessation groups

Although Tower Hamlets has adapted a G.P based screening service. Other PCTs have adapted diverse method of screening delivery. A case summary from vascular screening approaches adapted by other PCTs are presented below:

**Community outreach approach (Barking & Dagenham PCT)**

- Barking & Dagenham vascular check outreach goes live in March 2009. A screening van will conduct screening in places such as markets, shopping centres and community centres across the borough. The outreach service will also attend places of worship, including mosques and Pentecostal churches, as well as public events like the East London Mela and the Dagenham Town Show
- The screening is conducted by qualified nurses
- Visitors will have their blood pressure, cholesterol testes, measurement of BMI and waist circumference. They would also complete a lifestyle questionnaire (including physical activity, smoking, alcohol, and family history) in line with Department of Health recommendations.
- Vascular risk value will be calculated and anyone identified as hypertensive or at high risk will be given a letter to take to their GP or NHS drop-in centre. All results are also reported to the patient's GP via NHS Barking and Dagenham to allow follow up.

### **Health Check Events Scheme (NHS Bolton- Big Bolton Health Check)**

- To increase the accessibility of the service, checks are made available in GP surgeries from 8am to 8pm, Monday to Friday, as well as on Saturday mornings, with community events being held on Wednesdays and Saturdays at times to suit the invitees.
- Each venue is approached to host a Health Check event. Invitations to host an event are also advertised in the local paper.
- Advice from GP practices are sought to identify areas to hold outreach events.

### **Work Place Screening Scheme (West Sussex PCT)**

- Workplaces / community venues are contacted directly by the nurse managing the project and if interested in the scheme are given a template for booking health checks and an outline of their responsibilities for the day/s, which includes provision of a private room to hold the checks.
- To date health checks have been sited in various workplace locations including warehouses, office environments, and a bus depot in addition to various horticultural, retail and community venues to target hard to reach groups.
- Availability of checks in terms of time of day and days of the week are discussed and negotiated with the employer and designed to accommodate employees, including shift workers.

### **Pharmacy Partnership Scheme (South Birmingham PCT)**

- The Heart MOT service was developed and piloted with Lloydspharmacy and has now been extended to over 30 pharmacies across Birmingham, including independent pharmacies.
- The pharmacies were selected according to a range of criteria including geographical position by Index of Multiple Deprivation (IMD), local mortality due to CVD (by Standardised Mortality Ratio) and the ability of the pharmacies to deliver the service.
- All results are recorded on a secure IT programme developed by a private company called 'North 51'.
- The pharmacist discusses the results with the customer and prints two copies , one for the customer to keep and a second copy for the customer to give to the GP.
- Lifestyle advice is provided and all patients are given an information pack containing advice on a healthy diet, getting active, sensible drinking and stopping smoking
- Customers with a CVD risk  $\geq 20\%$  are referred to their GP practice.

- If appropriate, customers are also referred or signposted into appropriate established PCT programmes such as the Stop Smoking service.

#### **Collaborative scheme with Health Trainers (Knowsley PCT)**

- Checks are available in a wide range of community venues including community centre, social clubs, pubs, bingo halls, supermarkets, leisure centres and Metropolitan Borough Council One Stop Shops, in addition to GP surgeries.
- Clients receive instant feedback on the check and are provided with a letter that explains their results and the lifestyle advice given during the assessment.
- A Health Trainer is on site during each session to provide lifestyle advice and support, but clients may opt to be contacted at a future date if preferred.
- Clients receive instant feedback on the check and are provided with a letter that explains their results and the lifestyle advice given during the assessment.

Prior to establishing the pilot vascular screening programme in Tower Hamlets, a social marketing campaign was conducted by *Opinion Leader* to facilitate the establishment of this programme. Social marketing is the systematic application of marketing, alongside other concepts and techniques, to achieve specific behavioral goals, to improve health and reduce health inequalities (Stevens & French, 2006). Social marketing is a community-based approach that aims to gain in-depth understanding on the community and tailor intervention based on the insight gained. To date, social marketing has been used for various kinds of behavior modification intervention. For example the British Heart Foundation used social marketing as a basis to create the ‘give up before you clog up’ smoking cessation campaign in 2004. This campaign was designed based on the insight generated from having focus groups with smokers and health care professionals. In 2007, the Department of Health used Social Marketing to address problematic alcohol consumption. They used rigorous expert and stakeholder consultation and qualitative ethnographic research with hazardous and harmful drinkers to gain insight to create a campaign to address this problem. Over the years, social marketing has been used to address various issues (e.g. physical activity, breastfeeding, nutrition, infection control, teen-pregnancy, and screening).

The Department of Health’s recent report, *Ambitions for Health* (2008)<sup>3</sup>, recognised that while it cannot change people’s behaviour without the support of individuals, commercial and third sector organisations, the government can ‘*encourage, enable, and create the conditions*’ to build a social

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<sup>3</sup> Department of Health (2008). *Ambitions for Health: A strategic framework for maximising the potential of social marketing and health-related behaviour*. London: NHS.

movement for health. As part of its long-term programme to improve health and reduce health inequalities, the Government's 'Engage' strategy was introduced '*...to put people and their needs at the centre of all policy development and related service delivery...*' Social marketing is becoming an increasingly important approach to involve individuals and communities in policy, communications and delivery of interventions aimed to encourage behaviour change to improve health. Summarised in Table 1 below are the main concepts of the social marketing approach.

**Table 1. Social marketing concepts**

<b>Consumer orientation</b>	Gaining deep insight and understanding about the consumer, their knowledge, attitudes and beliefs, and the social context in which they live and work
<b>Behavioural and behavioural goals</b>	Understanding existing behaviour and key influences on it in order to enable the development of clear behavioural goals. These goals should be divided into actionable and measurable steps or stages, phased over time
<b>'Intervention mix' and 'marketing mix'</b>	Using a range of different interventions or methods to achieve a particular behavioural goal. When used at the strategic level, this is commonly referred to as the 'intervention mix': when used operationally it is described as the 'marketing mix' or 'social marketing mix'
<b>Audience segmentation</b>	Making use of audience segmentation in order to target effectively
<b>Exchange</b>	Using and applying the exchange concept (what people must give up or pay in order to receive the benefit). Understanding the real cost to the customer will enable a more effective exchange, whereby the potential benefit can be optimized and the 'cost' to the customer minimised
<b>Competition</b>	Understanding all the factors that compete for people's attention and willingness to adopt a desired behaviour (e.g. the influence of other people or organisations, or the internal drivers of pleasure)

The key feature of social marketing evaluation is to gain in-depth understanding of the target audience. Various methodologies can be employed to do this (e.g. focus groups, one-to-one interviews). The insight gained will help highlight the barriers and motivators faced by the target audience in implementing health related behaviors. Having gained this insight, interventions can be designed efficiently to fit the expectation of the target audience. Social marketers often draw upon behavioral health theories to help formulate an intervention (e.g. *Transtheoretical Model of Change*, health belief model). One crucial aspect of social marketing is audience segmentation. Audience segmentation will assist in creating a tailored intervention to accommodate different needs of different segments or groups.

Similar to other social marketing initiative, the current evaluation will aim to gain deep understanding of the target audience (e.g. users' views and perspectives of the screening). This will form a foundation for any future marketing techniques that would be employed to increase the uptake of the screening intervention. Engaging local residents in the design/modification of the vascular check programme would ensure the further success of this programme as it will foster community endorsement and word of mouth communication within the borough. Within this social marketing campaign, participants might be segmented using either psychographic characteristics (beliefs regarding preventive health, fatalism and attitude towards health services) or previous usage behaviour – (attendance/non-attendance of screening). It is expected that this segmentation methodology would highlight why individuals do or do not carry out health-related behaviors, such as attending health screening. This insight would help tailor the screening intervention appropriately and subsequently enhance screening attendance.

The key findings of the *Opinion Leader* Social Marketing Research are summarized in Table 2 below:

Table 2. Key Findings from the *Opinion Leader Social Marketing Research*

Barriers	HCP	Knowledge /Awareness	Vascular screening
<p><u>Language</u> Somali participants expressed that there were lack of information on health and wellbeing tailored for this community</p> <p><u>Behavior change</u> Older participants were less supportive of the screening as they were unsure if they would be ready for behavior change /modification</p>	<ul style="list-style-type: none"> <li>Participants’ wanted HCPs to be more proactive in advocating health related messages and screening services available</li> <li>GPs are viewed as being overloaded with work, hence providing a screening service within the G.P practice would increase their workload</li> <li>Some patients had bad experience with HCPs in the past. Hence avoiding the usage of the NHS unless absolutely necessary</li> <li>Participants viewed HCPs as extremely busy to explain results and treatment options adequately</li> <li>Participants wanted personally focused support and practical advice to facilitate behavior modification</li> </ul>	<ul style="list-style-type: none"> <li>Knowledge / awareness about screening services , CVD/diabetes prevalence in Tower Hamlets and health interventions available was low .Knowledge /awareness was particularly low in ethnic minorities</li> <li>Participants wanted various advertising campaign to provide education on health and screening <ul style="list-style-type: none"> <li>local media</li> <li>minority press</li> <li>referral from G.P</li> <li>door-to-door leaflet</li> <li>adverts in public places</li> <li>leaflets, posters and brochure (preferred when the message being delivered is concise, practically inclined, easy to read, eye catching and full of imagery)</li> </ul> </li> <li>Partnership work with community and voluntary sectors could be crucial to educate / enlighten ethnic minority patients on health and wellbeing</li> <li>Most common sources of health information cited by participants were TV, radio, newspaper, leaflets and posters seen at the G.P surgery</li> <li>Participants were keen on local workshops on health. Hence health workshops could be organized to educate the community on health and wellbeing</li> </ul>	<ul style="list-style-type: none"> <li>Was viewed favorably and majority of participants stated that they would attend the screening</li> <li>Wanted the service to be easy-to-use, quick and informal. Also wanted out of hours services</li> <li>Preferred stand-alone service that is not associated with existing local health services as attending G.P surgery/hospitals was associated with feeling ill</li> <li>Participants wanted letter of invitation from G.P (clearly stating the screening process to facilitate an informed decision)</li> </ul> <p><u>Screening venue</u> -Some participants wanted the screening to be available at the G.P surgery. -Some other participants preferred community centres and mobile units -Participants did not want screening to be conducted in pharmacies as they were doubtful of the medical expertise of the staffs at the pharmacy</p> <p><u>Screening staff</u> -Participants wanted staffs conducting the screening to be bright, welcoming and friendly -Bangladeshi participants preferred screening to be conducted by same sex staff -Participants wanted bad news about screening to be delivered by G.P or any other HCP who is able to allocate time to explain the results adequately. -Participants were willing to work with suitably trained / qualified person.</p>

## **Next Step**

The Pilot Vascular Screening conducted in Tower Hamlets will be evaluated by University of East London -Institute for Health and Human Development . The aim of this evaluation is to assess effectiveness of the screening and highlight what is working and what is not. Furthermore, measure of user satisfaction would be obtained and investigation will be conducted on how recommendations from the pre-pilot social marketing research project might be used to strengthen the service. Findings from the evaluation will inform how the pilot will be subsequently rolled out borough-wide to deliver best value to all residents of Tower Hamletss.

The approach adapted in this evaluation is based on an evaluation framework that triangulates several data collection methods and different stakeholder viewpoints to build a coherent picture of the programme's inputs, process, and outputs. The defining features of the framework are:

- A *whole system approach* that generates multi-stakeholder perspectives from both service providers and users
- A *mixed methods research design* that combines qualitative and quantitative methods to collect information
- A *social marketing element* that segments service users with a view to understanding appropriate communication channels and the most effective mix of intervention approaches

## **Conclusion**

The social marketing study conducted by *Opinion Leader* clearly indicates that residents of Tower Hamlets prefer a community based screening intervention. This form of intervention has been hugely successful in other PCT and could be very beneficial within Tower Hamlets. This step could be crucial in addressing health inequalities within Tower Hamlets. The knowledge/ awareness of residence in Tower Hamlets on the prevalence of vascular disease within the community was low. Hence, educational / advertising campaign is necessary to educate the public on the prevalence. Advertising / educational messages should be tailored for the diverse community of Tower Hamlets. Knowledge on the prevalence could further motivate people to attend screening and take constructive steps towards a healthier life. The *Opinion Leader* research also indicates that some community members, specifically the older participants were less keen on the screening programme, fearing that they are not ready for behavior change. Hence, messages targeting the older population should try to focus on other positive aspects of preventive screening (e.g. prolonging life, preventing disability). Messages should work on pulling the heartstrings of target audience and emphasize less on behavior change. On a positive note, Tower Hamlets has

adapted a very structured and evidence based approach to vascular screening. Both the research conducted by *Opinion Leader* and evaluation of the pilot vascular screening by UEL, would definitely form a foundation for further improvement of the vascular check intervention.

## **Appendix 4- Topic guide for NHS staff**

**INSTITUTE FOR HEALTH AND HUMAN DEVELOPMENT**

**TOWER HAMLETS PILOT VASCULAR CHECK PROGRAMME EVALUATION**



### **TOPIC GUIDE FOR NHS STAFF**

#### **SECTION 1. CONTEXT**

Describe the local context and target clients

Describe the programme delivery setting and its appropriateness

#### **SECTION 2. PROCESS**

Provide a step-by-step guide through the patient's journey through the programme, beginning with patient referral. Try to create a flowchart with the interviewee during the course of the interview.

Possible prompts: patient contact methods, appointments, procedures and interactions with staff, feedback mechanisms to assess service user experience, what facilitates effective practice, barriers and gaps in the service

#### **SECTION 3. ORGANISATIONAL CAPACITY**

Describe the range of experience and qualifications of staff involved in this programme - do practices have the right mix including administrative and other support staff?

Describe the workload - how do practices cope with the increased workload? How does it impact on the general workload including the need for a GP appointment post-check?

Describe impact on other services (internal and external) – prompts could include volume and type of onward referral, including gaps where there is no service to refer on to

#### **SECTION 4. COMMUNICATION**

Describe effectiveness of communication strategy – what was the strategy used to communicate information on risk? Is it effective? Why or why not?

Describe how communication strategies can be tailored to suit local context.

How can the communication strategy be improved?

#### **SECTION 5. RECOMMENDATIONS**

Provide any further suggestions to improve the programme

Highlight what works well and what can be changed

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#### **SECTION 6. Non-participant observation**

Observational notes will be taken concerning:

- Administrative and operating procedures
- Patient journeys through the system

## **Appendix 5- Topic guide for PCT leads**

**INSTITUTE FOR HEALTH AND HUMAN DEVELOPMENT**

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### **TOWER HAMLETS PILOT VASCULAR CHECK PROGRAMME EVALUATION**



#### **TOPIC GUIDE FOR PCT LEADS**

Describe the local context and target clients

Describe the overall aims and principles of the pilot scheme

Provide the structural and organisational contexts in which the pilot is being implemented to include the following dimensions:

- Demographic
- Epidemiologic
- Political
- Legal/regulatory
- Economic
- Social
- Technological

Provided an assessment of strengths, weaknesses, opportunities and threats to the service

**TOWER HAMLETS PILOT VASCULAR CHECK PROGRAMME EVALUATION**

**TOPIC GUIDE FOR CURRENT SERVICE USERS**

**SECTION 1. CONTEXT**

Describe the programme delivery setting and its appropriateness to service users

**SECTION 2. PROCESS**

Provide a step-by-step guide through the patient's journey through the programme, beginning with patient referral. Try to create a flowchart with the interviewee during the course of the interview.

Possible prompts: patient contact methods, appointments, what facilitates effective practice, barriers and gaps in the service

**SECTION 3. SERVICE USER EXPERIENCE**

Describe overall experience and satisfaction level

Possible prompts: client's readiness to take part in CVD screening, interactions with staff, acceptability and suitability of programme to client

Exchange theory: a) explore the *costs* to client for undertaking the service (e.g. financial, social, physical, time); b) explore the *benefits* to client for undertaking the service

**SECTION 4. COMMUNICATION**

Describe information given to client regarding: a) the scheme; and b) vascular risk. Describe strategies used to communicate information.

How did this information influence: a) knowledge; b) motivation; c) confidence and self-efficacy; d) skills; e) behaviour.

Describe current behaviour which may impact on vascular health (negatively or positively)

Competition analysis: a) explore the *internal factors* influencing client's behaviour (e.g. motivation, attitudes, knowledge, self-efficacy, confidence, skills, etc); b) explore the *wider influences* that promote counter behaviour

Describe how the communication strategy can be improved.

Possible prompts: how can communication strategies be tailored; what methods can be used – be as creative and varied as possible; how can it be mixed and matched to suit personal needs and local context

**SECTION 5. RECOMMENDATIONS**

Provide any further suggestions to improve the programme

Highlight what works well and what can be changed

**TOWER HAMLETS PILOT VASCULAR CHECK PROGRAMME EVALUATION**

**TOPIC GUIDE FOR FORMER SERVICE USERS**

**SECTION 1. CONTEXT**

Describe the programme delivery setting and its appropriateness to service users

**SECTION 2. PROCESS**

Provide a step-by-step guide through the patient's journey through the programme, beginning with patient referral. Try to create a flowchart with the interviewee during the course of the interview. Note specifically at which point they stopped attending and why.

Possible prompts: patient contact methods, appointments, what facilitates effective practice, barriers and gaps in the service

**SECTION 3. SERVICE USER EXPERIENCE**

Describe overall experience and satisfaction level

Possible prompts: client's readiness to take part in CVD screening, interactions with staff, acceptability and suitability of programme to client

Exchange theory: a) explore the *costs* to client for undertaking the service (e.g. financial, social, physical, time); b) explore the *benefits* to client for undertaking the service

**SECTION 4. COMMUNICATION**

Describe information given to client regarding: a) the scheme; and b) vascular risk. Describe strategies used to communicate information.

How did this information influence: a) knowledge; b) motivation; c) confidence and self-efficacy; d) skills; e) behaviour.

Describe current behaviour which may impact on vascular health (negatively or positively)

Competition analysis: a) explore the *internal factors* influencing client's behaviour (e.g. motivation, attitudes, knowledge, self-efficacy, confidence, skills, etc); b) explore the *wider influences* that promote counter behaviour

Describe how the communication strategy can be improved.

Possible prompts: how can communication strategies be tailored; what methods can be used – be as creative and varied as possible; how can it be mixed and matched to suit personal needs and local context

**SECTION 5. RECOMMENDATIONS**

Provide any further suggestions to improve the programme

**Appendix 8: Consultancy Evaluation Form**

Name of Project: Tower Hamlets Pilot Vascular Check Evaluation

Consultancy Period: 22<sup>nd</sup> June 2009-16<sup>th</sup> October 2009

<b>Part 1: Details of Evaluator</b>
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Name: \_\_\_\_\_

Role in the project: \_\_\_\_\_

Department: \_\_\_\_\_

<b>Appraisal</b>
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**Using the ratings defined above, please let us know if you agree or disagree with the following statements: The consultant...**

<b>Part 2: PERSONAL ATTRIBUTES:</b>					
	1-Strongly Agree	2 – Agree	3 – Disagree	4 – Strongly Disagree	N – Not Applicable
Had good attendance (punctuality, fulfilment of time obligation, etc.)					
Was initiative (self-starter, self-generator, etc.)					
Was dependable (can be counted on to follow through instruction)					
Displayed professionalism					

<b>Part 3: KNOWLEDGE AND SKILLS</b>					
	1-Strongly Agree	2 – Agree	3 – Disagree	4 – Strongly Disagree	N – Not Applicable
Demonstrated the technical skills needed to complete the job or project					

Demonstrated the procedural skills needed to complete the job or project					
Had adequate knowledge					
Performed satisfactorily					

<b>Part 4: PRODUCTIVITY</b>					
	<b>1-Strongly Agree</b>	<b>2 – Agree</b>	<b>3 – Disagree</b>	<b>4 – Strongly Disagree</b>	<b>N – Not Applicable</b>
Provided services that matched the specifications of the contract					
Produced satisfactory Results					
Made the job or project a success					

<b>Part 5: Communication</b>					
	<b>1-Strongly Agree</b>	<b>2 – Agree</b>	<b>3 – Disagree</b>	<b>4 – Strongly Disagree</b>	<b>N – Not Applicable</b>
Provided timely communication					
Was a good listener					
Returned phone calls and/or e-mails promptly					
Was available to the staff when needed					
Was easily accessed by my					

staff					
<b>Part 6: INTERACTION</b>					
	<b>1-Strongly Agree</b>	<b>2 – Agree</b>	<b>3 – Disagree</b>	<b>4 – Strongly Disagree</b>	<b>N – Not Applicable</b>
Worked well with key players in the organisation					
Was able to work as part of a team					
Provided updates and information as the job or project progressed					
<b>Part 7: OVERALL PERFORMANCE</b>					
	<b>1-Strongly Agree</b>	<b>2 – Agree</b>	<b>3 – Disagree</b>	<b>4 – Strongly Disagree</b>	<b>N – Not Applicable</b>
Delivered work/projects on time					
Demonstrated dependability					
Demonstrated ingenuity, creativity, and/or innovation					
Performed well under pressure					
Was effective when presenting ideas orally					
Expressed ideas clearly					
Used correct grammar in written communication					
Listened effectively					
Generated thoughtful and complete solutions					

Required little or no supervision					
<b>Part 8: FOR YOUR NEXT PROJECT...</b>					
	<b>1-Strongly Agree</b>	<b>2 – Agree</b>	<b>3 – Disagree</b>	<b>4 – Strongly Disagree</b>	<b>N – Not Applicable</b>
I would hire this consultant again.					
I would recommend this consultant to colleagues.					

Additional Comments:

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*Thank you*

**Teaching and Training 1 (Student Population)**

**Setting:** City University (London), Segi College (Malaysia) & Sunway University (Malaysia).

**Population:** MSc Health Psychology students at City University (London), BSc Psychology students at City University (London), BSc Psychology student Sunway University (Malaysia) and BSc Psychology students Segi College (Malaysia) .

**Description of work:** Throughout the Stage 2 training, various teaching and training sessions were designed, delivered and evaluated for two groups of student population (MSc Health Psychology students and BSc Psychology students) in two countries (London and Malaysia). Teaching topics included Social Marketing, Research Practicalities in Health Psychology and Stage 2 Health Psychology Training.

## **UNIT 4.1 - Plan and design training programmes that enable students to learn about psychological knowledge, skills and practice**

### **4.1a Assessing training needs**

Prior to preparing the teaching materials, an assessment of students' training needs was established by contacting module leaders of relevant modules. On all occasions one-to-one meetings were held with module leaders to discuss the teaching session and collaboratively establish a teaching structure that met the aims and objectives of the module. The teaching sessions of social marketing aimed to provide students with basic knowledge and background to social marketing. The objective of the research practicality session was to provide students with examples of health psychology research and tips on the practicalities of doing research. Sessions on Stage 2 training were aimed to provide students with in-depth knowledge on the training routes, core competencies and practical experience of doing the training (e.g. barriers faced and advantages of the training). A list of all teaching conducted for the student population is presented in **Appendix 1**.

### **4.1b Selecting training methods and approaches**

Upon establishing the training needs of the students, I submitted a proposed training plan to the module leader for review and feedback. The plan was altered based on the feedback provided by the module leader. Whilst designing the teaching materials, measures were taken to ensure that the teaching session would provide optimal learning within the allocated time. Further to these,

e-mails were sent to module administrative staff to obtain resources needed for the teaching sessions (e.g. laptop or desktop computers, a projector and flipcharts). The module administrative staff ensured the availability of these resources.

#### **Unit 4.1c - Select training methods and approaches**

In order to select an appropriate teaching method, various books and publications on teaching and learning methods were reviewed. Honey and Mumford (2000) identified four distinct learning styles. To optimise learning for various groups of learners, teaching approaches were designed to be didactic and interactive. Group tasks were designed to help students synthesise the knowledge gained during the teaching session. Feedback to the whole group was encouraged to help students to gain a comprehensive understanding on the viewpoints of other students in the class.

#### **Unit 4.1d - Produce training materials**

##### **Unit 4.1e - Use appropriate media to deliver training materials**

Training materials were produced using Microsoft Powerpoint. When designing the slides for the teaching session, information within the slide was kept simple, tidy and accurate. Each slide contained information that was concise and easily comprehensible. Measures were taken to avoid the slides from being wordy. When appropriate, diagrams, charts, pictures and videos were incorporated within the slides to enhance the presentation and facilitate learning. The completed presentation was sent to the module leader for review and comment. The comments provided by the module leader were used in a constructive way to amend the slides. Handouts of the final presentation were made to be circulated during the teaching session (**Appendix 2-6**). Handouts provide students with the ideal opportunity to follow the lecture, take essential notes to retain learning and take away the handout for future guidance on the topic. Preparing handouts for lectures is also an essential backup plan if and when technology fails. Module administrative staff

provided a laptop, presentation screen, flipcharts and a projector for the teaching.

## **Unit 4.2 - Deliver training programmes encompassing psychological knowledge, skills, and practices**

### **Unit 4.2a - Implement training methods & Unit 4.2b - Facilitate learning**

Prior to the actual teaching, I practiced the session numerous times to familiarise myself with the content of the lecture. On the day of the lecture, I arrived early to test the technology needed for the teaching session. Turning up early for the lecture also gave me allowance to seek help when technologies failed to work.

When conducting the lecture, I was extra cautious of my tonality, phase of delivery and body language. During the teaching sessions, students were provided ample opportunities to ask questions and seek clarification. When answering queries accurate feedback was provided. The interactive and group work was hard to implement within certain student groups. This was particularly the case with Malaysian students. These students were used to didactic teaching approaches. Hence students were reluctant to engage in group discussions and provide feedback to the whole group. This issue was addressed by actively engaging with students during groups and providing guidance when necessary. Teaching sessions were delivered to small (approximately 10 - 20 students) and larger (approximately 40 students) groups. Teaching approaches were adapted according to the group size. When teaching smaller groups, more time was allocated for questions and group work. When teaching larger groups, the 'parking lot' approach was used to stay within the allocated time frame. Pending issues were revisited at the end of the lecture. Break-times were negotiated and agreed with each group to avoid information overload. At the end of the teaching session, students were provided with contact details for follow-up questions and sources for further information.

Teaching session 2 (**Appendix 3**) was video recorded as per the requirement of the Stage 2 training requirement. The academic supervisor also provided an evaluation of the teaching session. Through the video recording I was able to observe my presentation style and body language. One of the key aspects I learnt from the video recording was my phase of delivery. I realised my phase of delivery was faster than intended. I learnt to be more cautious of my phase of delivery in future sessions.

#### **Unit 4.4 - Evaluate training programmes encompassing psychological knowledge, skills, and practices**

All the teaching sessions delivered to students did not require an assessment procedure. Teaching sessions were evaluated using a standard paper format asking trainees to rate the teaching (**Appendix 7 & 8**). All feedback received were generally positive. These feedback forms also helped identify the strengths and weaknesses of the lecture. The insight gained was used to modify the teaching session.

#### **Reflection**

My confidence in presenting teaching sessions has improved throughout the Stage 2 training. During my initial teaching session, I lacked confidence and was anxious. However, as I gained more experience in teaching, my anxiety reduced and my confidence increased. On reflection, having in-depth knowledge on the lecture material gave me the opportunity to enhance my presentation skills (e.g. maintaining good eye contact, less stammering, not reading off the slides). Through these teaching sessions I learned that I personally perform well in delivering a session when I understand the subject matter and the training materials well. Hence to incorporate this learning into practice, thorough preparations were made prior to teaching sessions.

As part of the Stage 2 requirements, one teaching session was video recorded. Being video recorded during the lecture was an anxiety provoking experience. However watching the recording was extremely insightful because I was able to observe my delivery style and incorporate changes within my practice. On reflection, I understand the importance of video recording teaching sessions. I would definitely incorporate video recording within my teaching practice when resources are available to promote reflective learning and enhance professional practice.

The evaluation forms reflected that students did appreciate group tasks allocated during the teaching sessions. Although group tasks were hard to implement with some groups of students, I would definitely incorporate group tasks within my teaching on a consistent basis to enhance

learning. Using evaluation forms within my practice also helped me gain insight into students' views of the lecture. I conducted a basic evaluation for all teaching sessions. In the future, I would like to have a before and after measure to assess students' learning. These forms of assessment would help me ascertain students learning with reference to the session's objective. This assessment procedure would also help me identify areas of the teaching that needs improvements.

Providing teaching sessions in two different countries helped me identify cultural differences in teaching and learning. This experience has taught me to be versatile when teaching and adapting teaching approaches to fit the population. Overall these teaching sessions have helped me to be confident and competent in teaching student populations.

**Reference:**

Honey, P. & Mumford, A. (2000). *The learning styles helper's guide*. Maidenhead: Peter Honey Publications Ltd.

**Appendix 1: List of teaching conducted**

<b>Session</b>	<b>Topic</b>	<b>Population</b>	<b>Date</b>
<b>Teaching Session 1</b>	Social Marketing	<ul style="list-style-type: none"> <li>BSc Psychology students at Segi Collage Malaysia</li> </ul>	25 <sup>th</sup> March 2009
		<ul style="list-style-type: none"> <li>BSc Psychology students at Sunway University Malaysia</li> </ul>	3 <sup>rd</sup> April 2009
<b>Teaching Session 2</b>	Research Practicalities & Stage 2 Health Psychology Training	MSc Health Psychology students at City University London	17 <sup>th</sup> April 2009
<b>Teaching Session 3</b>	Social Marketing & Stage 2 Health Psychology Training	BSc Psychology Students at City University, London	24 <sup>th</sup> March 2010
<b>Teaching Session 4</b>	Research Practicalities- Stroke Awareness Study	MSc Health Psychology students City University, London	29 <sup>th</sup> September 2011
<b>Teaching Session 5</b>	Stage 2 Health Psychology Training  (Jointly presented with Parmpreet Marway)	MSc Health Psychology students City University, London	30 <sup>th</sup> September 2011

## **Appendix 2**

## SOCIAL MARKETING

Jana Kanapathy

Trainee Health Psychologist NHS SW Essex  
2nd Year Dpsych Health Psychology Student

## MY EDUCATIONAL BACKGROUND...

- BSc Honors Psychology (Middlesex University)
- MSc Health Psychology (City University)
- Doctorate Health Psychology (City University)



Middlesex  
University



CITY UNIVERSITY  
LONDON

## MY PAST RESEARCH EXPERIENCE ..

- Conducted a study on computer anthropomorphism
- Conducted a study to test the efficacy of computer based intervention to reduce stress among psychology students at City
- Worked on various Social Marketing project for South West Essex PCT
- Currently working on establishing a intervention for moderate /risky alcohol consumers in SW Essex

## MY WORK EXPERIENCE

- Counselling for Dialysis Patients
- Career Counselling
- Cocaine addiction counsellor
- Currently working with South West Essex
- Consultant Researcher at UEL

SWESSEX

South West Essex

## SOCIAL MARKETING

What do you think  
the term social marketing means

### WHAT IS IT ?

- An adaptable approach, increasingly being used to achieve and sustain behaviour goals on a range of social issues.
- Its primary aim is to achieve a particular 'social good' (rather than commercial benefit), with clearly defined behavioural goals.

### WHAT IS IT ?

- It is a systematic process phased to address short, medium and long-term issues.
- It uses a range of marketing techniques and approaches (a marketing mix). In the case of health-related social marketing, the 'social good' can be articulated in terms of achieving specific, achievable and manageable behaviour goals, relevant to improving health and reducing health inequalities.

***"IT WOULD BE EASY TO GIVE THE PUBLIC INFORMATION AND HOPE THEY CHANGE BEHAVIOUR BUT WE KNOW THAT DOESN'T WORK VERY SATISFACTORILY. OTHERWISE NONE OF US WOULD BE OBESE, NONE OF US WOULD SMOKE AND NONE OF US WOULD DRIVE LIKE LUNATICS".***

**IAIN POTTER, DIRECTOR  
NEW ZEALAND HEALTH SPONSORSHIP COUNCIL**

## BRIEF HISTORY

### ⊗ Government 'Choosing Health' White Paper commitment

o Independent review of Social Marketing 2005 : Dept of Health and NCC undertake national review on Social Marketing's (SM) potential;

### ⊗ Recommendation - to adopt a SM approach to improve health

### ⊗ UK National Social Marketing Centre officially launched Dec 2006

## Defining social marketing

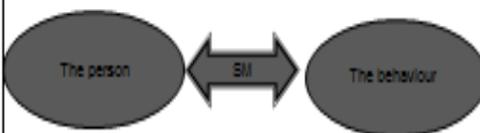
*"the systematic application of marketing and other concepts and techniques, to achieve specific behavioural goals, for a social or public good"*

Fleish, Bish-Stevens 2006



## SOCIAL MARKETING IS ALL ABOUT...

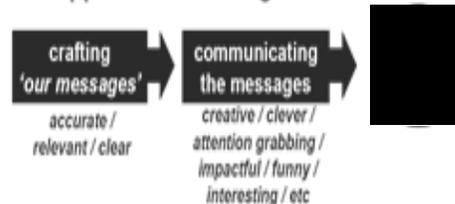
### UNDERSTANDING



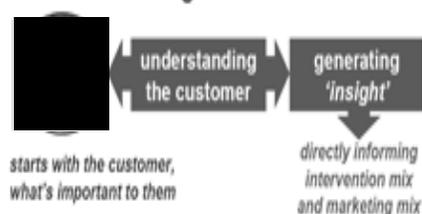
- \*People
- \*Community
- \*Citizens
- \*Customers
- \*Consumers
- \*Clients
- \*Patients

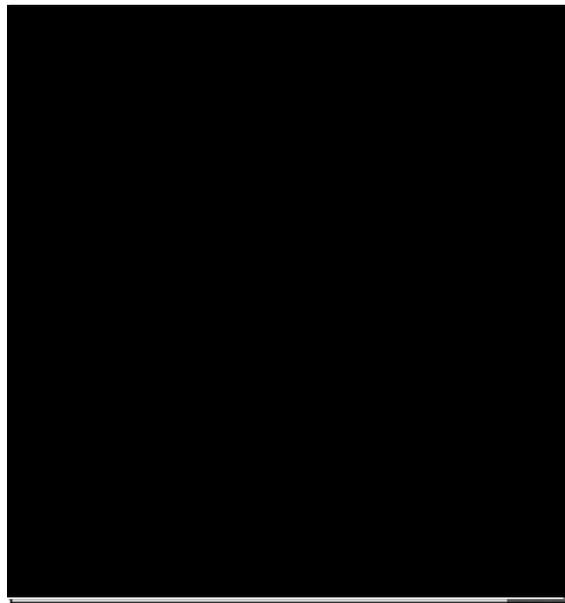
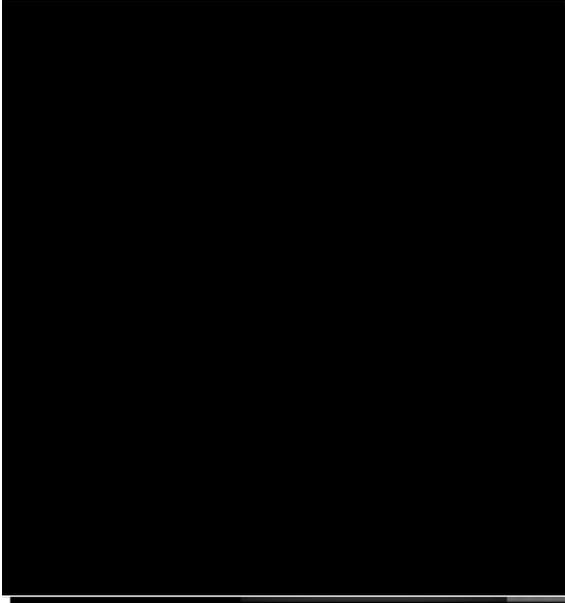
- \*What they do
- \*Why they do it
- \*Influences/Influencers
- \*Incentives /Barriers

## Old approach = 'message based'



## Social marketing = 'customer based'





## **8 BENCHMARK OF SM**

- ⊗ Customer orientation
- ⊗ Behaviour and behavioural goals
- ⊗ Theory
- ⊗ Insight
- ⊗ 'Exchange'
- ⊗ 'Competition'
- ⊗ 'Intervention mix' and 'marketing mix' -
- ⊗ Audience segmentation

## **CUSTOMER ORIENTATION**

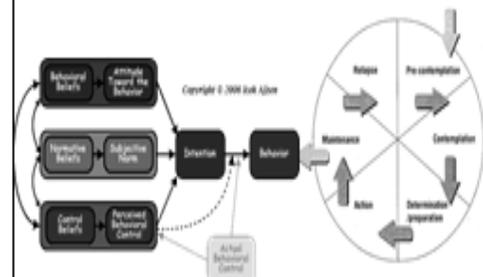
A strong customer orientation, with importance attached to understanding where the customer is starting from, their knowledge, attitudes and beliefs, and the social context in which they live and work

## BEHAVIOUR AND BEHAVIOURAL GOALS

A clear focus on understanding existing behaviour and key influences upon it, alongside developing clear behavioural goals. These can be divided into actionable and measurable stages, phased over time.

## THEORY

Using behavioural theories to understand human behaviour, and to build programmes around this understanding.



## INSIGHT

Gaining a deep understanding and insight into what moves and motivates people.



## 'EXCHANGE'

Use of the 'exchange' concept - understanding what is being expected of people, and the real cost to them.



## 'COMPETITION'

Use of the 'competition' concept. This means understanding factors that impact on people and compete for their time.



## 'INTERVENTION MIX' AND 'MARKETING MIX'

Using a mix of different interventions or methods to achieve a behavioural goal. When used at the strategic level this is referred to as the 'intervention mix'. When used operationally it is described as the 'marketing mix'.

## AUDIENCE SEGMENTATION

Clarity of audience focus using segmentation to target people effectively.

## YOUR TIME TO DO SOME THINKING ...



How can we benefit Health Psychology ?

# SOCIAL MARKETING

Examples

## 'VERB, It's what you do' U.S. Department of Health and Human Services Centres for Disease Control and Prevention

2002 to present



This is a national, multistage, social marketing campaign that aims to increase and maintain physical activity among teens (youth age 13-18). Underpinning this behavioral goal, the campaign has a number of specific objectives, which include knowledge, attitudes and beliefs about teens' regular participation in physical activity, parents and influence teachers, youth leaders, health professionals, practitioners support and encouragement of teens' participation in physical activity, as well as the facilitation of opportunities to teens participation in physical activity.

With an initial investment of \$125 million and a further \$75 million donated in custom donations and events by media partners, the campaign has been able to employ a number of strategies to achieve the above objectives. These include advertising, campaign partnerships, community events and communication.

After 1 year of the campaign, some significant behavioral shifts were evident. Levels of weekly five-time physical activity sessions among children 9-12 years of age who were aware of the campaign increased 34% compared to those unaware of the campaign, for girls, the increase was 27% among 14/16-year-old girls compared to girls unaware of the campaign.

## 'Give Up Before You Clog Up' British Heart Foundation

Jan & Oct 2004



This Department of Health funded campaign aimed to increase awareness among target audiences that smoking causes heart disease, as well as providing support and advice to give up.

It was developed based upon on focus group research and advice from smokers and health professionals, as well as lessons learnt from successful campaigns undertaken internationally. The central image was of a fat-filled cigarette, which made an iconic connection between cigarettes and clogged up human arteries.

The integrated campaign included: interactive TV and adverts, internet and press advertising, posters, beer mats in pubs, adverts, direct mail, and a dedicated microsite offering medical information, free SMS and email support messages, and a smoking costs calculator. These channels were supplemented by national briefings with BHF experts and heart attack survivors, case studies and news releases featuring statistics.

The campaign was highly successful in raising awareness, resulting in an increase from 55% to 75% of people who could cite the link between smoking and clogged arteries. Furthermore, thousands of people made demonstrable actions to give up smoking. 242,000 people visited the BHF website and over 25,000 people called the helpline. During the time of the campaign, record attendance and quit rates at the local NHS stop smoking services were also evident.

## Social Marketing Smoking Cessation Programme for Pregnant Women in Sunderland Dental School University of Newcastle upon Tyne

April 2002 onwards

This project aimed to increase the uptake of smoking cessation services and quit rates among pregnant women (mainly from deprived areas, social class C2D and E) in Sunderland. Its development was underpinned by qualitative research which explored what it was like to be a pregnant smoker in Sunderland and provided insights into the particular issues facing smoking pregnant women. The research found that many women felt stigmatised and that their baby is seen as the priority (not them) when they are pregnant, that they are information poor, that the baby language professional can be intimidating and that they don't want to be judged.

The intervention was developed based on this insight. It included: creative recruiting and support for smoking women as a dedicated worker, home visits, design and production of new marketing information-relevant and role play training health professionals to engage more effectively with smoking women.

The impact of the project was impressive. During the intervention, there was a 13-fold increase in the number of women taking a quit date and calling whilst pregnant.

**Australian National Drugs Campaign**  
 Phase One March 2001  
 Phase Two April 2005

The aim of this programme is to contribute to a reduction in the proportion of young Australians using illicit drugs. The campaign not only provides information about the negative consequences illicit drug use, but also promotes positive alternatives to drug use and ways for youth to seek the help they need.

In its scoping phase, the campaign used formative research to determine the different segments of young people who displayed varying degrees of risk of initiating illicit drug use, and had different needs and motivations toward its use. Recognizing this, three complementary strategy streams were designed to address the different sub-groups - lower risk, thrill seekers and reality swappers - with positive reinforcement between the three streams.

The youth campaign uses TV commercials to highlight the negative consequences of ecstasy, speed and cannabis, as well as television commercials targeting parents to encourage them to discuss drugs with their children. These are supplemented by a wide range of local activity which promotes positive alternatives to taking drugs, ways for youth to seek help and help for parents in building relationships with their children.

The campaign has so far resulted in a number of attitudinal and behavioral changes in parents and young people. 41% of parents who recognized the campaign reported that the campaign had prompted them to take some action, typically talking with their child about drugs (mentioned by 52%). Likewise, 65% of young people reported that the campaign had influenced them - the most common influences were: avoiding using drugs (36%), thinking about drugs/consequences of using them (19%) and avoiding drug use situations and communicating with friends (9%).

**NHS**  
 South West Essex



**CVD AWARENESS**  
 Conducted by the Health Psychology  
 Team of South West Essex

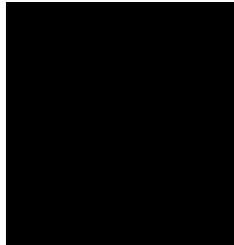
**CVD AWARENESS**

- £100,000 to research, design and implement a campaign
- CVD is the single largest cause of death in the UK, accounting for approximately 200,000 deaths per year.
- Deaths result from either heart disease or strokes.
- In 2000, BBC reported that the UK has one of the highest death rates from coronary heart disease in the world.

- CVD cost the UK economy £29.1 billion in 2004
- The major cost component of CVD was health care, which accounted for 60% of the cost, followed by productivity losses due to mortality and morbidity, accounting for 23%, with the remaining 17% due to informal care-related costs
- CVD is one of the four priority areas highlighted for action in the government's White Paper Saving lives our healthier nation?



- The following national target has been set to address CVD: To reduce the death rate from coronary heart two-fifths (40%) by the year 2010
- The 'Joint British Societies' guidelines on prevention of cardiovascular disease in practice', published in 2005, emphasized that all adults should be considered for an opportunistic comprehensive CVD risk assessment in primary care.



## AIMS AND OBJECTIVES

- To assess public awareness of CVD and prevention
- To gain understanding on ways to enhance CVD awareness and encourage people to attend CVD assessment
- Develop individual level and population level public health campaigns to increase awareness on CVD and the importance of CVD assessment

## AIMS AND OBJECTIVES

- To identify barriers that deter community members from gaining CVD assessments
- To aid in strategic and marketing guidance for further developing communications efforts to increase levels of awareness for CVD prevention and treatment in Basildon and Thurrock
- To evaluate the effectiveness of the CVD awareness campaigns
- To establish a foundation for people from local communities to be involved in the development of services and initiatives to reduce inequalities in CVD which aims to raise awareness and improve early identification of patients at high risk of CVD.

## RESEARCH ....

- Focus groups were conducted at Grays and Basildon.
- Specific areas with high level of deprivation were targeted.
- Six focus groups were conducted in each area

## SEGMENTATION

Males (40-49)	Females (40-49)
Males (50-59)	Females (50-59)
Males (60+)	Females (60+)

## ANALYSIS

- Template analysis is a method for identifying, analysing and reporting patterns (themes/ templates) within data.
- It minimally organizes and describes a data set in (rich) detail

## SOME OF THE ADVANTAGES OF THIS ANALYSIS METHOD...

- Flexibility.
- Relatively easy and quick method to do
- Results are generally accessible to educated general public.
- Useful method for working within social marketing paradigm, with participants as collaborators.
- Can usefully summarize key features of a large body of data, and/or offer a 'thick description' of the data set.

## RESULTS

Six themes were identified:

1. Awareness
2. Self Autonomy
3. Fatigue of Daily Life
4. Time
5. Relationship with Healthcare Professionals
6. Fear

## AWARENESS

Consists of 4 sub themes:

Need for more information

- Unaware of CVD services available to them
- Wanted large efforts to be made to raise awareness
- Older groups felt patronised as it was thought they are perceived as "unfit" due to their age

*"I think the younger people, because they're very fit, very active and because obviously as you get older you slow up, it doesn't mean to say that you're not fit but they perceive you to be fit and unwell"*

1. Mistrust

- Conflicting messages- caused confusion
- Lacked trust in messages/ led to ignoring health messages

*"And then you can eat that... and then a month later, it says you mustn't eat that..."*

*So really all you want to do is ignore the lot"*

## AWARENESS (2)

3. Knowledge about CVD

- All groups had knowledge on what a healthy lifestyle is
- Most participants felt that CVD was not preventable
- Felt that stroke is not treatable
- Placed huge emphasis on genetics
- Fatalistic attitude towards CVD

*"I don't think it is preventable... if you're going to die of a heart attack you're going to die from a heart attack"*

4. Awareness about stroke

- Very few people thought the term CVD encompassed stroke
- Thought CVD was heart attacks and angina
- Majority of people showed some awareness about stroke
- Often stroke was seen as more serious than CHD

## SELF AUTONOMY

The idea of personal autonomy is to have personal rule of the self while remaining free from controlling interference by others

Consists of two sub themes

1. Psychological Factors

- Motivation
  - Motivation affected ability to adopt healthier lifestyle
  - Gap between intention and action
  - Some stated laziness as a problem
  - Older people felt they had no role models to aspire to

*"It's fine actually buying healthy foods, but the exercise idea, it really needs inspiration of someone else, or other groups of people you're working with"*

## SELF AUTONOMY (2)

1. Psychological Factors

- Habits and Self Esteem
  - Resisting change due to lifelong habits
  - Clash between traditions vs current health guidelines
  - Dislike of interference by the "changing society"
  - Older groups stated they did "not want to live forever"- thus main aim is to enjoy life

*"Do you want to live forever? Am I going to lose this 4 stone...is it worth it?"*

2. Physical Capacity

- Affect of age on leading a healthy lifestyle
- 60+ - fear of over exertion/not being able-bodied
- Females 50-59 - menopausal change

*"I don't really exercise enough because I don't go out that much and because I've got arthritis it prevents me from walking too much"*

## FATIGUE OF DAILY LIFE

### Stress

- Seen to cause or contribute to illness
- Many thought stress was the main cause of stroke
- Financial stress seen as barrier- gym membership, paying for med., buying healthy food items
- Family stress- more common in females. Can cause false sense of security

*"I thought a stroke came from stress..."*

*"A lot of people probably can't or are probably thinking that if they did get to the doctors they couldn't afford the prescription anyway"*

### Lifestyle

- Convenience food- lack of time
- Peer/family pressure- must eat what is cooked
- Do not have enough time to cook healthy dish for oneself

*"good food takes more time to prepare than fast food"*

## TIME

### People have too much/too little time

- 40-59 group- Did not have time to be healthy
- Feel work and family take up all the time
- 60+ - time not an issue

*"Sometimes, people don't have the time, like when you're so busy, you go to work ... you come back with loads of things; you don't have time to eat very well"*

### G.P.'s do not have time

- Do not have enough time for consultations
- Will not put questions forward to G.P.
- More tailored service required
- Want a better understanding and exploration of health issues

*"...before you come into the GP and he is already telling you your time is up, or write you a prescription without having a proper diagnosis"*

## TIME (2)

### Accessibility

- Drop ins and mobile vans
- Risk assessments to be conducted at workplaces
- Pharmacists seen as more accessible
- Local service with longer opening hours to cater for people with 9-5 jobs

*"If it's only going to be done within certain hours, they may not be able to afford to have that time off to go and have it done, and therefore they don't bother...if it is going to cost you a day's pay to go and have this check, then more likely to turn around and say, well I will have to take a chance on that one, I can't afford to go"*

## RELATIONSHIP WITH HEALTHCARE PROFESSIONALS

⊗ Seen as a mediating factor as to whether medical advice was sought

⊗ Consists of five sub themes:

1. G.P. is seen as expert
2. G.P.'s are dictatorial
3. Pharmacists - new healthcare provider
4. G.P nurses liked
5. Communication- between G.P and patients & between providers

## RELATIONSHIP WITH HEALTHCARE PROFESSIONALS (2)

*"In my opinion, you don't go to your GP because you've sprained your foot, it's just wasting their time, and all they're going to do is say go down to the minor injuries unit"*

*"Chemist. I mean I'm...these days I find that I ask them quite a few things where I wouldn't have done years ago. You just didn't did you? But now you go and approach the chemist"*

*"Even if he took my blood pressure he says, good, good, good. What's the reading, it's good, you know and even now I'm having constant headache and I know it's stress but my blood pressure is good so what do I know, they're the professional"*

## FEAR

Consists of three sub themes

1. Fear of CVD risk assessment results
  - Ignorance is bliss
2. Desire to have fear based adverts
  - "shock-element"
3. Denial
  - Story telling- can happen to the healthiest
  - Blaming others- govt, food companies & genes

## FEAR (2)

*"I don't know if I want to go to this assessment centre, be assessed, and then have them turn around and say to me, don't fancy your chances... I think you'll frighten the life out of me... he might say you've got six months to live. ...that'd frighten the life out of me. I don't think I'd want to know"*

*"Well I went to a funeral, a friend's son, 38 years old, never drunk, never smoked in his life, and he was a bodybuilder, he had muscles on his muscles... He came in from work one night, had his evening meal, went up the stairs, collapsed, dead, heart attack"*

## RECOMMENDATIONS FOR SERVICES

Where will it take place?

1. Service needs to be offered in local places such as; G.P. surgery, pharmacies, workplaces, supermarkets.
2. Drop in and mobile units
3. R.A to be made available in supermarkets

## RECOMMENDATIONS FOR SERVICES

Who will carry it out?

1. Pharmacists
1. G.P.
2. G.P. nurses
3. CVD chips
4. Clinically trained professionals

## RECOMMENDATIONS FOR SERVICES

How should it take place?

1. Invitation Letter from G.P.
2. Health professionals (especially G.P.'s and pharmacists) discussing CVD R.A.
3. Information campaign alongside advertising campaign
4. Offer monetary or non-monetary incentives to patients
5. Develop tailored services for older age groups
6. Providers should have knowledge of the culture/traditions of the communities they are catering for
7. Greater communication between providers

## RECOMMENDATIONS FOR ADVERTISEMENT

⊗ Universal List:

1. Mobile units for assessments
2. Posters in job centres
3. Adverts in local papers
4. G.P. sending invitation letter
5. Checklist type format on leaflets
6. Incentives
7. NHS logo
8. Balanced campaign (-ve & +ve messages)

### MALES 40-49

- "Be selfish about yourself"
- Checklist format
- Traffic light style:
  - Red= high risk
  - amber= medium risk
  - Green= no risk

- Supermarkets
- Flyers through letterbox
- Taxis
- Trains
- Buses
- Schools
- Essex fm
- billboards

### FEMALES 40-49

- Focus on age
- Direct, straight to the point messages
- CVD- "sounds like a STD"- want simple terminology such as heart disease & stroke
- Children used in campaigns
- CVD can happen at any age

- G.P. surgeries
- Essex FM- Martin & Sue am programme
- Bus stops
- Letter from schools
- Pharmacies
- Supermarkets
- Directmail

## MALES 50-59

- Adverts with catchphrases
- Being "able-bodied" important
- Focus on CVD prevention
- Adverts playing with colour:
  - Red= healthy
  - Blue= unhealthy

- Radio
- Food shops
- Football stadiums
- Transport
- Supermarkets
- Post offices
- Bus stops

## FEMALES 50-59

- Checklist format
- Important for them to remain healthy
- Focus on maintaining good health
- Adverts "tugging at the heart strings"

- Leaflets
- G.P. surgery
- Schools
- Pharmacy
- Supermarkets
- Job centres
- Public toilets

## MALES 60+

- Focus on CVD can be prevented
- Factual information- use case study to advertise
- Prefer pictures to words
- Preference for red
- Want a celebrity endorsement! (a local role model)

- Sports pages in local paper
- Pages f 82 in local paper
- G.P. surgery
- Hospitals
- Football grounds
- Taxis
- Buses
- Swimming pools
- Post offices

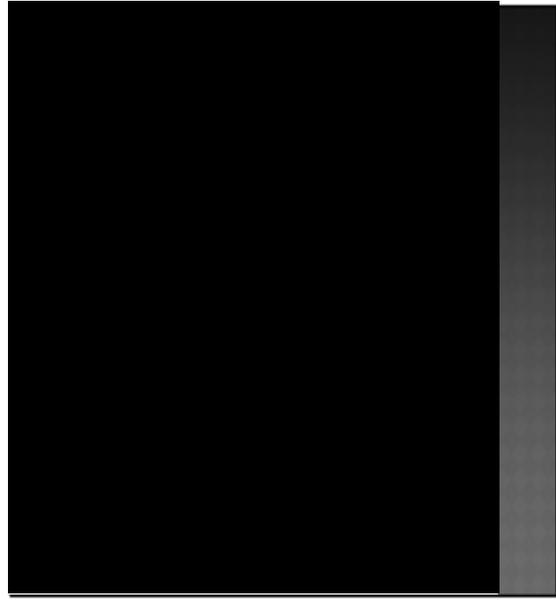
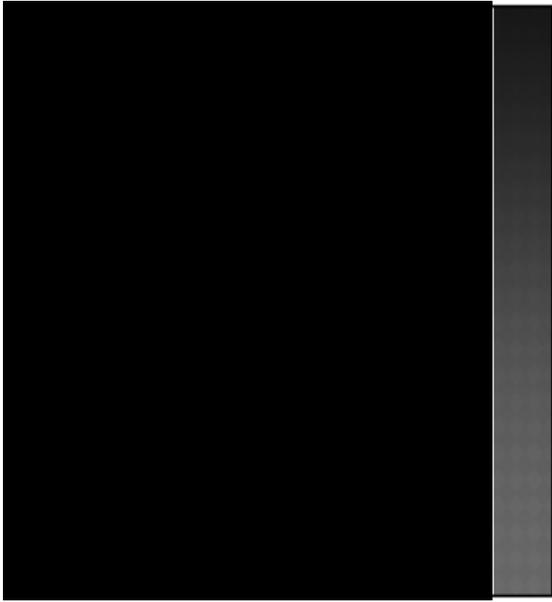
## FEMALES 60+

- What a person will leave behind
- Simple straightforward
- Address issue of time (e.g. add time to your life)
- Preference for colour red

- Shelter schemes
- Local services
- Public toilets
- Supermarkets

## CONCLUSION

- CVD risk assessments are attractive
- NHS cares
- Public scared of G.P.'s brushing them off
- Knowledge on:
  - heart conditions is high
  - Stroke is low
  - The term CVD is low
- Educational campaign as well as an advertising one
- Offer people choice in services



Questions  
are  
guaranteed in  
life;  
Answers  
aren't.

E-mail : [jananezwaryk@yahoo.com](mailto:jananezwaryk@yahoo.com)

## Appendix 3

### About me ...

- Completed my MSc in Health Psychology with City University in 2007
- Stage 2 student
- Work for South West Essex PCT
- Health Psychology Team – part of the Health Improvement Directorate.
- Areas of focus:
  - Research
  - Evidence based practice
  - Evaluation



CITY UNIVERSITY  
LONDON



South West Essex

### Teaching Structure

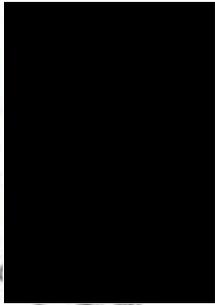
- My MSc research
- Fundamental flaws in my research
- Research Practicalities
- Stage 2 training

### MSc Research

Stress among psychology students and the evaluation of computer based "Stress Relief" Programme

### Stress

- Can be defined as the way a person feels when they are under too much pressure
- Academic life is undeniably stressful
- Among the stressors that students experience in their daily life could include deadlines, exams, coursework and financial issues



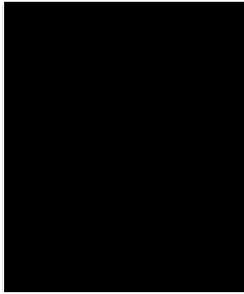
### Stress among students



- Tina Ozki died at a London hospital after taking an overdose of anti-malarial drugs because she was worried about her GCSE exams

### Stress among students

- Academic stress could also alter a student's physiological wellbeing
- Cell-mediated immune responses are suppressed during times of high stress
- Students are susceptible to viral infections and allergic/asthmatic



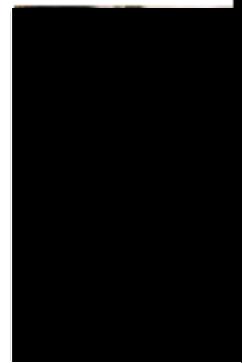
## Stress among psychology students

- Studies investigating stress in psychology student yield that time constraints accounted for the greatest variance in stress ratings (Cahir & Morris, 1991)



## Stress among psychology students

- Hudson and Regan (1994) found that the stressors below had a significant impact on the stress experienced by psychology students
  - number of children and
  - status of relationship,
  - number of hours student spends at work



## Computer based intervention for stress

- In recent years, computerized interventions for depression, anxiety, and other stress related conditions have been developed.
- Six prominent universities in the UK, purchased a computer based stress relief programme to help students.



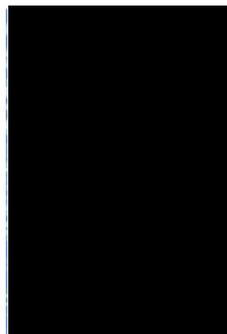
## However ...

- There is a very crucial aspect of computer interaction that has been overlooked by the creator of computer-based intervention.
  - ability
  - proficiency
  - skill
  - computer anxiety

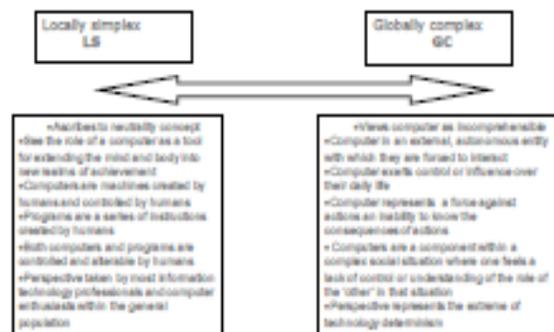


## Human computer interaction

- Is far more complex than anticipated by creators of computer-based intervention.
- There are many factors that influence the effectiveness of intervention administered using a computer.



## Marakas et al (2000)



## Aims of this study

- Is to Investigate the stresses experienced by psychology students
- Research on stress in student population has not proposed a solution
- This research aimed to overcome this void and investigate a form of computer-based Intervention .



## Method (Study 1)

- Apparatus
  - Consent form
  - 10-Item Perceived Stress Scale (PSS) aim to assess the participants' levels of stress.
  - Demographic questionnaire.

## Procedure

- Participants in this study were given a consent form.
- Students were administered with the 10-Item Perceived Stress Scale.
- Participants subsequently filled in a brief demographic questionnaire.

## Results

- The Perceived Stress Scale score can range from 0 to 40
- Higher scores indicate higher level of stress
- The results indicated a minimum stress score of 5 points and a maximum stress score of 30 points

## Results

- None of the participants in this study were highly stressed
- At the end of the demographic questionnaire, an open-ended question queried participants on three major causes of stress in their lives

## Results

- The answers provided by participants were categorized into five categories
- Participants' major causes of stress were related to academic stress, family factors, finance, daily hassle, and future prospects

## Study 2

- Aimed to investigate student's reaction (positive/negative) towards the Stress Relief programme
- Human interaction with computers are extremely complex
- The computer based stress relief programme might be helpful to some student but not all



## Computer interaction

- The computer anthropomorphism was used to investigate participant's interaction with computers
- The computer anthropomorphism has good internal validity, predictive validity and reliability



## Anthropomorphism

- Is attribution of human characteristics and qualities to inanimate things or objects
- Past research has proven that some computer users have the tendency to anthropomorphise computers



## Hypothesis 1

- *H0* - The level of anthropomorphism will have no effect on the way in which students react to the Stress Relief programme
- *H1* - The level of anthropomorphism will have an effect on the way in which students react to the Stress Relief programme



## Hypothesis 2

- *H0* - The level of stress will have no effect on the way in which students react to the Stress Relief programme
- *H1* - The level of stress will have an effect on the way in which students react to the Stress Relief programme

## Methods (Study 2)

### Apparatus

- Consent form
- The Stress Relief Computer Programme
- Questionnaire investigating participants response to the Stress Relief programme
- 14-item computer anthropomorphism questionnaire
- Demographic questionnaire

## Procedure

- All participants completed the questionnaires online
- An e-mail version of the questionnaire was send out to participants
- Participants were given electronic version of consent form

## Procedure

- Participants were also provided an electronic information sheet containing the procedure for the study
- The procedure form contained a username and password that provided participant the access to view the "Stress Relief" programme

## Procedure

- Upon viewing the programme, participants were instructed to fill in three questionnaires assessing their response to the Stress Relief Programme, participant's anthropomorphism level and demographic details.

## Results

- Hypothesis 1 of this study predicted that the level of anthropomorphism will have an effect students evaluation of the Stress Relief programme
- An Independent group t-test was conducted on the data

## Results

- The group statistics table of the t-test indicated that, on average, high anthropomorphic individuals did rate the stress relief programme more positively ( $M=25$ ,  $SE=1.57$ ), than low anthropomorphic participants ( $M=27$ ,  $SE=1.43$ ). However, the differences in means were small
- The effect size was calculated. This results represented a small sized effect  $r=0.2$

## Results

- Hypothesis 2 of this study predicted that the level of stress will have an effect on the way in which students react to the Stress Relief programme
- On average, highly stressed participants did rate the stress relief programme more positively ( $M=25.8$ ,  $SE=0.87$ ), than less stress participants ( $M=27.4$ ,  $SE=3.20$ )
- However this difference was not significant  $t(15) = 0.65$ ,  $p>0.05$ .
- The effect size was calculated. This results represented a small sized effect  $r=0.2$

## Flaws in my study...

- Because of time constrain and lack of planning , this research was conducted during summer holidays , which was definitely not an appropriate time to obtain student stress score

## Flaws in my study...

### Lack of participants

- Because this study was conducted during the summer vacation period, recruitment was extremely difficult
- According to the power calculation that was conducted prior the commencement of this study, hundred and fifty participant were needed for both the studies. However, due to summer vacation and time constrain, only a modest forty participants were recruited successfully

## Research Practicalities

## Ethics

- It's important to review the BPS ethical code of conduct prior to conducting a research
- Some of the ethical issues that should be considered during research :
  - *Protection of participants*
  - *Informed consent*
  - *No coercion*
  - *The right to withdraw*
  - *Anonymity and confidentiality*
  - *Additional safeguards for research with vulnerable populations*

## Reviewing literature

- **Be creative**
  - Databases search
  - Asking an expert
  - Conference papers

## Assessing the practical feasibility of a research

- Upon completing the literate review , a researcher should be able to assess the practical feasibility of conducting a research
- E.g. participants required for the study
  - how many
  - participant availability
  - will the participants be willing to participate in the research
  - will payments/incentive be necessary to entice participants to participate in the research

## Assessing the practical feasibility of a research

- Decide on data analysis method in advance
- Refreshing knowledge and understanding on the analysis methodology could be beneficial especially when using quantitative analysis
- Address the concerns you have in adopting the methodology with your supervisor or other professionals, so you are confident and clear on using the analysis method in your research

## Methodology

When choosing a methodology, a number of factors need to be taken into consideration – first is your expectation of the research

## Methodology

- If your research is on an area that has been researched thoroughly and assessment tools are available – then quantitative approach may be used
- If the research is being conducted in an area which has not been widely researched – an exploratory or qualitative approach may be appropriate

## Methodology

- If you are interested in people's behavior not their beliefs and intentions then experimentation study may be appropriate
- If you are interested in the meaning that a behavior has on participants, then you may use a method such as ethnography

## Formulate a timetable

- Create an explicit timetable for your research
- The timetable needs to contain stages of the research and deadline for each stage
- Time allocated for MSc research is extremely limited
- Hence, try not to be very ambitious; better well conducted, simple piece of research which is easy to interpret, than an over ambitious one which yields no clear cut results – scientific knowledge mainly increases in small increments

## Stage 2 training

## Bursary scheme

- The bursaries consist of a payment of £13,500 per annum (tax free) plus fees over two years
- I work 3 days per week in the sponsoring agencies (SW Essex PCT) and spend the remaining 2 days per week meeting the requirements of the training programme

## My involvements ...

## Social Marketing on CVD awareness

- The team was assigned to research, design and implement a CVD awareness campaign
- The aims of this project were :
  - To assess public awareness of CVD and prevention
  - To gain understanding on ways to enhance CVD awareness and encourage people to attend CVD assessment
  - Develop individual level and population level public health campaigns to increase awareness on CVD and the importance of CVD assessment

## Social Marketing study on Stroke Awareness

- This study is being conducted for 5 PCT's within Essex
- The aims of this study are similar to the CVD awareness study
- This large scale study utilizes quantitative methodology

## CCBT

- Submitted the proposal to establish a CCBT Intervention within the PCT
- However the Mental Health Team, was already utilizing the programme
- Hence, we created a referral process for patients accessing the Vitality Wellbeing service to gain access to the CCBT Intervention

## Web-based smoking cessation intervention

- Working on designing, piloting and implementing a web based smoking cessation intervention

## Appendix 4

### Role of Health Psychology in the NHS

### What is a Health Psychology

- Broad discipline
- Relatively new
- 'practice and application of psychological methods to the study of human (thinking and) behaviour relevant to health, illness and health care'  
NHS (2007)

### Three major areas

- Health behaviour change
  - Biological, psychological and social determinants of health related behaviour and outcomes
- Health care delivery and healthcare environments
  - Effective communication, understanding the impact of type of healthcare experience on physical health outcomes
- Understanding illness experience
  - Gaining information about illness experience, quality of life and so on particularly in relation to chronic disease and painful conditions – can help inform better healthcare

### Overlaps with...

- Social Psychology
- Clinical Psychology
- Occupational Psychology
- Forensic Psychology
- Environmental Psychology
- Neuropsychology
- Cognitive Psychology

### What is a Health Psychologist?

- Experts in applying psychological knowledge, research and interventions to promote and improve health, the health care system and to inform health policy.
- They work with patients, carers/families, healthy community members, and health care professionals, in groups, with individuals and with organisations.
- Health Psychology is a rapidly-growing area within the NHS.

### Leading causes of death.

- Heart disease
- Cancer
- Stroke
- Accidents

**All have a lifestyle component:  
therefore psychology has a role.**

## Lifestyle choices play a major role in health.

- Smoking
- Drinking Alcohol
- Recreational and addictive drugs
- Overeating
- Poor nutrition
- Lack of exercise
- Risky sexual behavior

## Nicotine

- Lung cancer.
- Many forms of cancer.
- Heart disease.

### Smoking



- Although on the decline since the '60's, today
  - 28% adult men still smoke
  - 23% adult women still smoke

#### Health effects

- Earlier deaths due to
  - Cancer
  - Heart disease
    - Hypertension
    - Stroke



#### GIVE IT UP!

- It can be done!
  - Health effects return to normal after 15 years
- The less smoked, the better the success rate
  - 25% successful



## Diet.

- Poor diet has been implicated in:
  - Colon, stomach, pancreatic, prostate, and breast cancer.
  - Hypertension (high blood pressure).
  - Diabetes (body weight, sugar, fats).

## Exercise

- Lowers blood pressure
- Protects heart against rhythm disturbances
- LDL-cholesterol and raises HDL-cholesterol (the good cholesterol)



## Alcohol abuse

- Accidents.
- Cirrhosis of the liver.
- Some forms of cancer.
- Fetal alcohol syndrome in new-born.
- Cognitive impairment.

### Drinking Alcohol

- THE most common of the "drugs"
- Over 68% of average adults drink
- Over 85% of undergrads drink

**Short-term, negative effects**

- Physical effects... "the hangover"
- Poor decision-making and accidents
- Increased vulnerability
  - For other risky behaviors, e.g., SEXUAL ACTIVITY
  - For manipulation & exploitation
- Some people, prone to aggression

**DRUNK DRIVING**

- DANGEROUS
- DEADLY
- ILLEGAL

### The relationship between HEART DISEASE and STRESS.

**Coronary heart disease (CHD):**

- Atherosclerosis (furring of the arteries).
- Angina Pectoris (chest pains).
- Myocardial infarction (heart attacks).

### Other stress-linked disorders:

- Cancer**
- Rheumatoid Arthritis**
- Respiratory infections**
- Immunosuppression Disorders**

### In Summary

- The major killers today are cancer, heart disease and strokes.
- These major killers all have a lifestyle component.
- Health psychology has a major role to play in all these lifestyle areas.

### What areas within the NHS Health Psychologist work?

**PUBLIC HEALTH SERVICES**

**MEDICAL/ILLNESS SERVICES**

### PUBLIC HEALTH SERVICES

Health Psychologists are working to

- improve adherence to public health screening programmes and targets;
- increase outcomes on smoking cessation, drug and alcohol rehabilitation programmes;
- implement strategic planning and service development to advance health check programmes, improve quality of life outcomes and reduce health risks;
- reduce GP attendance by increasing public awareness of risks to health and increase self-management of illness;
- training primary care staff ;
- research / evaluation / consultancy

## MEDICAL/ILLNESS SERVICES

Health Psychologists support hospital and community services through

- direct psychological work with patients, families and carers (for example helping them to adjust to illness and treatment);
- psychological preparation for surgery and confidence building within rehabilitation (this can reduce bed days);
- pacing and goal setting for rehabilitation programmes; and
- support for allied health professions to increase communication and psychological skills.

## My Job

## Doctorate in Health Psychology

- 2 year full time / 4 year part time programme
- 6 competency
  - Generic Professional
  - Research
  - Teaching & Training
  - Consultancy
  - Optional 1
  - Optional 2
- 3 days work with sponsors & 2 Uni days

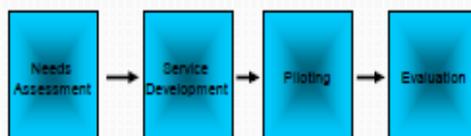
## Research

- Thesis (40-45,000 words )
- Systematic Review

## My Research Competency

- Thesis - Development of an Alcohol Service based on community insight for hazardous /risky alcohol consumers

- Consist of four stages



## Needs Assessment (Stage 1)

- Focus groups with hazardous /risky alcohol consumers
- 8 focus groups to be conducted in 2 SW Essex locality (Brentwood & Basildon )
- Data will be analysed using template analysis & would be used to develop an alcohol service for this target group

## Training Primary Care Staff

Part of the Core competency for Stage 2 Health Psychology Training

## Training Primary Care Staff

- Research Methods
- Theories of Behaviour Change
- Health Promotion
- Individual Differences in Behaviour Change
- Survey Design
- Motivational Interviewing
- Individual Difference in Behavior change for SW Essex Health Trainer

## Past Projects

- CVD Awareness Evaluation
- Stroke Awareness Evaluation
- Vitality Brand Awareness Evaluation
- Smoking Audit
- Pharmacy Needs Assessment

## Stroke Awareness Evaluation

*Commissioned by the Essex Stroke & Cardiac Network*

## Aim

- To have a greater and deeper understanding of the differences in the awareness of stroke and services available within Essex
- To identify the demographic and geo-demographic differences within the region.

## Quantitative Design

Assessed participants' socio-demographic characteristics, general knowledge of stroke, awareness of stroke warning symptoms, risk factors of stroke, consequences of stroke, sources providing knowledge of stroke and questions about advertisement preference to assist the development of a campaign to enhance stroke awareness in Essex.

## Act On Smoking

- 6,000 DVD's are soon to be circulated in schools across SW Essex as the culmination of the Act On Smoking project.
- The aim of the evaluation is evaluate the change (if there is one) in attitudes of the young people after having watched the DVD

## Tower Hamlet Pilot CVD Screening programme Evaluation

- My role would involve undertaking focus groups and one-to-one interviews with patients, HCP's and G.P's who were part of this pilot programme
- Findings from the evaluation will inform how the pilot will be subsequently rolled out to all residents of Tower Hamlets

## What have I gained ?



## How do you train?

- BPS accredited degree providing GBR
- 2:1 or above
- BPS accredited MSc Health Psychology
  - Stage 1 qualification towards chartered status
- Stage 2 qualification
  - Through supervised portfolio route
  - Or accredited doctoral programme
  - City University , Staffordshire, UCL, University of Surrey & Institute of Psychiatry all offer doctorates

## How much can you earn?

- Research posts start at around £24 000 +
- Lectureships - £28 000 +
- Pay can go up to £46-50 K +
- NHS has different pay scales but not dissimilar
- Opportunities for extra income (consultancy, books, external examining)
- Perks (e.g. foreign travel)

## More information

- **Courses:** Contact courses direct for more information about content, entry requirements, application procedure etc....  
[http://www.bps.org.uk/careers/accredited-courses/accredited-courses\\_home.cfm](http://www.bps.org.uk/careers/accredited-courses/accredited-courses_home.cfm)
- **SMG:** the Students Members Group of the BPS. A networking group for undergraduates in psychology. The website has very useful interviews on with psychologists on various career paths.  
[http://www.bps.org.uk/sub-sites/smg/smg\\_home.cfm](http://www.bps.org.uk/sub-sites/smg/smg_home.cfm)
- **DHP:** the Division of Health Psychology of the BPS. Access to publications, conferences, and special interest groups and chat rooms with membership.  
[http://www.bps.org.uk/sub-sites/dhp/dhp\\_home.cfm](http://www.bps.org.uk/sub-sites/dhp/dhp_home.cfm)
- <http://www.bps.org.uk>

## Appendix 5

**Invited Speaker**  
Jana Kanapathy  
3<sup>rd</sup> Year Dpsych Health Psychology Student

**What areas within the NHS  
Health Psychologist work?**

**PUBLIC HEALTH SERVICES  
MEDICAL/ILLNESS SERVICES**

**PUBLIC HEALTH SERVICES**

Health Psychologists are working to

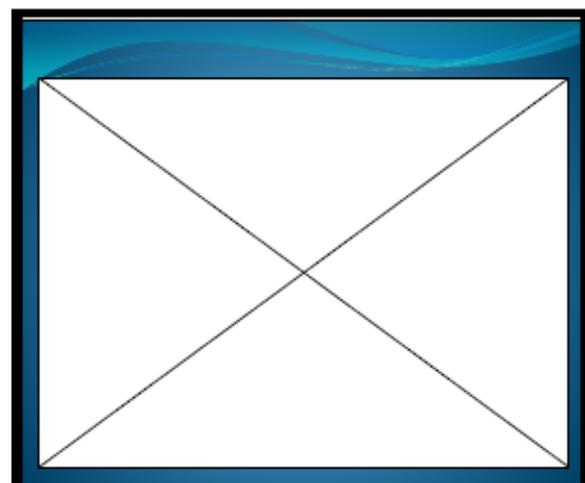
- improve adherence to public health screening programmes and targets;
- increase outcomes on smoking cessation, drug and alcohol rehabilitation programmes;
- implement strategic planning and service development to advance health check programmes, improve quality of life outcomes and reduce health risks;
- reduce GP attendance by increasing public awareness of risks to health and increase self-management of illness;
- training primary care staff ;
- research / evaluation /consultancy

**MEDICAL/ILLNESS SERVICES**

Health Psychologists support hospital and community services through

- direct psychological work with patients, families and carers (for example helping them to adjust to illness and treatment);
- psychological preparation for surgery and confidence building within rehabilitation (this can reduce bed days);
- pacing and goal setting for rehabilitation programmes; and
- support for allied health professions to increase communication and psychological skills.

**Stroke Awareness  
Evaluation**  
*Commissioned by the Essex Stroke & Cardiac Network*



## Intro

- Stroke has been described as 'an earthquake in the brain'
- Stroke is a 'brain attack' caused by a disturbance to the blood supply to the brain
- Stroke is one of the top three causes of death in England and a leading cause of adult disability.
- Approximately 110,000 stroke and further 20,000 transient ischemic attacks occur in England every year.

## Personal Impact of Stroke

- There are at least 300,000 people in England living with moderate to severe disability as a result of stroke.
- A third of people who have a stroke are left with long-term disability.
- Effects can include aphasia, physical disability, loss of cognitive and communication skills (e.g. leading to aphasia), depression and other mental health problems.

Stroke costs the NHS and the economy about  
£7 billion a year

## Aim

- To assess public awareness of stroke and prevention
- To gain understanding on ways to enhance stroke awareness
- Develop individual level and population level public health campaigns to increase awareness on stroke
- To identify barriers that deter community members from gaining stroke related information and services.
- To aid in strategic and marketing guidance for further developing communications efforts to increase levels of awareness for stroke prevention and treatment in Essex.

## TASK

- Information gathering from Essex Stroke & Cardiac Network
- Proposal - What would be included in the proposal (e.g. what methodology, why)
- What questions would you include to meet the aims of this research

## Information gathering from Essex Stroke & Cardiac Network

- **Clarifying the question**  
What exactly are you being asked to do  
Why is there a need for this work now?
- **Identifying outcomes**  
What outcomes need to be achieved? And when (i.e. timeline)  
Does client have accurate perception of what you can offer?
- **Understanding the background and organisational context**  
How will work fit with national policy/agenda e.g. NSFs?  
What is desired outcome of work for the organisation?
- **Identifying responsibilities**  
Who is responsible for making things happen?  
Engaging with key contacts within the organisation

## Structure of written proposal

1. Intro with relevant background, national and local
2. Measurable aims/objectives
3. Methodology - why particular method selected
4. Reporting and dissemination of results - state how you propose to analyse data (quant/qual) and how they will be reported
5. Key responsibilities (those undertaking work, client responsibilities)
6. Project team (e.g. Stakeholders - key personnel influencing planning and delivering of services)

### Next steps

Presentation to client  
Amendments to proposal, if necessary  
Specify how work will be monitored and reported (i.e. Setting up regular meetings)

## Stroke Awareness Evaluation

*How this evaluation was carried out*

## Design

- Questionnaires were administered to the general public across the five PCT areas in Essex
- Questionnaires were circulated online and in public places
- Efforts were made to administer the questionnaire to people of all ages, backgrounds and social grade to provide a fuller picture.
- A total of 634 completed questionnaires were obtained

## Questionnaire Format

- The questionnaire consisted of closed and open-ended questions
- It took the participants on average 10-15 minutes to complete
- The questions assessed participants' socio-demographic characteristics, general knowledge of stroke, awareness of stroke warning symptoms, risk factors of stroke, consequences of stroke, sources providing knowledge of stroke and questions about advertisement preference to assist the development of a campaign to enhance stroke awareness in Essex

## Analysis

- The SPSS statistical package was used to analyse the data obtained from this evaluation, as it permitted detailed analysis of the large data set
- ANOVAs were conducted on the data set.
- ANOVA can be used to tease apart any significant relationships, to pin point whether the introduction of two or more variables influence the strength of the relationship.
- This statistical test was able to explore stroke awareness of the participants based on their demographic information (e.g. gender, PCT area, age, employment status and educational qualification).

## Analysis

- The data obtained from the open-ended questions was analysed using template analysis
- Template analysis is a method for identifying, analysing and reporting patterns (themes/templates) within data. It minimally organizes and describes a data set in (rich) detail
- Some of the advantages of this analysis method are listed below.
  - ◊ Can usefully summarize key features of a large body of data, and/or offer a 'thick description' of the data set.
  - ◊ Can highlight similarities and differences across the data set.
  - ◊ Can generate unanticipated insights.

## Results

- Existing knowledge base
- Gaps in knowledge
- Lifestyle and Preventability

## Results

### Existing knowledge base

- Older participants were more knowledgeable/aware of the risk factors of stroke compared to younger participants
- Knowledge of the biological cause of stroke is high overall.
- Participants with medical/nursing background were more aware of stroke (risk factors, consequences, treatment, etc)
- The majority of participants knew that stroke requires emergency treatment (78%).

## Results

### Gaps in knowledge

- Majority of participants underestimated the prevalence of stroke being a top 3 killer in the UK
- Their knowledge on warning symptoms was poor
- Participants placed more emphasis on the physical impairment caused by stroke and knew less about psychological and cognitive impairments

## Results

### Lifestyle and Preventability

- This evaluation found that participants lack in awareness about the effect lifestyle could have on stroke
- Only half of the participants believed that stroke was preventable, hence, steps should be taken to highlight how stroke can be prevented through lifestyle choices

## Recommendations 1

- It was obvious that even vulnerable groups lacked knowledge on risk factors of stroke.
- It is recommended that specific efforts should be made to make this group more aware of the risk factors leading to a stroke.

## Recommendations 2

- Previous literature on stroke awareness found the younger age groups to be more aware of stroke, however this is contradicted by the findings of this study
- This age group should also be targeted in raising awareness, as they were significantly less aware of the risk factors and the symptoms of stroke
- Schools could be a suitable platform to disseminate information about stroke through handing out information packs and teaching about stroke during PSHE lessons.

## Recommendations 3

- It became apparent that the older age group (58+) were that stroke was a CVD
- This is further supported by the CVD study finding that the vast majority of participants did not associate stroke with CVD
- Efforts should be made to make this age group more aware of the biological causes of stroke and how CVD and stroke is associated (i.e. stroke is a cardiovascular disease because it can affect the arteries leading to the brain)

## Recommendations 4

Healthcare professionals, carers, residential care home staff as well as school staff need to be trained on aspects of stroke (consequences, risk, treatment, local services), so they can effectively provide the necessary information and care for the Essex population

Measures that should be taken if a questionnaire is not available to measure the issue that is being investigated

## Questionnaire design

### Guidelines to create a questionnaire

1. Determine clearly what it is you want to measure
2. Generate Item Pool
3. Determine format for measurement
4. Have initial pool of item reviewed by expert
5. Piloting and amendment of questionnaire
6. Administer questionnaire to target population

## Determine clearly what it is you want to measure

- Many researchers think they know clearly what they want to measure only to realise that their ideas are more vague than they thought
- Some points to think about initially
  - Should the scale be based on theory
  - Specificity of the scale
  - Be clear what to include in the measure

## Generate Item Pool

- **Avoid leading questions**- *"Wouldn't you say that..."; "Isn't it fair to say..."*
- **Be specific. Avoid words like**- *"regularly"; "often", or "locally"* - as everyone's idea of what is regular, often or local will be different.
- **Avoid jargon and colloquialisms** - ensure your language caters for all levels of literacy. Remember for some respondents English may be their second language.

## Generate Item Pool

- **Avoid double-barrelled questions** - *"Do you enjoy playing badminton and tennis?"*. Ask for one piece of information at a time.
- **Avoid double negatives** - e.g. instead of asking respondents whether they agree with the negative statement, *"Smoking in public places should not be abolished"*, use the positive *"Smoking in public places should be abolished"*.
- **Minimise bias**

## Generate Item Pool

- **Handling difficult or embarrassing questions.**
  - To encourage a greater response to difficult questions, explain why you need to know that information.
- **Ensure options are mutually exclusive**- e.g. *"How many years have you worked in academia: 0-5, 6-10, 11-15, over 15."* Not, *"0-5, 5-10, 10-15..."*

## Determine format for measurement

Open questions	Closed questions
Elicit 'rich' qualitative data	Elicit quantitative data
Encourage thought and freedom of expression	Can encourage 'mindless' replies
May discourage responses from less literate respondents	Are easy for all literacy levels to respond to
Take longer to answer and may put some people off	Are quick to answer and may improve your response rate
Are more difficult to analyse - responses can be misinterpreted.	Are easy to 'code' and analyse

## Have initial pool of items reviewed by expert

- You can ask your panel of experts to rate
  - How relevant they think each item is
  - Evaluate item clarity
  - Tapping the phenomenon that you have failed to include

## Piloting

- Administer the scale to a small sample of target audience
- Would help determine if the wording and phrases used within the scale is comprehensible to the target audience

## Administer items to a development sample

- Administer the amended questionnaire to the development sample
- Sample size would depend on the nature of the study, but it is recommended to have a large sample size

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## **Appendix 6**

### **Our Journey of Becoming Trainee Health Psychologists**

2008-2010

**Parmpreet Marway**

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**Jana Kanapathy**

[jananezwarj.kanapathy@sussex.nhs.uk](mailto:jananezwarj.kanapathy@sussex.nhs.uk)

### **Position Before Applying for Bursary Scheme**

- Student on the MSc Health Psychology Course (2007/2008)
- Were due to complete the course in Summer 2008
- Multiple voluntary work experience

### **Work Experience - Jana**

- Been involved with the CBT Crack group at CRI Brent since September 2007 under the supervision of a Chartered Clinical Psychologist
- Among the aspects covered through the crack group includes shoring up motivation and commitment to stop, coping with cravings, refusal skills and assertiveness, developing a coping plan and problem solving.

### **Work Experience - Parm**

- Children with Learning Difficulties
- BME community with mental health problems
- Health Trainers – Providing training and evaluation of the training
- Participatory Action Research

## Bursary Scheme

- Offered to candidates entering the training programme in September 2008 at City University
- The bursaries consisted of a payment + payment of fees over two years.
  - 3 days p/wk were allocated to the sponsoring agencies
  - 2 days p/wk allocated for fulfilment of stage 2 training programme
- The two sponsors of the bursaries scheme were:
  - Barking and Dagenham PCT
  - South West Essex PCT

## Placement at SW Essex

- Identified the need for specialist input and expertise in the form of health psychology capacity
- General support around evaluation and outcomes measurement for PCT programmes/ interventions
- Particularly interested in developing work around the following areas:
  - Social Marketing
  - CCBT
  - Positive Psychology
  - Health Trainers

## Placement at SW Essex

- The required capacity entailed the need for two Doctor of Health Psychology students – each taking a lead role in two of the listed work areas
- Flexibility within these remits to work across different project areas
- Actively encourage a support/learning role in the wider work of the directorate.

## Bursary Scheme

Placement ideal for student as:

- Negotiation was completed on behalf of the students
- Lifts burden on having to find a job and negotiate working hours
- Having the role of Trainee Health Psychologist provided more opportunities to fulfil the competences efficiently within the job role

## Application Process



## Expectations & Job Role

Clinical Health Psychology	Public Health Psychology
<ul style="list-style-type: none"><li>• 1-2-1 work</li><li>• Delivery of interventions</li></ul>	<ul style="list-style-type: none"><li>• Research</li><li>• Evidence based service design</li><li>• Epidemiology / Audits</li></ul>
<ul style="list-style-type: none"><li>• Patients with specific disorders</li></ul>	<ul style="list-style-type: none"><li>• Vulnerable population groups</li></ul>
<ul style="list-style-type: none"><li>• Case studies</li><li>• IPA</li><li>• Assessment</li><li>• Therapy</li></ul>	<ul style="list-style-type: none"><li>• Assessment of disease awareness, etc</li><li>• Health promotion</li><li>• Outcomes - smoking cessation/ dietary changes</li><li>• Health policy</li><li>• Epidemiology - statistical prevalence</li></ul>

## Hurdles

- Time to settle in
- First full-time placements
- Trust policies and objectives dictating longevity of projects
- Current economical climate

## Learning's

- Varied skill set
- Time management
- Application of health psychology to public health
  - Audit
  - Strategy building
  - Commissioning
  - Questionnaire design/ selection of outcome measures/ large data-sets
- Stage 2 training provides a platform



## Individual Research Projects

<b>Jana</b>	<u>Alcohol Consumption</u> - Harmful Drinkers - Hazardous Drinkers
<b>Parm</b>	<u>Stress</u> - Experiences of stress (lay people) - HCP's experiences of patients reporting stress

- NHS Ethics
- Service Design
- Intervention Design

## Tasks

Examples of current job/placement roles  
Where and how can you incorporate health psychology into your remit?

Brainstorm placement ideas - in respect to the new NHS framework

How can you raise the profile of health psychology?

**Appendix 7: Teaching evaluation form used in teaching sessions 1-4**

Teaching Evaluation

Module: \_\_\_\_\_

Date: \_\_\_\_\_

Please indicate your impressions of the items listed below.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. The training met my expectations.	<input type="radio"/>				
2. I will be able to apply the knowledge learned.	<input type="radio"/>				
3. The content was organized and easy to follow.	<input type="radio"/>				
4. The materials distributed were pertinent and useful.	<input type="radio"/>				
5. The trainer was knowledgeable.	<input type="radio"/>				
6. The quality of instruction was good.	<input type="radio"/>				
7. Class participation and interaction were encouraged.	<input type="radio"/>				
8. Adequate time was provided for questions and discussion.	<input type="radio"/>				

11. How do you rate the training overall?

Excellent      
 Good      
 Average      
 Poor      
 Very poor

10. What aspects of the training could be improved?

11. Other comments?

**THANK YOU FOR YOUR PARTICIPATION!**

**Appendix 8: Teaching evaluation form used in teaching session 5**

Evaluation Form

Please rate the following:

	<b>1 Poor</b>	<b>2 Satisfactory</b>	<b>3 Good</b>	<b>4 Excellent</b>
<b>Information on the training route for health psychology</b>				
<b>Information on applied health psychology within public health</b>				
<b>How well did the speakers address your learning objectives identified in the session</b>				
<b>Were there enough opportunities for you to ask questions</b>				
<b>Please rate the time allocated for questions</b>				
<b>The facilitators' knowledge on the training route</b>				
<b>The facilitators' knowledge on applied health psychology</b>				
<b>Content of slides</b>				
<b>Relevancy of the presentation</b>				
<b>The organisation of the material</b>				
<b>The speakers' ability to explain the points coherently and clearly</b>				
<b>The relevancy of the tasks</b>				

**2. Please state what you found most useful from the presentation?**

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**3. Are there any other ways the presentation could have been improved?**

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**4. Additional comments**

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## **Teaching and Training 2 (Healthcare Professionals)**

**Setting:** NHS SW Essex

**Population:** Healthcare Professionals - Health Trainers.

**Description of work:** The health trainer initiative was launched by NHS SW Essex in the beginning of 2009. Health trainers are local people with a genuine understanding of local communities. These professionals are equipped with the wealth of knowledge that comes from living in our communities and are aware of the challenges of everyday life (North East London NHS Foundation Trust, 2009). In January 2009, approximately twenty health trainers were recruited by NHS SW Essex. Health trainers were provided training to enhance population health by tackling issues such as healthy eating, weight management, stop smoking, alcohol/drugs, physical exercise and sexual health. As part of training for the health trainers, I was requested by the Health Trainer Initiative Lead to deliver a training session on Individual Differences in Health and Behaviour Change.

### **UNIT 4.1 - Plan and design training programmes that enable students to learn about psychological knowledge, skills and practice**

#### **4.1a Assessing training needs**

Prior to preparing the teaching materials, an assessment of training needs was established by contacting the Health Trainer Initiative Lead. On all occasions one-to-one meetings were held with the Health Trainer Initiative Lead to discuss the teaching session and collaboratively establish a teaching structure that met the aims and objectives of the training. The main aim of this training session was to provide health trainers with basic knowledge and background of Individual Differences in Health and Behaviour Change.

#### **4.1b Selecting training methods and approaches**

Upon establishing the training needs of the health trainers, I submitted the proposed training plan to the Health Trainer Initiative Lead for review and feedback. The plan was then altered based on the feedback provided. Whilst designing the teaching materials, measures were taken to ensure that the teaching session would provide optimal learning within the allocated time. Further to these, measures were also taken to deliver the training session using layman terms to enable health trainers to comprehend the training well. An e-mail was sent out to the Health Trainer

Initiative Lead requesting resources needed for the teaching sessions (e.g. laptop or desktop computers, a projector and flipcharts). The Health Trainer Initiative Lead ensured the availability of these resources.

#### **Unit 4.1c- Select training methods and approaches**

The health trainers are individuals from the local community who do not necessarily have formal education in the area of health or experience of working within the healthcare setting. Hence the training approaches were adapted to meet the needs of the trainees. Literature on teaching and training suggest that the less academically successful the individual, the more important it is to accommodate learning-style preferences (Dunn et al, 1995). Flemings (2001) proposed that learners have three different learning styles (visual, auditory and kinaesthetic). To optimise learning, the training session incorporated didactic delivery, pictures/diagrams and group work. It was anticipated that this approach would accommodate the learning needs of the trainees and contribute to optimal understanding.

#### **Unit 4.1d - Produce training materials and Unit 4.1e - Use appropriate media to deliver training materials**

The training was delivered using Microsoft Powerpoint (**Appendix 1**). When designing the slides for the training session, information within the slides were kept simple and accurate. Each slide contained information that was concise and easily comprehensible. Measures were taken to avoid the slides from being wordy. When appropriate, diagrams, charts, pictures and videos were incorporated into the slides to enhance the presentation and to facilitate learning.

The completed presentation was sent to the Health Trainer Initiative Lead for review and comment. The comments provided by the Health Trainer Initiative Lead were used in a constructive way to amend the slides. Handouts of the final presentation were made to be circulated during the training session. Handouts provide trainees with the opportunity to follow the training, take essential notes to retain learning and take away the handout for future guidance on the topic. Preparing handouts for training is also an essential backup plan if and when technology fails to function. The Health Trainer Initiative Lead provided a laptop, a presentation screen, flipcharts and a projector for the training.

## **Unit 4.2 - Deliver training programmes encompassing psychological knowledge, skills, and practices**

### **Unit 4.2a - Implement training methods & Unit 4.2b - Facilitate learning**

Prior to the actual teaching, I prepared myself fully by familiarising myself with the content of the training. On the day of the training, I arrived early to test all equipment needed for the teaching session. Unfortunately, on this day technology failed to work. Handouts prepared helped to facilitate the delivery of training despite the technology glitch. The training was delivered at a slow pace to facilitate learning.

When delivering the training, I was extra cautious about my tonality, pace of delivery and body language. During the teaching sessions, trainees were provided ample opportunities to ask questions and seek clarifications. When answering queries, accurate feedback was provided.

The training was delivered to a relatively small number of health trainers (20 participants). Hence, group discussion and group work were incorporated to enhance learning. It was observed that when separated into smaller groups, trainees were more likely to voice questions and queries regarding the topic. The group work also helped monitor learning and focus attention on areas that required further clarity. At the beginning of the training, break times were negotiated and agreed with each group to avoid information overload. During the training, a 'parking lot' approach was used to stay within the allocated timeframe. Pending issues were revisited at the end of the lecture. At the end of the training session, trainees were provided with contact details for follow-up questions and sources for further information. Further to that, e-mail addresses of trainees were also obtained. An electronic copy of the presentation was e-mailed to the trainees.

## **Unit 4.4 - Evaluate training programmes encompassing psychological knowledge, skills, and practices**

The training session did not require an assessment procedure. The training session was evaluated using a standard paper format asking trainees to rate the teaching (**Appendix 2**). All feedbacks received were generally positive. These feedback forms also helped identify the strengths and weaknesses of the training. The insight gained was used to modify the training session.

## **Reflection**

This was the first training session I had ever conducted. Hence, the planning and presentation of this training was an emotional roller-coaster. The main lesson from this training was to keep my nerves under control and deliver the training efficiently. Having short breaks during the training session helped me to deal with my nervousness and at the same time to deliver the training in chunks, which enhanced learning for the trainees.

Through this training I learned that I should always prepare handouts for teaching/training session, as without the handouts this training would not have been successfully delivered due to the unexpected technology glitch. During this session, all measures were taken to rectify the issues with the technology. In future, other measures such as testing out the technology a day prior to the training will be carried out to avoid replication of this situation.

This training helped me understand the importance of addressing Individual Differences in Health and Behaviour Change with future Healthcare providers. Training conducted for primary healthcare staff does not always include aspects of health psychology which are pertinent to primary healthcare service deliveries. Although measures were taken to deliver this training to other primary care staff, these measures were not fruitful.

However, since my move to Malaysia, I have once again taken active measures to contact members of health departments and private organisations specialising in healthcare to seek and pursue opportunities to deliver training on health psychology models and theories. Corresponding with my research interest through in-depth research and literature review, I have identified the need for training on Health Psychology theories and models amongst diabetes care staff in Malaysia. In the future, I intend to design and deliver a training session for this group of health care professionals. This training will be tailored to meet the needs and demands of the Malaysian population.

**References:**

Dunn, R., Griggs, S. A., Olson, J., Beasley, M., & Gorman, B. S. (1995). A meta-analytic validation of the Dunn and Dunn model of learning-style preferences. *The Journal of Educational Research*, 88(6), 353-362.

Fleming, N., & Mills, C. (2001). *VARC: A guide to learning styles*. Retrieved January 25, 2013 from <http://www.vark-learn.com>.

Swessex community National Health Service (UK). (2009). *NHS South West Essex Community Services- Health Trainers*. Retrieved May, 28, 2009 from <http://www.swessexcommunity.nhs.uk/your-services/our-services/health-trainers.aspx>.

## Appendix 1

### Individual Differences

#### What is Individual Differences?

- What does individual differences mean to you ?
- Can you think of an example of a situation in your life when individual differences was apparent
- Why is individual differences important in your role as a Health Trainer ?

(5Minutes )

"No two persons are born exactly alike; but each differs from the other in natural endowments, one being suited for one occupation and the other for another."

-Plato-

#### Western psychology approach to individual differences assumes ...

- People vary on a range of psychological attributes
- It is possible to measure and study these individual differences
- Individual differences are useful for explaining and predicting behavior and performance

## Why is individual differences important?

- Imagine this situation :
- A researcher is interested in resting metabolic rate in humans.
- The researcher gathers a sample of men, women, and children, measures their metabolic rate and gets a single average.

## Why is individual differences important?

- The researcher then tells the whole population that they should be eating 1,900 calories a day.
- What's wrong with this study?

## Why is individual differences important?

The researcher has neglected individual differences in activity level, body size, sex, age, and other factors that influence metabolic rate.

## Why is individual differences important?

- The average reported based on the results is masking multiple dimensions that should be used to determine daily caloric intake.
- Therefore, his or her conclusions are misleading if not outright false.
- This is an extreme example to make a point, but it illustrates the problems that can arise by averaging across groups.

## Individual Difference

- Gender
- Personality
- Ethnicity

## "Big Five" personality traits

- "Five Factor Model"
- Commonly used personality trait
- Lewis Goldberg

## "Big Five" personality traits

- **Openness** - appreciation for art, emotion, adventure, unusual ideas, imagination, curiosity, and variety of experience.
- **Conscientiousness** - a tendency to show self-discipline, act dutifully, and aim for achievement; planned rather than spontaneous behavior.
- **Extraversion** - energy, positive emotions, urgency, and the tendency to seek stimulation and the company of others.

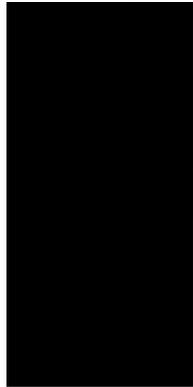
## "Big Five" personality traits

**Agreeableness** - a tendency to be compassionate and cooperative rather than suspicious and antagonistic towards others.

**Neuroticism** - a tendency to experience unpleasant emotions easily, such as anger, anxiety, depression, or vulnerability; sometimes called emotional instability.

## Why is personality important?

Knowing one's placement on the factors is useful for insight and improvement through therapy (Costa & McCrae, 1992).



## CONTRIBUTIONS OF PERSONALITY TO SMOKING

- Smokers score higher than nonsmokers on personality factors such as neuroticism (a tendency for emotional upset and turmoil) and sensation-seeking (an interest in thrills and novelty).
- However, there is no consistent evidence supporting the role of a specific "addictive personality" in smoking. Personality differences are modest and not very specific to addictions.

## Gender

### Task

- Pair up someone of opposite sex
- Discuss how gender effects health
- See how males/females view health
- Discuss what are the barriers they face in being healthy?

## Gender and Health

- Women more likely to see doctor but if reproductive issues are excluded, visits are less often than men .
- 'Bad' health practices often central to notions of masculinity

## Gender and Health

- Lack of contact with HCP
  - During a recent study conducted by the Health Psychology team , findings indicated that men rarely visited their GP's
- Misconception
  - e.g.: Many people think of CHD as a male problem. In fact, it accounts for the death of more women than any other disease.

## Gender and Smoking

- Smoking was historically more common among men, but men and women now have similar smoking prevalence
- Smoking among men has dropped, and women have caught up.
- This pattern is evident in several developed countries. In the developing world, sharp gender differences are still the norm.

## Gender and Smoking

- Even though prevalence has equalized, men still smoke more heavily than women.
- More than men, women report that they smoke in order to deal with stress and emotion.
- Despite their lighter smoking, women appear to be less successful at quitting smoking.

Psychobiology of Nicotine Addiction Neil E. Grunberg, Ph.D., Chair

## Ethnicity

## Ethnicity and Health

Afro-Caribbean ethnic minorities are at high risk of stroke and hypertension.

## Ethnicity and Health

The relatively poor health of black American people in the U.S. and black Caribbean people in England is a consistent finding in the health inequalities literature.

## Ethnicity and Health

- The prevalence of diabetes is three to five times higher in UK South Asians than Whites.
- Hugely attributed to lack of education about the disease in South Asian patients

## Ethnicity and Health

Hypertension remains a major health issue amongst immigrant and UK born African Caribbean people

## Ethnicity and Health

Language barriers present a major obstacle to minority ethnic communities accessing primary healthcare.

## Individual difference in behavior change

## Transtheoretical Model



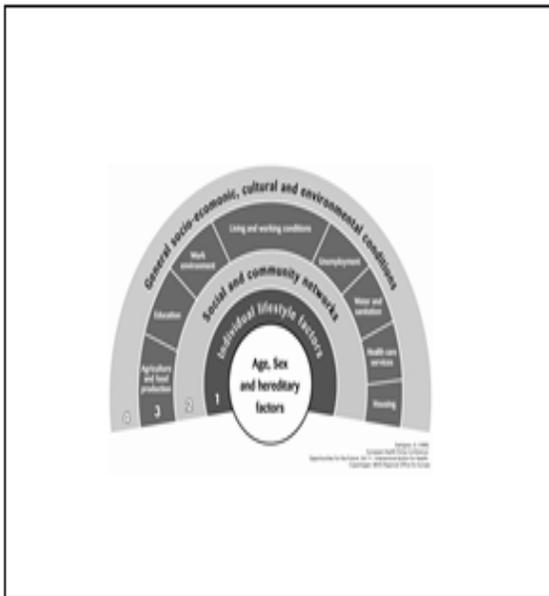
Pre-contemplation	22%
Contemplation	43%
Action	76%

Ockene et al (1992)

- The TTM will allow Health Trainers to identify a person who will be receptive to changing smoking-related behaviours.

## Biopsychosocial Model





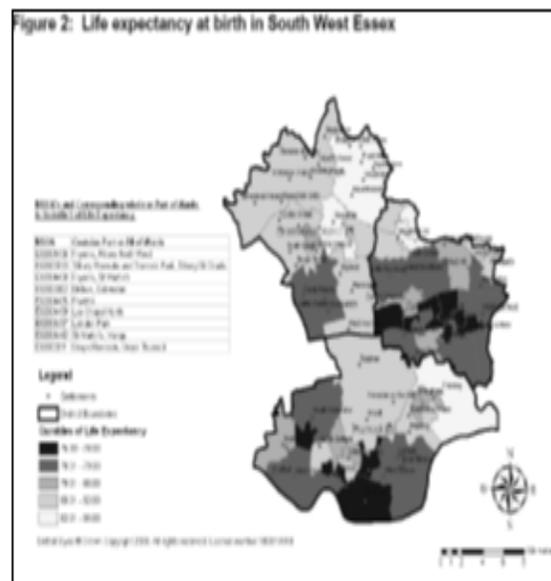
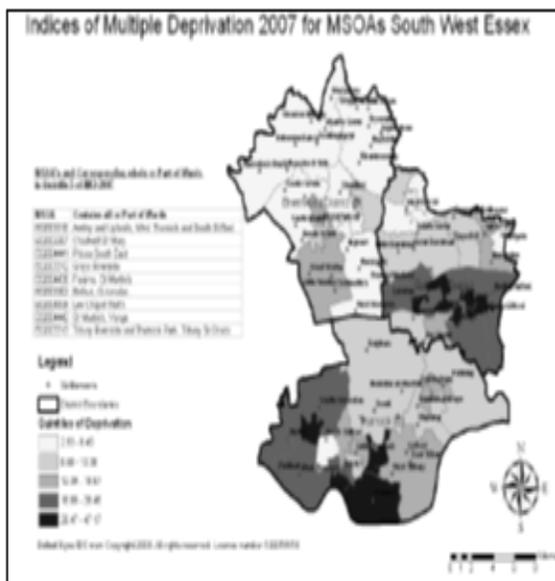
Layer	Approach	Examples
1. Individual lifestyle factors	Strengthening individuals	Smoking; Diet; Fitness
2. Social and community influences	Strengthening communities	Social integration; Cohesion; Social capital; Social support
3. Living and working conditions	Improving access to essential facilities and services	Supply of clean water; Literacy; Health services (e.g. immunisation; medicines)
4a. General socioeconomic, cultural conditions	Encouraging macroeconomic changes;	National GDP; Income inequality; War;
4b. environmental conditions	Encouraging environmental protection	Natural disasters; Climate change

### Health Inequities in SW Essex

- There is a 10 year difference in life expectancy between Brentwood, Basildon and Wickford.
- The greatest levels of deprivation are in parts of Basildon, Tilbury, Grays and Ockendon.
- The average reading age is 12 years.

### Example of Health Inequalities In Relation To Deprived Areas

- Higher levels of obese and overweight people in Thurrock and Basildon.
- This is significantly higher than the national average.
- However it is significantly lower in Brentwood.



## Lifestyle & Health

*(the indirect effect on health)*

- Health Survey for England (2006)
  - Highlighted significant differences in lifestyle behaviours across SW Essex.
  - i.e. deprived areas = unhealthy lifestyles
- Lifestyle is influenced by deprivation

**Appendix 2: Teaching evaluation form**

Teaching Evaluation

Module: \_\_\_\_\_

Date: \_\_\_\_\_

Please indicate your impressions of the items listed below.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. The training met my expectations.	<input type="radio"/>				
2. I will be able to apply the knowledge learned.	<input type="radio"/>				
3. The content was organized and easy to follow.	<input type="radio"/>				
4. The materials distributed were pertinent and useful.	<input type="radio"/>				
5. The trainer was knowledgeable.	<input type="radio"/>				
6. The quality of instruction was good.	<input type="radio"/>				
7. Class participation and interaction were encouraged.	<input type="radio"/>				
8. Adequate time was provided for questions and discussion.	<input type="radio"/>				

11. How do you rate the training overall?

Excellent	Good	Average	Poor	Very poor
<input type="radio"/>				

10. What aspects of the training could be improved?

11. Other comments?

**THANK YOU FOR YOUR PARTICIPATION!**

## **Optional Unit 5.5 Promote Psychological Principles, Practices, Services and Benefits**

### **TITLE: QUALITATIVE EVALUATION WITH MODERATE/ RISKY ALCOHOL CONSUMERS**

#### **Introduction**

According to World Health Organization (WHO, 2002), there are many forms of excessive drinking that cause substantial risk or harm to the consumer. They include high level drinking each day, repeated episodes of drinking to intoxication, drinking that is actually causing physical or mental harm and drinking that has resulted in the person becoming dependent on alcohol. Excessive drinking causes illness and distress to the drinker and his or her family and friends. It is a major cause of breakdown in relationships, trauma, hospitalisation, prolonged disability and early death. Alcohol-related problems represent an immense economic loss to many communities around the world.

In 1980, a WHO expert committee stressed the need for efficient methods to identify persons with harmful and hazardous alcohol consumption before health and social consequences become pronounced. There was an urgent call for the development of strategies that could be applied in primary health care settings with minimum time and resources.

Most adults in England, more than 90 per cent, drink alcohol and the majority do so sensibly. However, around 10 million adults consume alcohol at 'hazardous' levels (that is, above the recommended limits). More than 8 million people in England (26 per cent of the population) have an alcohol use disorder and around 1.1 million people are dependent on alcohol (3.6 per cent of adults are alcohol-dependent – 6 per cent of men and 2 per cent of women) (Drummond et al, 2004). NHS (2008) recommends that men should not regularly drink more than 3-4 units of alcohol a day and women should not regularly drink more than 2-3 units a day.

The reasons for an individual's drinking patterns leading to alcohol misuse are complex and varied (Biswas, 2010). Past research findings provide some evidence to enhance understanding

on how and why people's drinking habits develop and change over time. For example, various studies have found that drinking parents raised children who also drank and that families who abstained from drinking alcohol had children who also abstained (Kandel et al., 1978; Kushner and Sher, 1993; Chalder et al., 2006). Empirical evidence also indicates that alcohol problems could be influenced by psychological factors such as stress, anxiety and depression. Seemen & Seemen (1992) undertook a survey with more than 500 men with drinking problems; they found that drinking problems were closely related to stressful experiences (e.g. illness or death of a loved one) and chronic occupational stressors. In a separate study, Crum and colleagues (1995) found that men employed in high-strain jobs generally had a higher risk of developing alcohol use disorders when compared with men in low-strain occupations. These findings coincide with tension reduction theory (Conger, 1951) which explains that the major motivation for drinking is to reduce anxiety/ stress. Previous research has indicated that tension reduction theory of alcohol consumption has received little empirical support (Polivy et al, 1976). For example, studies have found evidence confounding to this theory. Some studies conducted in 1960's and 1970's investigating this theory found that alcohol was anxiety inducing rather than anxiety reducing (Steffen et al., 1974; McNamee et al., 1968; Mendelson et al., 1964; Nathan & O'Brien, 1971).

Marks & Evans (2005) proposed various theories to explain problematic alcohol consumption. For example, genetics theory proposes that drinking problem is caused by an inherited predisposition. Family, twin and adoption studies have convincingly demonstrated that genes play an important role in the development of alcohol dependence, with heritability estimates in the range of 50% to 60% for both men and women (Dick & Bierut, 2007).

Health psychology theories such as the Theory of Planned Behaviour (TPB) have also been used to study alcohol consumption (Schlegel et al, 1992; Norman, Bennett, & Lewis, 1998; Conner et al, 1999). TPB which was proposed by Ajzen (1991) outlines three main influences on a person's behaviour: his/her perception of the social pressure to engage in the behaviour (i.e. subjective norm), his/her perception of control over performing the behaviour (i.e. perceived behavioural control) and specific beliefs focusing on the consequences of performing the behaviour (i.e. behavioural attitude). In a longitudinal survey of Canadian school students, Schlegel et al. (1992) found that the three main components of the TPB contributed to the prediction of intentions to

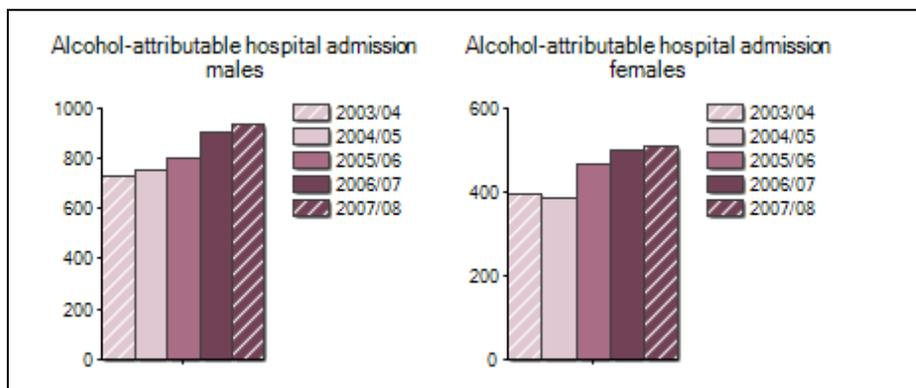
get drunk which, in turn, were predictive of the frequency of getting drunk in non-problem drinkers (cited in Norman, 1998).

**Component 5.5a – Seek opportunities for the promotion of health psychology AND**

**Component 5.5b provide accurate responses to information requests**

NHS South West (SW) Essex serves a population of 420,000 people. This covers a mixed urban/rural area made up of relatively affluent towns of Billericay and Brentwood, and relatively deprived towns of Basildon and Thurrock. A ten year gap in life expectancy exists between the most and least deprived areas of Basildon and Brentwood respectively. Within SW Essex, Basildon has the 3<sup>rd</sup> highest male alcohol-attributable hospital admission rate in Essex for issues such as alcoholic liver disease, chronic pancreatitis (alcohol induced) and ethanol poisoning. Thurrock has the highest rate of binge drinking in pan-Essex (Essex County Council: Health Inequalities Strategy, 2009).

Basildon and Thurrock University Hospital Annual Report 2005/2006 states that out of 86,000 Accident and Emergency (A&E) attendances during the 12-month period, 14,620 attendances were for alcohol related problems. In Brentwood, alcohol-related hospital admissions are showing a year-by-year increase. This trend is presented in (**Graph 1**) below:



**Graph 1: Alcohol attributable hospital admission in Brentwood**

The East of England is following national trends, with rising consumption particularly among young women. According to the publication by the Institute of Alcohol Studies: *Women and*

*Alcohol (2008)*, the fact that women are participating in the workforce could be an important influence on drinking habits, as generally the employed drink more on average than the non-employed. Higher disposable income and greater financial independence underlie the increase in women's drinking.

Within my role as a trainee health psychologist, I was assigned to scrutinize the alcohol service provision and identify gaps that existed. Measures would then be taken to rectify these gaps. Various policy documents relevant to alcohol services within NHS SW Essex were assessed and evaluated. Among the documents assessed was the alcohol service specification document, which was designed by the Alcohol, Smoking and Drugs Commissioning Manager of NHS SW Essex. Upon reviewing all the necessary documentation available on alcohol services it was apparent that within NHS South West (SW) Essex, thus far, the Primary Care Trust (PCT) has often looked to their local Drug and Alcohol Action Teams to take the lead in commissioning services to tackle alcohol harm, but these bodies focus primarily on specialist services for dependent users of illegal drugs and alcohol. They are not equipped to meet the needs of the much larger groups of 'hazardous' and 'harmful' alcohol abusers that may go on to become dependent users.

Drawing upon principles of Social Marketing (SM), it was deemed crucial to gain a deep understanding and insight into service users' behaviours and key influences relevant to alcohol consumption prior to formulating advice and guidance on new service design. A community engagement initiative was designed by me to engage with hazardous/harmful alcohol consumers within Basildon and Brentwood in order to obtain information about current attitudes and behaviours towards alcohol and to develop behaviour change interventions aimed at reducing harmful alcohol consumption. It was anticipated that the community engagement initiative would also provide a platform to understand areas of unmet needs and provide a clear set of objectives to work towards meeting these needs. Furthermore, the findings would highlight how to use resources to improve the local population's health in the most effective and efficient way. Importantly, it would provide a method for monitoring and promoting equity in the provision and use of health services and addressing inequalities in health.

To engage with a sample of hazardous/harmful drinkers in Basildon and Brentwood a qualitative research methodology (i.e. focus groups) was proposed. Focus groups are ideal for exploring people's experiences, opinions, wishes and concerns (Barbour & Kitzinger, 1999). The participants for the focus groups were identified using the Alcohol Use Disorders Identification Test (AUDIT) (Saunders et al, 1993). The results of the study would help develop an intervention to prevent this group of drinkers from becoming dependent alcohol consumers and being admitted to specialist services. I took the lead in this initiative. Hence, I was responsible for the design of the focus group template, data collection, analysis and write-up.

Brentwood has a population of around 72,000 people. This is an affluent borough. Approximately 20% of the population are 60 years of age and over and this is the single biggest demographic group, closely followed by the 0-16 age group. There is a thriving evening economy, which attracts large numbers of visitors to the town centre, particularly on Friday and Saturday nights, with some of the expected crime and disorder issues surrounding alcohol consumption. Due to its small size, the borough has suffered historically in terms of its service provision from some of its partner organisations, in that it is bolted onto delivery teams in neighbouring areas. Hence, there are limited resources available within Brentwood to tackle various issues faced in this borough. Therefore, both the quantity and quality of the support available for Brentwood is adversely affected.

The Health Profile (2009) for Brentwood reports that the health of the population in Brentwood is generally better than the England average. However, road injuries and deaths are significantly higher than average. In Brentwood, the proportion of people with an unhealthy lifestyle is lower than the national and regional average. Nonetheless, large numbers of people could reduce their health risks by changing their behaviour.

On the other hand, Basildon lies in the southern part of Essex. The District includes the towns of Basildon, Billericay and Wickford. Some 70% of the District is rural with large areas of open farmland and scattered rural developments. Basildon Council serves a population of 168,000 people. The main areas of employment are engineering, retail, distribution and financial services. 2.1% of the population is unemployed and a number of neighbourhoods feature amongst the

most deprived areas nationally. 3.1% of the population are from an ethnic minority community (Source: Census 2001).

Basildon reports the worst health in SW Essex with over 9% of the population reporting that they are not in good health, and 18% reported having a long term limiting illness (Health Status Basildon, 2007). The Health Profile (2009) for Basildon reports that the health of the population in Basildon is generally close to the England average. A relatively high proportion of the population are at increased risk of poor health due to smoking, obesity, alcohol or poor diet. However, there are fewer alcohol-related hospital stays and there is less drug misuse in Basildon than the England average.

Conducting this study within these two localities could provide a great platform to gain understanding of the variations that exist in terms of alcohol consumption in an affluent locality like Brentwood and a deprived locality like Basildon. A recent study in England and Wales reported higher levels of alcohol-related mortality in more socio-economically deprived areas (Breakwell et al, 2004). On the other hand, greater affluence is associated with a higher likelihood of hazardous drinking and greater wine consumption (Cook et al, 2008).

**Component 5.5c – Evaluate methods and resources for use in the promotion of psychological principles, practices and services AND**

**Component 5.5d – select promotional resources and services to demonstrate the value of health psychology principles, practices and services**

In order to establish an alcohol service informed by health psychology research principles, an evaluation with harmful/hazardous alcohol consumers was necessary. The aims of this evaluation were as follows:

- To assess public awareness of UK recommendations for alcohol consumption
- To gain understanding on ways to enhance knowledge of the harmful effects of alcohol
- To establish a foundation for people from local communities to be involved in the development of services and initiatives to raise awareness and improve early identification of patients at high risk of harmful alcohol consumption.
- To develop an intervention for the target group (mild/moderate alcohol consumers)

There was a lack of funds available to conduct this evaluation. With the guidance from the Commissioning Manager of NHS SW Essex, an evaluation proposal (**Appendix 1**) was created and was submitted to the Drug and Alcohol Reference Group at Brentwood & Basildon to obtain funding. The Drug and Alcohol Reference Group from these localities provided funding for this evaluation. In addition, alcohol consumption was a key area of focus identified by the Basildon District Local Strategic Partnership (outlined in *Securing a future for Basildon*, 2008). This publication identified the need to develop and implement a partnership Alcohol Strategy aimed at encouraging the community to drink responsibly. Similarly *Brentwood Crime & Disorder Reduction Partnership Strategic Assessment and Partnership Plan (2008-2011)*, highlighted the importance of focusing prevention efforts to address alcohol misuse. This plan identified harmful adult drinkers as their key target group.

Participants who scored between 8 -19 on the AUDIT scale (**Appendix 2**) were recruited for the study. Participants were recruited by me. I conducted four focus groups in each area. Each focus group was facilitated by me. Table 1 displays the demographics of participants for the focus groups:

<b><i>Basildon</i></b>	
Males	18-35years old
	35-65 years old
Females	18-35 years old
	35-65 years old
<b><i>Brentwood</i></b>	
Males	18-35 years old
	35-65 years old
Females	18-35 years old
	35-65 years old

**Table 1: Participant segmentation**

Each focus group lasted approximately 45 minutes. Consent and information sheets were provided to participants before they took part in the focus group (**Appendix 3 & 4**). At the end of the focus group participants were given a debriefing form that consisted of information on the purpose of this evaluation, sources to obtain further knowledge on alcohol and how to contact the investigator (**Appendix 5**). A focus group interview template was created (**Appendix 6**). This focus group template was designed by me. In the focus group, participants were asked questions on:

- Alcohol Consumption
- Alcohol Awareness
- Participants' views on Alcohol Service Development (e.g. nature of the service, mode of delivery, location of service)

A total of 32 participants (9 males, 23 females) attended the focus groups. Participants ranged from 18 years old to 63 years old. 27 participants were British White while 4 participants were

Black British African. One participant was British Asian (Indian). Audio recording from the focus groups were transcribed and analysed for emerging themes using thematic analysis methodology.

The outcome of this evaluation was written-up as a report by myself and submitted to the Commissioning Manager of NHS SW Essex for feedback and comments. Based on the feedback obtained, the report was revised and amended. The main feedback received was that the initial report looked more like an academic report and was not suitable to the audiences of this report, who are mostly members of NHS SW Essex and key decision makers of Drugs & Alcohol Services of Brentwood and Basildon. Hence, measures were taken to ensure that the report was less technical and was suitable to the needs of the target audience.

Overall, the evaluation highlighted important gaps within the current service provision for alcohol consumers. Further to this, the findings of the evaluation provided a clear set of steps to work towards to address these gaps. The report provides clear and concise guidelines that will form a foundation for the development of an intervention for the target group (harmful/hazardous alcohol consumers).

One clear gap identified through this evaluation was that based on patient self-report, it appears health care professionals rarely raised the issue of alcohol consumption with their patients. Only two participants reported being asked about their alcohol consumption. Future research/evaluation would be important to identify potential barriers faced by health care professionals in raising the issue about alcohol consumption with patients.

The final report (**Appendix 7**) was submitted to key stakeholders within NHS SW Essex and members of the Drug and Alcohol Reference Group at Brentwood & Basildon. Members of the Reference group provided feedback on the project and informed that the information gathered was very informative and the next step would be to discuss the feasibility of establishing a new alcohol service.

## **Reflection**

Since the beginning of the Stage 2 training, lack of confidence was a major issue I faced. Within this project, I initially found it very difficult to attend meetings, communicate and conduct the evaluation project independently with minimal supervision. I worked very closely with another trainee Health Psychology at NHS SW Essex who provided assistance on this project. I also sought supervision from my supervisor at NHS SW Essex on a constant basis to ensure I was on the right track. My biggest lesson during this project was that when my knowledge on the project improved, my confidence also improved. Before undertaking the evaluation, I read a lot of policy and research documents to enhance my knowledge. With this knowledge, I was able to recognise the need for this project and communicate this need efficiently. I have utilised this learning during my involvement in other projects with NHS SW Essex as I realised that a good knowledge base of the project not only increased my confidence but also contributed towards my optimal performance within other projects.

One of the biggest challenges faced on this project was the recruitment of participant. This was mainly because the focus of the study was on harmful/hazardous alcohol consumers. The recruitment process took much longer than anticipated. To overcome this challenge, I established links with various organisations, clubs and groups within this locality to facilitate recruitment. Incentives were also offered to participants to attract them to participate in this project. Further to these, links established with the Drug & Alcohol Reference group at Brentwood and Basildon also helped with the recruitment of participants. The project could not be completed within the given timeframe due to this issue. In future, when providing a timeline for projects, I learned the importance of the need to factor in a few extra months to deal with unanticipated circumstances as faced within this project.

The project was completed prior to my contract with NHS SW Essex ending. Due to the financial crisis the NHS was facing at that time, my contract was not extended. As such, I was unable to monitor whether my recommendations were taken forward. However, it is my understanding that the whole alcohol service within NHS SW Essex was restructured due to financial constraints and many services were de-commissioned. Nevertheless, this project still

served as a crucial insight into the alcohol consumption of harmful/hazardous alcohol users and could potentially be used for service commissioning in the future.

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**Appendix 1: Project Proposal**



***South West Essex***

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**QUALITATIVE EVALUATION WITH MODERATE /RISKY ALCOHOL CONSUMERS  
(PROJECT PROPOSAL)**

## **Introduction**

There are many forms of excessive drinking that cause substantial risk or harm to the individual. They include high level drinking each day, repeated episodes of drinking to intoxication, drinking that is actually causing physical or mental harm, and drinking that has resulted in the person becoming dependent on alcohol. Excessive drinking causes illness and distress to the drinker and his or her family and friends. It is a major cause of breakdown in relationships, trauma, hospitalization, prolonged disability and early death. Alcohol-related problems represent an immense economic loss to many communities around the world.

In 1980, a WHO (World Health Organization) expert committee stressed the need for efficient methods to identify persons with harmful and hazardous alcohol consumption before health and social consequences become pronounced. There was an urgent call for the development of strategies that could be applied in primary health care settings with a minimum of time and resources.

Most adults in England, more than 90 per cent, drink alcohol, and the majority do so sensibly. However, around 10 million adults consume alcohol at 'hazardous' levels (that is, above the recommended limits). More than 8 million people in England (26 per cent of the population) have an alcohol use disorder, and around 1.1 million people are dependent on alcohol (3.6 per cent of adults are alcohol-dependent, 6 per cent of men and 2 per cent of women) (Drummond *et al* 2004).

## **Proposed Needs Assessment**

Focus groups with moderate /risky alcohol consumer will be conducted. The target audience would be identified using the AUDIT questionnaire. Participants who score between 8 -19 on the AUDIT scale will be recruited. Participants will be recruited by the Health Psychologist of NHS SW Essex from public venues (e.g. council offices, colleges). Participants will be paid £20 pounds incentives for their participation in the focus group.

### **Participants**

36 from Brentwood & 36 from Basildon

Target age: 18-65 years old

Gender: Males and Females

## **Participant Segmentation**

<i>Basildon</i>	
Males	18-29 years old ( 6 people) 30-49 years old (6 people) 50-65 (6 people )
Females	18-29 years old ( 6 people) 30-49 years old (6 people) 50-65 (6 people )

<i>Brentwood</i>	
Males	18-29 years old (6 people) 30-49 years old (6 people) 50-65 (6 people )
Females	18-29 years old (6 people) 30-49 years old (6 people) 50-65 (6 people )

## **Methodology**

Collectively 12 focus groups will be conducted. Each focus group would last approximately 45minutes. Discussion topic will include general health, alcohol consumption (quantity, frequency, reason, and purchase) and their views on desirable alcohol intervention. A template for the discussion will be created in due course. During the focus group, participants will be allocated a number which they would use throughout the focus group for the purpose of identification. This will ensure the anonymity of the participants. Focus groups will be voice recorded and transcribed. The data obtained from the focus group will be subjected to template analysis.

### **Aims / Objectives**

- To assess public awareness of UK recommendations' for alcohol consumption
- To gain understanding on ways to enhance knowledge on the harmful effects of alcohol
- To establish a foundation for people from local communities to be involved in the development of services and initiatives to raise awareness and improve early identification of patients at high risk of harmful alcohol consumption.
- To develop an intervention for the target group (mild/moderate alcohol consumers )

### **Conclusion**

The findings from the focus groups, together with service recommendation will be written up as a report for the commissioners of SW Essex and other external funders. In the second phase of this project, a service /intervention would be established for moderate /risky alcohol consumers. Additional funding will be obtained from NHS SW Essex for the 2<sup>nd</sup> phase.

**Appendix 2: Alcohol Use Disorders Identification Test (AUDIT), Saunders et al (1993) – A validated and reliable measure for screening alcohol consumption.**

Questions	Scoring system				
	0	1	2	3	4
How often do you have a drink containing alcohol?	Never	Monthly or less	2 - 4 times per month	2 - 3 times per week	4+ times per week
How many units of alcohol do you drink on a typical day when you are drinking?	1 -2	3 – 4	5 - 6	7 - 9	10+
How often have you had 6 or more units if female, or 8 or more if male, on a single occasion in the last year?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
How often during the last year have you found that you were not able to stop drinking once you had started?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
How often during the last year have you failed to do what was normally expected from you because of your drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
How often during the last year have you needed an alcoholic drink in the morning to get yourself going after a heavy drinking session?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
How often during the last year have you had a feeling of guilt or remorse after drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
How often during the last year have you been unable to remember what happened the night before because you had been drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
Have you or somebody else been injured as a result of your drinking?	No		Yes, but not in the last year		Yes, during the last year
Has a relative or friend, doctor or other health worker been concerned about your drinking or suggested that you cut down?	No		Yes, but not in the last year		Yes, during the last year

**Appendix 3: Consent Form**

**QUALITATIVE RESEARCH WITH MODERATE /RISKY ALCOHOL CONSUMERS**

I confirm that I have read and understood the information sheet for the above study and have had an opportunity to ask questions.

I understand the responses I give will be treated as confidential, my contact details will always remain separate from the data and I will only be recognised by my participant number.

I understand that participation in this study is entirely voluntary and refusal to take part involves no penalty and I may withdraw from the study at any point during the focus group.

**I understand that standardized debriefing will take place once the focus group has taken place. The debriefing will include the purpose of the study, background research and the design of the study so that I can recognize my contribution to the research.**

**By signing this form I am stating that I am over 18 years of age, and that I understand the above information and consent to participate in this study being conducted by an employee of South West Essex PCT.**

**Participant Number:**

**Signature:** \_\_\_\_\_  
(of participant)

**Signature:** \_\_\_\_\_  
(of researcher)

**Today's Date:** \_\_\_\_\_

**Today's Date:** \_\_\_\_\_

**Appendix 4: Information Sheet**

## **QUALITATIVE RESEARCH WITH MODERATE /RISKY ALCOHOL CONSUMERS**

I am a trainee health psychologist doing a professional Doctorate in Health Psychology at City University and working for South West Essex PCT. I would like to invite you to participate in research that I am carrying out regarding drinking alcohol. Before you make a decision about participating, please read this information sheet to understand why the research is being done and what it will involve.

### **What is the purpose of the study?**

The aim of the study is to explore your views on drinking alcohol, your current drinking habits and what you think may help to promote safer drinking levels in South West Essex. The results from the discussion will help us to understand the local people's needs regarding alcohol, and views on alcohol management. It is hoped that this will enable us to develop a tailored alcohol management service.

### **What do I have to do?**

If you decide to take part in this study you will be invited to take part in a group discussion called a focus group with approximately seven other people. The discussion will typically last 45 minutes.

We are interested in your views about alcohol and on ways we can develop a new alcohol service for the people in SW Essex. With your agreement the focus group will be audio recorded to help us collect what has been said but you will not be identified in any of the information obtained. All of the information will be put together to identify common themes and this will all be summarised together.

### **Expenses and Payment**

You will be given £20 cash as a thank you for taking part in the discussion, which will be funded by South West Essex PCT but your travel expenses will not be reimburse.

**Will my taking part in this study be kept confidential?**

If you consent in taking part in the study, all the information which is collected about you and from you will be kept strictly confidential. The information under no circumstances will be passed on to anybody. Your name will always remain separate from the answers that you give and you will be given a participant identification number. Your personal details and the audiotape of the focus group will be destroyed after the study is completed

**What will happen to the findings of the focus group?**

The findings from the focus groups will be used to develop individual level and population level public health campaigns to help raise awareness about drinking and to help reduce harmful drinking in SW Essex. If you would like a summary of the research findings, please contact the Jana Kanapathy (Lead Researcher) – contact details below.

**Do I have to take part?**

Taking part is entirely voluntary. If you decide to take part you are still free to withdraw at any time and without giving a reason and without any consequences.

**Contact Details**

If you have any questions, queries or would like to take part then please contact

**Jana Kanapathy** (Lead Researcher)

*Trainee Health Psychologist*

Contact Number: [REDACTED]

**Parmpreet Marway** (Assistant researcher)

*Trainee Health Psychologist*

Contact Number: [REDACTED]

Thank you for taking the time to consider this study.

## **Appendix 5: Debriefing form**

### **QUALITATIVE RESEARCH WITH MODERATE /RISKY ALCOHOL CONSUMERS**

Thank you for taking your valuable time out to take part in this research. Your contribution is very much appreciated. The aims of the study are below:

- To gain information about current drinking habits in SW Essex
- To gather information about what methods and techniques might help people in SW Essex stay drinking within safe limits
- To design an intervention for moderate alcohol consumers based on the information obtained

The results from the focus group discussions will help us to understand the needs of the local people and will enable us develop an alcohol intervention/service for moderate /risky alcohol consumers. This will enable us to improve the overall health and well-being of the people in SW Essex as well as help improve the overall community through the influence on reducing incidences of alcohol-related violence and crime as well as reducing the burden on health services due to alcohol-related illnesses and injuries.

If you would like to discuss any issues further, please consult the researcher who will direct you to the appropriate services, or alternatively please contact your GP. If you would like further information on alcohol then please contact any of the services below:

**Drink Line: 0800 917 82 82**

**Alcohol Concern: 0207 264 0510**

**Thurrock Substance Misuse Helpline: 0800 633 5202**

**Basildon 24/7 Helpline: 0845 603 7634**

**Essex 24/7 Helpline: 0845 603 7634**

## **ALCOHOL CONCERN**

The national agency on alcohol misuse for England and Wales. General information on alcohol and can help put you in touch with your nearest alcohol advice centre.

Call 020 7264 0510 or visit the [www.alcoholconcern.org.uk/](http://www.alcoholconcern.org.uk/)

## **ALCOHOLICS ANONYMOUS**

This website will provide information on how you can access local AA groups in your area. This is a national telephone number for more information.

Call 0845 769 7555 or visit the [www.alcoholics-anonymous.org.uk/](http://www.alcoholics-anonymous.org.uk/)

If you have further questions about this study or if you wish to lodge a complaint or concern then please contact:

### **Jana Kanapathy(Lead Researcher)**

Trainee Health Psychologist

Contact Number: [REDACTED]

### **Parmpreet Marway (Assistant Researcher)**

Trainee Health Psychologist

Contact Number: [REDACTED]

The Health Psychology Team declares that the information provided above is in accordance to the best of our knowledge.

## **Appendix 6: Focus Group Template**

### **QUALITATIVE RESEARCH WITH MODERATE /RISKY ALCOHOL CONSUMERS**

Hello, my name is \_\_\_\_\_ and I am a trainee health psychologist with South West Essex PCT.

I am here today to ask you some things about alcohol consumption. This is not a test; there are no right and wrong answers. I am here to find out your opinions and its okay to have a different opinion to everyone else. (Mention tape recorder/confidentiality/mention incentives, **ground rules**).

#### **Current Alcohol Behaviour**

1. Let's begin by discussing people's current drinking

**Prompt** : how often do people drink? , how much do people tend to drink in a night?  
who you drink with, where do you drink .

2. What are the good/bad aspects of alcohol consumption?

**Prompt:** Relax, socializing, and relieves boredom, hangover, and health hazards

3. What would they say influences them to drink more than usual
4. What would they say influences them to drink less
5. Or – are there times when people in the group sometimes drink more or less – what influences this? – any examples?

#### **Alcohol Awareness**

1. In your view, what is too much drinking & what is safe drinking
2. Some drinks contain more alcohol than others. The amount is sometimes measured in terms of 'units of Alcohol'. Have you heard about measuring alcohol in units? Do you keep a check of how many units of alcohol you drink?
3. What sort of alcohol media campaign are you aware of? Do these campaigns have an impact on your drinking behaviour?

4. Are you aware of any local campaigns within SW Essex on alcohol?
5. In your opinion, do you think people in the community have sufficient knowledge on the negative impact of alcohol consumption?

**Prompt:** why

6. Could you suggest ways to enlighten community members on harmful alcohol consumption?

### **Service Development**

1. What kind of services / interventions would help people reduce their alcohol intake/drink within safe levels?

**Prompt:** Information on health risk, increase alcohol prices, advice from GP, advertising, other training/education on alcohol intake

2. Who do you think should provide this service /intervention?

**Prompt:**

3. Where and when should this service /intervention take place?

**Prompt:** workplace, healthcare places, and specific times

4. How do we encourage people to attend the service /intervention?

**Prompt:** voucher, incentives

5. What would discourage people to attend the service/intervention?

**Prompt:** ignorance, denial

6. How should participants be recruited for the service / intervention?

**Prompt:** from GP, adverts, pamphlets

7. Have any HCP's spoken to you about your alcohol consumption

8. Have you ever received advice from anyone or any other sources regarding alcohol consumption?

**Prompt:** websites / friends

**Appendix 7: Final Report**



**QUALITATIVE EVALUATION WITH MODERATE /RISKY ALCOHOL CONSUMERS**

**June 2010**

**Author:**

Jana Kanapathy

## **Introduction**

There are many forms of excessive drinking that cause substantial risk or harm to the individual. They include high levels of drinking each day, repeated episodes of drinking to intoxication, drinking that is actually causing physical or mental harm, and drinking that has resulted in the person becoming dependent on alcohol. Excessive drinking causes illness and distress to the drinker and his or her family and friends. It is a major cause of breakdown in relationships, trauma, hospitalization, prolonged disability and early death. Alcohol-related problems represent an immense economic loss to many communities around the world.

In 1980, a WHO (World Health Organization) expert committee stressed the need for efficient methods to identify persons with harmful and hazardous alcohol consumption before health and social consequences become pronounced. There was an urgent call for the development of strategies that could be applied in primary health care settings with a minimum of time and resources.

Most adults in England, more than 90 per cent, drink alcohol, and the majority do so sensibly. However, around 10 million adults consume alcohol at 'hazardous' levels (that is, above the recommended limits). More than 8 million people in England (26 per cent of the population) have an alcohol use disorder, and around 1.1 million people are dependent on alcohol (3.6 per cent of adults are alcohol-dependent, 6 per cent of men and 2 per cent of women) (Drummond *et al* 2004).

### **Alcohol consumption in SW Essex**

NHS South West (SW) Essex serves a population of 420,000 people. This covers a mixed urban/rural geography including relatively affluent towns of Billericay and Brentwood, and the relatively deprived towns of Basildon and Thurrock. A ten year gap in life expectancy exists between the most and least deprived areas of Basildon and Brentwood respectively. Within SW Essex, Basildon has the 3<sup>rd</sup> highest male alcohol-attributable hospital admission rate in Essex for issues such as alcoholic liver disease, chronic pancreatitis (alcohol induced), ethanol poisoning etc, Thurrock has the highest rate of binge drinking in pan-Essex (Essex County Council: Health Inequalities Strategy, 2009).

Basildon and Thurrock University Hospital Annual Report 2005/2006 stated that out of 86,000 Accident and Emergency (A&E) attendances during the 12 month period, 14,620 attendances were for alcohol related problems. In Brentwood, alcohol related hospital admission, is showing a year-by-year increase.

The East of England is following national trends, with rising consumption particularly among young women. According to the publication by the Institute of Alcohol Studies: *Women and*

*Alcohol (2008)*, the fact that women are participating in the workforce could be an important influence on drinking habits, and generally the employed drink more on average than the non-employed. Higher disposable income and greater financial independence underlie the increase in women's drinking.

Alcohol consumption by males in South West (SW) Essex indicates that harmful drinkers are again above the regional average at 7.4% compared to 6.6%, whilst hazardous drinkers similar to the regional average at 20.5%

### **Aims / Objectives**

The aims of this project are as follow:

- To assess public awareness of UK recommendations' for alcohol consumption
- To gain understanding on ways to enhance knowledge on the harmful effects of alcohol
- To establish a foundation for people from local communities to be involved in the development of services and initiatives to raise awareness and improve early identification of patients at high risk of harmful alcohol consumption.
- To develop an intervention for the target group( mild/moderate alcohol consumers )

### **Justification for proposed evaluation**

This research will provide an ideal opportunity for engaging with hazardous/harmful alcohol consumers within Basildon and Brentwood in order to obtain information about current attitudes and behaviours towards alcohol and to develop behaviour change interventions aimed at reducing harmful alcohol consumption. Furthermore, it will provide a platform to understand areas of unmet need and will provide a clear set of objectives to work towards to meet these needs. Findings from this research will also highlight how to use resources to improve the local population's health in the most effective and efficient way. Importantly, it will provide a method of monitoring and promoting equity in the provision and use of health services and addressing inequalities in health.

### **Methodology**

This evaluation was qualitative in nature. Focus groups with moderate/risky alcohol consumer were conducted in Brentwood and Basildon. The target audience were identified using the AUDIT questionnaire (*see appendix 1*). Participants who scored between 8 -19 on the AUDIT scale were recruited for the study. Participants were recruited by the Health Psychologist of NHS

SW Essex. Four focus groups were conducted in each area. Table 1 displays the segmentation of participant for the focus group:

<i>Basildon</i>	
Males	18-35years old 35-65 years old
Females	18-35 years old 35-65 years old
<i>Brentwood</i>	
Males	18-35 years old 35-65 years old
Females	18-35 years old 35-65 years old

Each focus group lasted approximately 45 minutes and consisted of 2-7 people. Consent and information sheets were provided to participants before they took part in the focus group. At the end of the focus group participants were given a debriefing form that consisted of information on the purpose of this evaluation, sources to obtain further knowledge on alcohol and contact details of the investigators.

In the focus group, participants were asked questions on:

- Alcohol Consumption
- Alcohol Awareness
- Participants' view on Alcohol Service Development (e.g. nature of the service, mode of delivery, location of service)

## **Participants**

A total of 32 (9 males, 23 females) attended the focus groups. Participants ranged from 18 years old to 63 years old. 27 participants were British White while 4 participants were Black British African. One participant was British Asian (Indian).

## **Results**

<b>Themes</b>	<b>Subthemes</b>
Social Factor and Alcohol Consumption	<ul style="list-style-type: none"><li>▪ Peer influence/ Conformity</li><li>▪ Alcohol Consumption Norms (Buying rounds, muscularity)</li><li>▪ Confidence</li></ul>
Stress	<ul style="list-style-type: none"><li>▪ Relaxation</li><li>▪ Emotion /Mood</li><li>▪ Drowning a problem</li></ul>
Alcohol Abstaining	<ul style="list-style-type: none"><li>▪ Personal (hangover)</li><li>▪ Family</li><li>▪ Responsibility (driver /working days)</li></ul>
Enforcement	<ul style="list-style-type: none"><li>▪ Arrest Referral</li><li>▪ Responsible licensing</li></ul>
Alcohol Awareness	<ul style="list-style-type: none"><li>▪ Need for information</li><li>▪ Education in schools</li></ul>
Alcohol Limits	

## **Social Factor and Alcohol Consumption**

This theme explores the social factors associated with alcohol consumption. Social factors have crucial and long-lasting effects on alcohol intake which, in some instances, lead to excessive alcohol intake. The majority of participants admitted to consuming more alcohol within a social environment compared to when they were consuming alcohol in isolation. Participants admitted

to consuming more alcohol at enjoyable social situations. Further to this an individual's social network and number of drinking buddies are related with increased alcohol consumption. This theme consisted of three sub themes, which were: *Peer influence/ Compliance, Drinking culture and Confidence.*

### **Peer Influence / Compliance**

This subtheme was very dominant across the dataset. Peer pressure and compliance contributed significantly to the increase in alcohol consumption

#### **Example A**

*Peer pressure. For example a stag do or a birthday. Every time you go to a bar you get shots.*

In addition to this, many participants admitted to drinking more because they were complying with the drinking patterns of their friends/peers.

#### **Example B**

*It is more keeping up you know. So that people try to please other people, even against your own health*

#### **Example C**

*If it was like a lads' night out, they would probably be more likely to keep up with their friends*

### **Alcohol Consumption Norms**

This subtheme explores how certain alcohol consumption norms contribute to higher consumption of alcohol. This subtheme consisted of two factors , which were: *buying rounds, and masculinity*

- Buying rounds

When in the company of a group of people in a pub, a system of 'rounds' is traditionally used, whereby each person in turn will buy, or offer to buy, a drink for all others in the company. It is not the done thing to just buy yourself a drink without making the offer to buy one for everyone else – and those who fail to at least offer to 'stand their round' in this way risk being looked upon as mean and unsociable. According to many participants, these norms contribute to excessive alcohol consumption.

#### **Example D**

*You would have had one but you might find your mates, saying “okay, this is my round I will get the next round”. And even when you are saying that, you know they will try to persuade you.*

- Masculinity

Within this factor, men expressed how their alcohol consumption is related to their beliefs about masculinity, and the importance of drinking to their masculine identities. Some men believed that alcohol consumption is a marker of masculinity and behaved accordingly.

### **Example F**

*Being a guy you naturally order a beer*

### **Confidence**

This subtheme explores how some young people consume more alcohol to benefit from increased confidence that will help them in a social environment (e.g. to communicate with members of the opposite sex).

### **Example G**

*The good side is you lose some of your inhibitions don't you ...you are more social, you have more fun.*

<b>Stress</b>
---------------

Stress reduction is perhaps the most mentioned reason for alcohol consumption. According to some participants the calming effect of alcohol is a motivation for drinking. Drinkers reported positive expectations /reactions when drinking. Further to this, alcohol consumption was also related to stressful experiences. This theme has three sub-themes: *Relaxation, emotion/mood, drowning a problem.*

### **Relaxation**

The main notion of this sub-theme was that having a drink allows participants to relax and feel less stressed than they might normally be.

### **Example H**

*It can relax you; it's nice...especially if I don't drink in the week. It feels more rewarding*

### **Emotion /Mood**

Mood and emotion was an important factor that determined participants alcohol consumption and quantity of consumption . Participants expressed that they were more likely to drink more when they have negative emotions.

### **Example I**

*If for example you have left your house angry, may be your partner or your wife provoked you, and you decide to go out and have a drink, definitely you drink too much, even if you are drinking at home you will.*

### **Drowning a problem**

Participants admitted using alcohol to deal with stressful/unpleasant life situations (e.g. relationship breakup). Findings indicate that people consume alcohol to help them cope with various forms of stressors, such as economic stress, job stress, and relationship problems.

### **Example J**

*I think it just helps me deal with stuff sometimes by having a bit of a drink.*

## **Alcohol Abstinence**

This theme explores various reasons mentioned by participants as reasons to abstain from alcohol consumption. The main factor that contributed to alcohol abstinence was the negative physical consequences associated with excess consumption. Other reasons stated included family history that they didn't want to repeat, upbringing and negative experiences they have had in the past as a result of alcohol consumption. This theme has two sub-themes: *personal experience*, *family alcoholism*

### **. Personal experience**

This sub-theme explores how the experience of having a bad hangover can prevent individuals from drinking excessively in the future.

### **Example K**

*I do feel really lousy the next day. Almost at a psychological level as well you feel a little bit depressed in a way and it takes like a day to get back to normal, which is not very nice*

### **Family Alcoholism**

This sub-theme explores how some participants knew of people who abstain from consuming alcohol as they had family history of alcoholism. Witnessing how alcohol can destroy lives has turned these individuals against alcohol.

### **Example L**

*My granddaughter, she doesn't drink very much, because like I said, my son in law too was an alcoholic, and my grandson doesn't drink at all.*

### **Responsibility**

This sub-theme explores various responsibilities that promote alcohol abstinence. This sub-theme has two factors: *designated driver, working day*

- Designated driver

This was a reoccurring theme throughout the focus groups. Many participants said that they would not consume alcohol if they are the designated driver for the evening. Further to this, some participants expressed that they would volunteer to be the driver for the evening to abstain from drinking. However many expressed that abstinence was mainly due to the legal consequences of drunk driving and not associated with personal doubt in the ability to drive.

### **Example N**

*I would never drink and drive*

- Working day

The majority of participants were weekend drinkers and did not usually consume alcohol during the week as they had an occupational responsibility and did not want to have a hangover at work. Drinking patterns also differed depending on the day of the week. When consuming alcohol during the week participants expressed they would drink much less in terms of quantity and alcohol strength.

### **Example O**

*If I don't have to go to work the next day I would drink lager like Stella, because it is light, like a can, that is if I have to drink, not like I have to drink everyday now. But if it is like a Friday night I can decide either to have a beer or I can have wine. So my drink, what I drink actually it depends on what day it is.*

## **Alcohol Awareness**

This theme explores participants' views on alcohol awareness. Many participants admitted that people in the community do have sufficient knowledge but the knowledge is basic and does not have a personal effect. Further to this, almost all participants felt that children should be educated from young on the harmful effect of alcohol. This theme has two sub-themes: *need for information* and *education within school*.

### **Need for information**

Within this sub-theme, participants felt that their alcohol-related knowledge was basic. This finding amplifies the need for more information.

### **Example M**

*I know that drink is not good for me but I don't really care 'cos I don't know what it's doing to me.*

### **Example N**

*People do not have as much as they should be.*

### **Education within schools**

This sub-theme explores participants' view that alcohol education should be provided in school from a young age, to prevent alcohol consumption among youngsters and the future generation.

### **Example O**

*Schools. Let's be fair half the kids now at 15, I know when I started drinking I was 15. I was going into pubs and I am pretty sure it is like that for a lot of ... certainly for girls these days; you know 15/16 going into pubs and things like that. They need to get in well before that to teach them the effects of alcohol and what it does.*

## **Alcohol Limits**

This theme explores views on alcohol consumption limits and guidance. It is clear that there is a general lack of understanding about alcohol unit measurement among residence. Further to this, participants used various personal alcohol limits to measure their alcohol intake.

### **Example P**

*For me it's enough when I start to feel like, I'm going to throw up right now, you know that's when you say no, that's it, I'll stop now.*

### **Example Q**

*I think when I'm out I'll have three glasses of wine and I'm okay. If I have a fourth one, then I know that I'm not. So that's good*

### **Example R**

*To be quite honest people don't think about units, they think more ... I am a 10/12 pint man or whatever.*

## **Enforcement**

Within this theme, participants expressed the need for greater enforcement to tackle alcohol related problem. This theme has two sub-themes: *arrest referral scheme* and *responsible licensing*.

### **Arrest Referral Scheme**

Participants voiced the need for alcohol referral schemes within this locality. This suggestion was dominant in all the male focus groups.

### **Example S**

*Similar to the sort of speeding courses that they do, instead of getting three points on your licence you get offered a speeding course, and you could have the same thing that you get caught and picked up on the street and that, you get referred to a drinking awareness course or something like that.*

### **Responsible Licensing**

Within this sub-theme, participants expressed that alcohol traders should be more responsible when trading. Further to this, participants voiced the need for an enhanced licensing conditions and education for alcohol traders to curb alcohol problems.

#### **Example T**

*In Australia they have something called the RSA, which is Responsible Service of Alcohol, and everyone that works in a bar has to do this course, it takes a full day to do it, and you're taught basically like units, and how you can tell if someone's had enough, and if someone's had too much to drink you give them a glass of water and then maybe let them start drinking an hour later or something ... I think perhaps if that was something that was enforced in England or in our local area then it might stop people from ... if they can't drink and they're told they're not allowed to, they will hopefully leave, not be allowed in anywhere else, and go home, and that might teach them that ...*

<b>Recommendation</b>
-----------------------

In light of the current findings of this study, recommendations for an alcohol service for mild/moderate alcohol consumers have been identified, and are stated below.

### **Service structure**

- The service should consist of the following :
  - Enlightenment on personal alcohol consumption and related harm
  - Alcohol & health
  - Tips for cutting down
  - Education on alcohol units
  - Personal goal setting
  - Planning instrument for dealing with high risk situation
  - Alcohol related facts (accidents, emergency room admission)
  - Real life examples (Case studies /Case examples)

- Participants wanted the service to have an educational function, and not take a preachy stance. Focus should be placed on raising awareness on alcohol and alcohol-related harm rather than alcohol abstinence.
- Taking into consideration the target audience of this intervention, a reoccurring intervention (2-3 sessions) would not be appropriate and might have high drop-out rate. Hence a one off intervention of 30-40minutes will be more appropriate.
- Service users must be given a choice of group or one-to-one intervention. Some participants preferred a one-to-one setting as they did not want to discuss their drinking habits within a group. Others felt that a group setting would be more beneficial to counteract the negative social influences associated with alcohol consumption.
- During or post intervention participants should be provided with self help materials.
- Motivational Interviewing techniques should be incorporated within this service. Motivational interviewing is a directive, patient centred counselling style that aims to help patients explore and resolve their ambivalence about behaviour change.
- Elements of stress management programmes/materials would be useful within this intervention as many participants indicated that they consume more alcohol when under stress/pressure.
- Incentives could enhance participants' attendance to the service (e.g. gym membership, food voucher, other activity vouchers).
- Follow up and assessment procedure should be outlined and implemented to assess the efficacy of the intervention.

## **Referral**

- Primary Care workers should take an active role in screening and referring people on to the service.
- Self-referral pathway should also be established. A website facilitating self-referral could be highly beneficial. Alternatively a free-phone number should be made available for self referral.
- Liaison through partnership protocols with other agencies and professionals in criminal justice, health and social care fields (including probation, courts, housing, and employment support) to enhance number of referrals to the service.

## **Screening Process**

The AUDIT scale could be used as an assessment tool. The AUDIT was developed by the World Health Organization (WHO) as a simple method of screening for excessive drinking and to assist in brief assessment. It can help identify excessive drinking as the cause of the presenting illness. It provides a framework for intervention to help risky drinkers reduce or cease alcohol consumption and thereby avoid the harmful consequences of their drinking. The AUDIT also helps to identify alcohol dependence and some specific consequences of harmful drinking. It is particularly designed for health care practitioners and a range of health settings, but with suitable instructions it can be self-administered or used by non-health professionals. A copy of this scale is attached in (*appendix1*) of this report.

## **Where will it take place?**

- Younger participants preferred the intervention to be held in community setting, while older participants preferred the intervention to be held in a medical setting.
- To cater for these variance in preference, the invention should be made available at various locations including community hospitals, GP surgeries and community settings.

## **Who should deliver the service?**

- Many participants wanted the service to be delivered by Health Care Professionals (HCPs) who are non-judgemental. HCPs should be provided with Brief Intervention Training, Motivational Interviewing and structured training directly relevant to this intervention/service.
- Some Participants expressed that it would be beneficial if the service was delivered by two facilitators. 1 facilitator from health background and 1 lay member from the society who has had problems with alcohol.

## **Advertising**

- It is important when advertising this service, to refrain from using the word ‘alcohol service’. According to participants this term is associated with problematic alcohol consumers and would not like be associated with an ‘alcohol service’.
- When advertising the service , participants preferred positive advertising that focussed on raising awareness on alcohol

- Participants expressed the need for shock tactics within the advertising campaign.

### **Partnership working**

- Partnership working with local police (e.g. Arrest Referral Scheme) should be established. An offender under the influence of alcohol at the time of committing the offence should be referred to the alcohol intervention service. This is likely to offer choice to people who are issued with a Fixed Penalty Notice because they have committed an alcohol related offence. These will usually be for Drunk and Disorderly conduct, or for Public Order offences. This form of intervention is already in place at Gloucestershire, Ealing and Plymouth.

<b>Conclusion</b>
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Overall this evaluation has highlighted important gaps within the current service provision for alcohol consumers. Further to this the findings of this project provides clear set of steps to work towards to meet these needs. This report provides a clear and concise guidelines that will form a foundation for the development of an intervention for the target group (mild/moderate alcohol consumers).

One clear gap identified through this research was that health care professionals have rarely raised the issue of alcohol consumption with patients. Only two participants were asked about their alcohol consumption, and this was due to routine treatment policy. In future research/evaluation it would be important to carry out qualitative work with health care professionals addressing their issues with talking about alcohol consumption.

With regards to the current project, the next step would be to disseminate the findings to key stakeholders within NHS SW Essex, and explore the feasibility of establishing a new alcohol service.

## **Optional Unit 5.8 Disseminate Psychological Knowledge to Address Current Issues in Society**

### **Background:**

This case study is based on an occasion when I presented the findings of a systematic review I conducted at a Diabetes conference. The title of the systematic review was the effectiveness of cognitive behaviour therapy for depressed patients with diabetes. The findings of the systematic review was presented at the Asian Diabetes Conference, 2012. The conference was held in Kuala Lumpur, Malaysia between 17<sup>th</sup> - 21<sup>st</sup> October 2012. This conference is held annually and is organised by The National Diabetes Institute, Malaysia also known as NADI.

NADI provides a dedicated and comprehensive service for diabetics. It works to prevent and control diabetes, its complications and associated diseases. NADI is managed by a Board of Trustees and the former Prime Minister YABhg. Tun Dr. Mahathir Mohamad serves as a Patron of this organisation. The main objectives of NADI are to be a National Diabetes Education Resource Centre for the country and establish and run a comprehensive health facility including a National Diabetes Hospital for the management of diabetes and its complications. NADI also coordinates and conducts research in diabetes and related conditions. Further to these, this organisation also serves as the national coordinating centre for diabetes in Malaysia in respect to statistics, education, management, research, policy and planning on diabetes and associated diseases.

The Asian Diabetes conference is organised to bring together experts in the field of diabetes research. This conference also provides a platform for researchers to disseminate research findings. This conference was attended by approximately 400 healthcare professionals who work in diabetes care (e.g. doctors, dieticians, researchers, nurses, psychologists and allied health therapists). This conference was attended by professionals from various countries (e.g. Finland, United Kingdom, Malaysia, Singapore and Japan). Some of the international invited speakers

who attended the conference in 2012 were Professor Phillip Home of Newcastle University and Professor Edward Horton from Harvard University.

### **Depression amongst Diabetic Patients**

Depression is common among patients with diabetes (Lustman et al., 2000). The presence of diabetes doubles the odds of co-morbid depression (Ryan et al., 2001; Egede et al., 2002; Anderson et al., 2001). Researchers from various countries have rigorously investigated the prevalence of depression amongst patients with diabetes. For example, Ali et al. (2006) conducted a systematic literature review consisting of ten randomised controlled studies which included a total of 51, 331 patients to estimate the prevalence of clinical depression in adults with Type 2 diabetes compared with those without Type 2 diabetes. The review found that the prevalence of depression among Type 2 diabetes patients to be 8.9% higher compared to those without diabetes.

Depression for those with diabetes has a negative impact on quality of life (Goldney et al., 2004; Brown et al., 2004; Schram et al., 2009; Eren & Şahin, 2008). A large population-based study conducted in Australia by Goldney et al. (2004) found a clear difference in the quality-of-life scores for the diabetic and depression group when compared with the diabetic group without depression. The researchers concluded that depression for those with diabetes is a pivotal co-morbidity that requires careful management as it has a severe negative impact on quality of life.

Depressed diabetic patients have a higher risk of diabetes-related complications, such as myocardial infarction (Scherrer et al., 2011) and retinopathy (Roy et al., 2007). Groot et al. (2001) used a meta-analytical approach to examining the strength and consistency of the relationship between depression and diabetes complications in studies of type 1 and type 2 adult diabetic patients. Twenty-seven studies were included in the meta-analysis. The study found a significant association between depression and a variety of diabetes-related complications such as diabetic retinopathy, nephropathy, neuropathy, macrovascular complications and sexual dysfunction. A costing analysis conducted by Egele et al., (2002) found that depression in individuals with diabetes is associated with increased health care use and expenditure. Among

individuals with diabetes, total health care expenditure for individuals with depression was 4.5 times higher than that for individuals without depression.

This systematic review was conducted as depression is common among patients with diabetes (Lustman et al., 2000). The presence of diabetes doubles the odds of comorbid depression (Egede et al., 2002; Anderson et al., 2001). Further to these various meta-analysis and systematic reviews have provided support for the efficacy of cognitive behavior therapy in treating patients with depression (Gaffan et al., 1995; Gloaguen et al., 1998; Reinecke et al, 1998). However, the feasibility and effectiveness of cognitive behavior therapy for depressed diabetic patients have not been systematically reviewed.

In conducting this systematic review, an extensive literature search was conducted to identify suitable studies. Systematic literature searches were performed using Ovid, CINAHL EMBASE, PUBMED, PsycINFO, Web of Science and Cochrane Library to retrieve published articles that fulfilled all inclusion criteria of this review. Further to these, bibliographic search was also conducted. The search terms used are attached as **Appendix 1**.

The findings of this systematic review were submitted on August 2012 for presentation at the Asian Diabetes Conference. The application form is attached as **Appendix 2**. The letter of acceptance from NADI was received on September 2012 **Appendix 3**. Disseminating the findings of this systematic review at this conference would highlight the importance of health psychology principles, practices, services and benefits within diabetes management. For example, this presentation would highlight the importance of psychological interventions in dealing with psychosocial factors such as depression among diabetic patients.

Presentation materials were produced using Microsoft PowerPoint (**Appendix 4**). When designing the slides for the presentation, information within the slide was kept simple, tidy and accurate. Each slide contained information that was concise and easily comprehensible. Measures were taken to avoid the slides from being wordy. When appropriate, diagrams, charts, pictures and videos were incorporated to enhance the presentation.

At the beginning of the presentation, I introduced myself and my role as a trainee Health Psychologist. I felt it was very crucial for my audience to understand my role as they were from various different healthcare backgrounds and would probably have a poor understanding of the field of health psychology. This is mainly because the majority of conference attendees were not from a psychological background. Furthermore, health psychology is a relatively new field in Malaysia.

When conducting the presentation, I was aware of my tonality, pace of delivery and body language. This was crucial as it would contribute to the effectiveness of my presentation. During the presentation, the audience were provided with ample opportunities to ask questions and seek clarification. However, no questions were asked. The PowerPoint slides of this presentation are attached as Appendix 3. The presentation lasted for 15 minutes, and 10 minutes was allocated for questioning. This presentation was judged by Dr. G.R Lethuman from the MOH Malaysia, Professor Juliana Chan from Nanyang Technology University, China and Professor Jaakko Tuomilehto from the University of Helsinki.

Approximately 20 presenters competed for the Young Investigators Award. The judging criteria of this competition was not revealed. I presented the findings of the systematic review to approximately 50 conference attendees. There were other sessions running at the same time. Following my presentation, Professor Juliana Chan from Nanyang Technology University commented that the systematic review acknowledges the important issue of depression among diabetic patients, which she stated adversely impacts diabetic management. Further to that, she also explained that this research emphasises the need for healthcare professionals to work together to optimise diabetes management. For example, she spoke of the need for doctors to work in collaboration with psychologists to help manage depression and other psycho-social issues that contribute towards poor diabetes management.

Prior the conference presentation, the slides were sent off to a colleague from City University for peer review, feedback and comments. I also did a mock presentation to this colleague through Skype. I obtained constructive feedback from this colleague and made the necessary amendments to my slides and presentation. The main feedback obtained from my colleague was

that the introduction slides contained too much information. I was advised to cut down the information. Further to that, my colleague also advised that due to my awareness of time constraints, I was speaking very fast and at times it was hard to follow my presentation. I was advised to slow down the pace of delivery. Furthermore, I had initially designed the slides to provide an overview of CBT. My colleague advised to use a picture that depicts the principles of CBT and to explain the principles when presenting.

### **Reflection**

Personally, this was a big step in my development as a competent Health Psychologist. Throughout my Stage 2 training, to this point, I had avoided presenting at conferences. This was mainly due to my confidence issues in presenting to a group of professionals. I did not think I was capable of presenting in front of other professionals and I feared that I would be unable to answer the questions that would come up after the presentation. Further to that, I also feared that my research might be scrutinised and I would not be able to justify the research and methodology employed. During the Stage 2 training, I have attended various conferences such as the British Health Psychology Conference (2008, 2009) and the UK Public Health Conference (2010) but avoided presenting my work at them. Through my participation in these conferences, I understood the importance of the conference presentation. I gained an understanding that in order to progress in this field, I would have to present at conferences, especially if I was involved in academic employment as it is an important aspect of academic work. Conference presentation is an important means of disseminating research findings, raising the profile of health psychology amongst other health professions in addition to raising one's own profile as a researcher in the field. Hence, although I was very apprehensive about presenting in a conference, I was confident that my systematic review and its findings should be shared to a bigger audience of researchers who have an interest in diabetes as it has clinical implications. I was also confident with the methodology I used for this systematic review and was certain that I knew my subject areas well to be able to deliver this presentation competently. Due to my in-depth knowledge, I was also convinced that if any questions were asked post-presentation, I would be able to answer those questions adequately.

As previously stated, this conference was attended by various healthcare professionals who work in diabetes care, from various countries. By the end of the day, I realised that many healthcare professionals had a poor understanding of health psychology and of the unique skill set health psychologists possess. I was glad that I had been given the opportunity to promote the field of health psychology. I was confident that through my presentation, other healthcare professionals attending the session had gained an understanding of the skills and capabilities of a health psychologist.

Through this presentation I realised the importance of presenting research findings at conferences as it enables other professionals to gain insight into the nature and importance of the research conducted and further provides a platform for promotion of health psychology. Conference presentations also have the potential to open up opportunities to work collaboratively with other healthcare professionals and researchers. This was a very valuable experience for me. After this presentation, I gained confidence in my ability to present in conferences.

I also learned about questions that could arise in a conference presentation by observing the presentation of other participants. For example, by observing a qualitative research presentation, I learned that the judges did not fully understand the nature of the qualitative investigation and questioned its validity and reliability. Through this observation, I learned that in future if I intend to present a qualitative paper, I should fully be prepared for questions of this nature. I also learned about certain downfalls that other researchers have made in their research. For example, one researcher investigated obesity among Malaysian diabetic population but used the western cut-off point for obesity. The judges made comments that the research was flawed as the Asian cut-off point of obesity was lower than the western cut-off point for obesity. This observation highlighted the importance of cultural specific literature reviews when embarking on future research.

The next step would be to publish the systematic review within a peer-reviewed journal. I intend to publish this work in a diabetes-related journal such as *DiabetesCare*. A publication would be highly beneficial to me in my career development and doctoral journey. Prior to doing so I will need to familiarise myself with the process of publishing a research paper. I intend to seek the

guidance of my University supervisor on this issue. I also intend to use the help of my peers who have experience in publishing their research findings.

Due to the nature of this conference, it was not feasible to evaluate the presentation to establish the impact of the message. Three presenters won the Young Investigator award. I secured the 3rd Prize (**Appendix 5**). Due to the prize allocated to this presentation, it would appear that this presentation was well received by its audiences. Winning this award increased my confidence as a researcher. I have always been passionate about research but lacked confidence to present the findings. I viewed this award as a recognition of my research capabilities. It has motivated me to participate in higher calibrated research with real life implications.

In future, if it is feasible, I would like to evaluate the impact of my presentation using a method such as an exit evaluation form. I intend to use a form that would evaluate the quality of the information, structure of the presentation, interpretation of findings, presentation skills and coverage of the topic. This form of evaluation would enable me to identify and enhance my presentation skills.

## **Appendix 1: Search criteria used**

- Diabet\**or*
- Diabetes *or*
- Diabetic

AND

- Cognitive therapy *or*
- Behaviour therapy *or*
- Behavior therapy *or*
- Cognitive behaviour therapy *or*
- Cognitive behavioural therapy *or*

AND

- Depression
- Depressive

**Appendix 2: Conference Application Form**

**“Young Investigators Award”**

I would like to submit my **oral presentation** paper titled:

**The effectiveness of cognitive behaviour therapy for depressed patients with diabetes: a systematic review of recent evidence.**

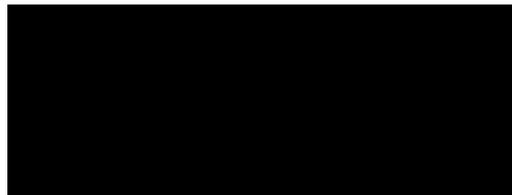
for consideration of the “Young Investigators Award”.

I declare that:

1. My age is \_\_\_29\_\_\_ years
2. My contribution to this original research is > 60%
3. I am the main author and presenter of this paper
4. I agree to abide by the rules of the award and will be willing to present my findings at the Awarding Ceremony.

\_\_Jana Kanapathy\_\_\_\_

(Name)



\_\_31/08/2012\_\_\_\_

(Date)

Please fax or mail (with your Registration Form) to:  
**Conference Secretariat**  
**National Diabetes Institute (NADI)**  
No. 1, Jalan SS 3/50  
47300 Petaling Jaya, Selangor, MALAYSIA  
Tel: +603-7876 1676 / 7876 1677 Fax: +603-7876 1679  
Email: enquiry@nadidiabetes.com.my

**The effectiveness of cognitive behaviour therapy for depressed patients with diabetes: a systematic review of recent evidence.**

**Authors:** Jana Kanapathy (City University, London), Dr Catherine Skyes (City University, London)

**Abstract:**

**Background review:** Depression is common among patients with diabetes. The presence of diabetes doubles the odds of comorbid depression. Depression for those with diabetes has a negative impact on quality of life. Depressed diabetes patients have higher risk of diabetes related complications such as diabetic retinopathy, nephropathy, neuropathy, macrovascular complications, and sexual dysfunction. Cognitive behaviour therapy has been proven to be effective in treating depression. Although research has focused on applying cognitive behaviour intervention for depressed diabetes patients, thus far the effectiveness of this intervention has not been systematically reviewed.

**Objective(s):** To systematically review literatures published on cognitive behaviour therapy for depressed diabetes patients to establish the effectiveness if this intervention.

**Methods:** Systematic literature searches were performed using Ovid, CINAHL EMBASE, PUBMED, PsycINFO, Web of Science and Cochrane Library to retrieve published article which fulfilled all inclusion criteria. Methodological quality assessment and data synthesis were then performed.

**Results & Conclusion:** Initial searches identified 52 articles of which 5 were eligible for inclusion. Of these, only 2 were randomized control trial. Two studies were ranked low in the methodological quality. Cognitive behaviour therapy has demonstrated some level of favourable outcomes, specifically in reducing depressive symptoms among depressed diabetes patients.

However, cognitive behaviour therapy did not have a significant impact on diabetes related outcome such as glycaemic control. Limitations and areas for future research are discussed.

### **Appendix 3: Conference Acceptance Letter**



**NATIONAL DIABETES INSTITUTE**  
**INSTITUT DIABETES NEGARA**

Tel : 603-7876 1676 / 7876 1677  
Fax : 603-7876 1679  
Email : enquiry@nadidiabetes.com.my  
http://www.diabetesmalaysia.com.my  
No. 1, Jalan SS 3/50, 47300 Petaling Jaya, Selangor, MALAYSIA.

**PATRON**

Tun Dr Mahathir Mohamed

**BOARD OF TRUSTEES**

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Prof Dato' Anuar Zaini Md Zain

**Representatives**

Dato' Sri Dr Hasan Abdul Rahman  
(MOH)

Dr. G. R. Letchuman  
(MEMS)

Prof. Dato' Ikram Shah Ismail  
(PDM)

05 September 2012

Dear Ms Jana Kanopathy,

(via email)

**11th CPD: "Diabetes Asia 2012" Conference & Workshop**  
**October 17-21, 2012**  
**Hotel Istana, Kuala Lumpur, MALAYSIA**

Thank you very much for your interest to present a paper at our 'Diabetes Asia 2012' Conference.

We are pleased to inform that the secretariat have received and accepted your paper entitled:

***The effectiveness of cognitive behaviour therapy for depressed patients with diabetes: a systematic review of recent evidence***

The Scientific Committee will review all abstracts and you will be notified accordingly via email on whether your abstract has been scheduled for oral or poster presentation. The decision of the Scientific Committee is final. All abstracts accepted will be published in the programme book that will be distributed to all congress attendees.

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Thanking you in advance for helping to make 'Diabetes Asia 2012' Conference a success.

With best regards,

Yours sincerely,  
**National Diabetes Institute**



**Chairman, Scientific Committee**

Appendix 4: Conference Presentation slides



# The effectiveness of cognitive behaviour therapy for depressed patients with diabetes: a systematic review of recent evidence

JANA KANAPATHY  
(CITY UNIVERSITY, LONDON)

## Introduction

- Depression refers to a wide range of mental health problems characterised by the absence of a positive affect
- There are various psychological, physical and social symptoms associated with depression
- Depression is common among patients with diabetes
- The presence of diabetes doubles the odds of comorbid depression

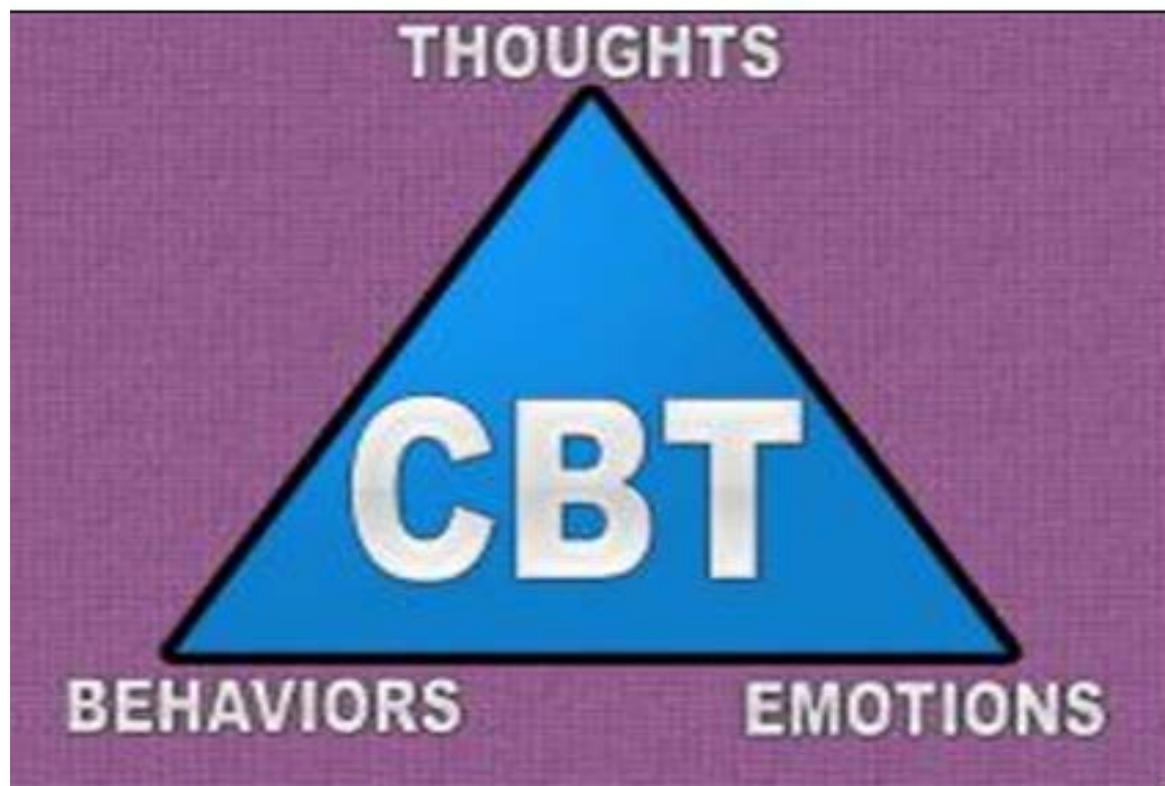
## Depression & Diabetes

- Depression for those with diabetes has a negative impact on quality of life
- Depressed diabetes patients are less likely to adhere to oral hypoglycemic regimens and dietary recommendation
- Depressed diabetes patients have higher risk of diabetes related complications such as myocardial infarction and retinopathy

## Depression & Diabetes

- Groot et al (2001)
  - used a meta-analytical approach to examine the strength between depression and diabetes complications
  - Twenty-seven studies were included within this meta-analysis.
  - This study found a significant association between depression and a variety of diabetes related complications such as diabetic retinopathy, nephropathy, neuropathy, macrovascular complications, and sexual dysfunction.

**Based on evidence to date,  
psychological therapy (particularly  
cognitive behaviour therapy, CBT) is the  
treatment of choice for depression**



## AIM

**The aim of this review was to identify and present the evidence on the effectiveness of cognitive behaviour therapy for depressed diabetes patients**

## Methodology

### **Search strategy and data sources**

- **Systematic literature searches were performed using Ovid, CINAHL, EMBASE, PubMed, PsycINFO, Web of Science and Cochrane Library databases. The results obtained from the database search were screened to identify studies that met the inclusion criteria of this review.**
- **Keywords used :**
  - Diabetes/Diabetic/diabet\*
  - Cognitive therapy/ Behaviour therapy/Cognitive behaviour therapy
  - Depression/ depressive

## Study Inclusion Criteria

- **Participants**
    - Depressed diabetes patients (Type 1 & 2)
  - **Interventions**
    - Included studies have evaluated cognitive behaviour interventions aimed at depressed diabetes patients. **This review included studies that used cognitive behaviour therapy as a sole form of treatment.** Published studies that used cognitive behaviour therapy in combination with other forms of intervention such as exercise prescription, pharmacological intervention or holistic treatments were excluded from this review.
- Types of outcome measures**
- Studies that reported depressive symptoms and glycaemic control were included in this review.

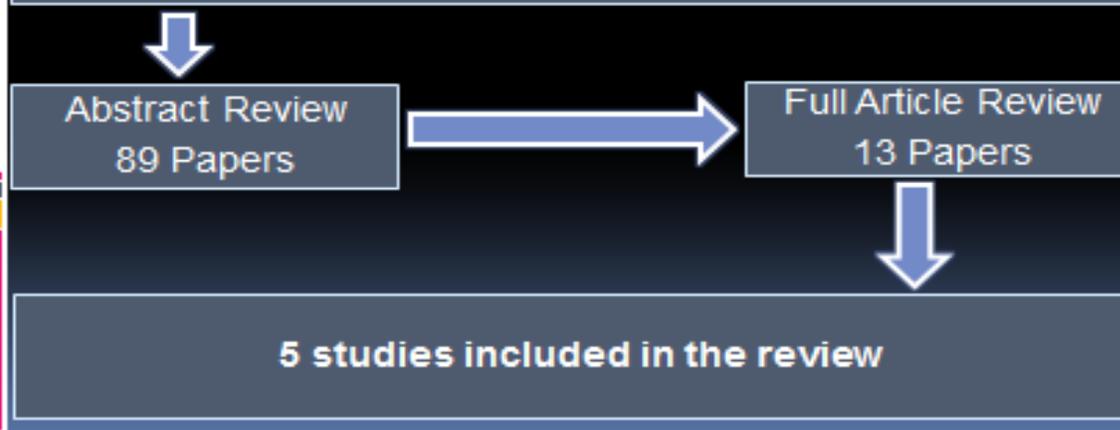
## Results

### Electronic Databases

Psyinfo/CINAHL/MEDLINE/PSY Articles/Behavioural sciences - 74

EMBASE/OVID - 62

Total : 136



Assessment criteria	Gonzalez et al (2004)	Rosello et al (2006)	Bastelaar et al (2011)	Georgiades et al (2011)	Lustman et al (1998)
<b>Description Criteria</b>					
Eligibility Criteria Specified	✓	✓	✓	✓	✓
Description of intervention	✓	✓	✓	✓	✓
Long term follow-up (> 6 months post Intervention)				✓	
Similar baseline data	✓		✓	✓	✓
<b>Internal validity Criteria</b>					
Randomization performed			✓		✓
Method of randomization performed			✓		✓
Blind assessment reported			✓		✓
Drop-outs rates reported		✓	✓	✓	✓
<b>Statistical Criteria</b>					
Power analysis conducted			✓	✓	
Point estimates and measure of variability		✓	✓	✓	✓
<b>TOTAL</b>	<b>3</b>	<b>4</b>	<b>9</b>	<b>7</b>	<b>8</b>

Authors	Intervention	Decline in HbA1c	Decline in depression symptoms	Other significant findings
Rosello et al (2006)	12 session group CBT Intervention	NS	Depressive symptoms decreased significantly (p .0005) <sup>+</sup>	Self concept <sup>++</sup> Self-efficacy for diabetes <sup>+</sup>
Bastelaar et al (2011)	Web CBT	NS	Depressive symptoms decreased significantly (p .0001) <sup>++</sup>	Emotional distress <sup>++</sup> Clinically significant improvement <sup>++</sup>
Georgiades et al (2007)	16 CBT sessions were delivered in small closed-end groups.	NS	Depressive symptoms decreased significantly (p .0001) <sup>++</sup>	NA
Lustman et al (1998)	10 CBT sessions were delivered in small closed-end groups.	Significant decrease found <sup>+</sup>	Depressive symptoms decreased significantly (p .0001) <sup>++</sup>	NA
Gonzalez et al (2004)	CBT for adherence and depression (CBT-AD)	Significant decrease found <sup>+</sup>	Depressive symptoms decreased significantly (p .0001) <sup>++</sup>	Diabetes self care <sup>++</sup>

## Conclusion

- Small review
- Mixed Results
- Best practice examples
- Optimal quality research is still needed

**Appendix 5: Award Certificate**



*Certificate of Commendation*

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# **Section D**

## **Systematic Review**

## Abstract

**Background review:** Depression is common among patients with diabetes. The presence of diabetes doubles the odds of co-morbid depression. Depression for those with diabetes has a negative impact on quality of life. Depressed diabetes patients have a higher risk of diabetes-related complications such as diabetic retinopathy, nephropathy, neuropathy, macrovascular complications, and sexual dysfunction. Cognitive behavioural therapy has been proven to be effective in treating depression. Although research has focused on cognitive behavioural therapy for treating depressed diabetes patients, thus far the effectiveness of this intervention has not been systematically reviewed.

**Aim(s):** The purpose of this systematic review is to explore the effectiveness of cognitive behavioural therapy for depressed diabetic patients. No previous systematic reviews have been carried out on this topic. The aim of this review is to determine whether CBT interventions are effective in reducing depressive symptoms and improving glycaemic control among depressed diabetic patients.

**Methods:** A systematic literature search was performed using Ovid, CINAHL EMBASE, PUBMED, PsycINFO, Web of Science and Cochrane Library. A bibliographic search was also conducted. Data extraction and methodological quality assessment and data synthesis were then performed by two independent reviewers.

**Results & Conclusion:** Five studies met the inclusion criteria of the systematic review. This review found that the quality of two studies reviewed was not optimal. The results reveal diversified application of CBT for depressed diabetic patients. Studies included in this review employed various methodological designs. A meta-analysis was not conducted because of the heterogeneous nature of the studies. It was challenging to draw a definitive conclusion on the effectiveness of CBT for depressed diabetic patients due to this issue. All studies reported that cognitive behavioural therapy had a positive impact on depressive symptoms. However, only two studies found an improvement in HbA1c. One study also demonstrated that CBT interventions improved self-efficacy for diabetes and self-concept. This review clearly highlights the need for more controlled studies with longer-term follow-up to ascertain with certainty the effectiveness of CBT for depressed diabetic patients.

## **Introduction**

### **1.1 Depression – Definition, Prevalence and Cost**

Depression refers to a wide range of mental health problems characterised by the absence of a positive affect (a loss of interest and enjoyment in daily activities and experiences), a low mood, and a range of associated emotional, cognitive, physical and behavioural symptoms (NICE, 2009). There are various psychological (e.g. continuous low mood or sadness, low self-esteem, helplessness/hopelessness, suicidal thoughts), physical (e.g. change in appetite or weight, disturbed sleep, lack of energy or lack of interest in sex), and social (e.g. lack of interest in social activities, avoiding contact with friends, having difficulties with family life) symptoms associated with depression. Depression is diagnosed using diagnostic tools such as ICD-10 and DSM-IV. A diagnosis is based on the presence of a number of depressive symptoms and the persistence of symptoms. The presence of more than four depressive symptoms that persist for at least 2 weeks is necessary for a positive diagnosis of depression. Furthermore, the presence of one or two key symptoms such as low mood, loss of interest and pleasure, and loss of energy is necessary to facilitate diagnosis (NICE, 2009).

According to the World Health Organization (WHO, 2012), depression affects 121 million people worldwide. Within the British population, the Office of National Statistics (2013) estimates that depression occurs in one in 15 adults or 19 per cent of the population in Britain. The Global Burden of Diseases Analysis (2010) found that depressive disorders were the second leading cause of years lived with disability (YLDs) in 2010 and a leading cause of disability-adjusted life years (DALYs). This analysis also identified major depressive disorder as a contributor to suicide and ischemic heart disease.

Berto et al. (2000) conducted a review to examine studies published in international literature in order to describe and compare the social costs of depression in various countries. The authors reviewed seven studies which conducted in-depth cost comparative analysis in the USA, UK and Italy. The studies were published between 1987 and 1993. The findings of this review indicated that in the US, direct and indirect expenditure of depression amounted to US\$43.7 billion in 1990. The expenditure increased to US\$65 billion in 1998. In the UK, the cost of depression was estimated at £417 million in 1993. In Italy, the cost was estimated at 2.5 million a year in 1998 (or US\$1.6 billion). This review indicated that hospitalisation costs

contributed between 43% and 75% of the average per patient cost. The cost of medication only contributed towards 2%–11% in five out of seven studies. In a separate review, Sobocki et al. (2006) estimated the total cost of depression in Europe based on published epidemiologic and economic evidence. This review included evidence gathered from 28 countries and found that in 2004, depression accounted for 42 billion euros in direct costs and 76 billion euros in indirect costs. The results of this study indicated that depression was the most costly brain disorder in Europe.

## **1.2 Depression and Chronic Illnesses**

Depression is common among patients with chronic illnesses such as stroke (Sims et al., 2009), HIV/AIDS (Rabkin, 2008), asthma (Goldney et al., 2003), heart disease (Levenson, 2006), arthritis (Pincus et al., 1996), chronic pain (Banks and Kerns, 1969), cancer (Spiegel and Giese-Davis, 2003), and kidney disease (Murtagh et al., 2007). Reidv et al. (2008) explained that the high prevalence of depression among patients with chronic illness could be attributed to the symptoms and consequences of these illnesses, such as treatments and side effects, disruptions to a person's work and/or social life, and financial difficulties. Shimoda and Robinson (1999) suggested that the high prevalence of depressive symptoms among stroke patients could be attributed to an anatomical alteration that occurs in the brain during stroke.

Empirical evidence suggests that long-term depression has a profound impact on the course and outcome of chronic diseases (Greden, 2001). For example, depression among patients with stroke decreases the patient's quality of life and increases the risk of a further stroke and mortality (Brown et al., 2012). Studies have demonstrated that depression exacerbates the course of chronic illnesses such as HIV (Leserman, 2008), cancer (Spiegel and Giese-Davis, 2003), and rheumatoid arthritis (Zautra and Smith, 2001). Grenade et al. (2012) conducted a meta-analysis on 31 studies with an accumulated total of 18,245 participants. The main aim of this analysis was to investigate depression and medication adherence in the treatment of chronic diseases. The findings of this analysis confirmed that depression is associated with poor adherence to medication across a range of chronic diseases. Despite its high prevalence, depression often goes unrecognised (Davis and Gershtein, 2003).

### 1.3 Depression and Diabetes

Depression is common among patients with diabetes (Lustman et al., 2000). The presence of diabetes doubles the odds of co-morbid depression (Ryan et al., 2001; Egede et al., 2002; Anderson et al., 2001). Researchers from various countries have rigorously investigated the prevalence of depression among patients with diabetes. For example, Ali et al. (2006) conducted a systematic literature review consisting of 10 randomised controlled trials, which included a total of 51,331 patients, to estimate the prevalence of clinical depression in adults with type 2 diabetes compared with those without type 2 diabetes. The review found the prevalence of depression among type 2 diabetes patients to be 8.9% higher than those without diabetes.

Numerous studies have been conducted to investigate the factors that contribute to the onset of depression in diabetes patients. Empirical findings suggest that depression is more prevalent in females (Anderson et al., 2001; Lee et al., 2009; Ali et al., 2006; Blazer et al., 2002; Egede et al., 2003), those less educated (Egede et al., 2002; Cowie, 1995), and those of a lower socio-economic status (Anderson, 2001; Blazer et al., 2002). Katon et al. (2004) conducted a population-based mailed survey to determine the behavioural and clinical characteristics of diabetes that are associated with depression; 4193 participants from nine primary care clinics in western Washington completed the survey. The findings of this study indicated that independent factors such as younger age, gender (i.e. female), less education, being unmarried, BMI  $\geq 30$ , smoking, and higher non-diabetic medical co-morbidity were associated with major depression among diabetic patients. Moreover, younger age, less education, non-Caucasian status, BMI  $\geq 30$ , smoking, and longer duration of diabetes were associated with minor depression among diabetic patients.

Depression for those with diabetes has a negative impact on quality of life (Goldney et al., 2004; Brown et al., 2004; Schram et al., 2009; Eren and Şahin, 2008). A large population-based study conducted in Australia by Goldney et al. (2004) found a clear difference in the quality-of-life scores for the diabetic and depression group when compared with the diabetic group without depression. The researchers concluded that depression for those with diabetes is a pivotal co-morbidity that requires careful management as it has a severe negative impact on quality of life.

Ciechanowski et al. (2000) conducted a study utilising a questionnaire design of 367 patients with types 1 and 2 diabetes to explore the impact of depressive symptoms in primary care patients with diabetes on diabetes self-care, adherence to medication regimens, functioning, and health care costs. The results of the study found that depressed diabetic patients were less likely to adhere to oral hypoglycaemic regimens and dietary recommendations. In addition, numerous studies have found a significant association between depression and non-adherence to the diabetes treatment regimen and self-care behaviour (Gonzalez et al., 2008; Egede and Osborn, 2010). Studies have also found a significant association between depression and poor glycaemic control (Lustman et al., 2000; Roy et al., 2007).

Depressed diabetic patients have a higher risk of diabetes-related complications such as myocardial infarction (Scherrer et al., 2011) and retinopathy (Roy et al., 2007). Groot et al. (2001) used a meta-analytical approach to examine the strength and consistency of the relationship between depression and diabetes complications in studies of type 1 and type 2 adult diabetic patients. Twenty-seven studies were included within the meta-analysis. The study found a significant association between depression and a variety of diabetes-related complications, including diabetic retinopathy, nephropathy, neuropathy, macrovascular complications, and sexual dysfunction. A costing analysis conducted by Egele et al. (2002) found that depression in individuals with diabetes is associated with increased health care use and expenditure. Among individuals with diabetes, total health care expenditure for individuals with depression was 4.5 times higher than that for individuals without depression.

Lehnert et al. (2011) systematically reviewed 11 studies to determine the cost of illness and the economic impact for diabetic patients with co-morbid depression. The results of the review indicated that patients with depression and diabetes incurred between 35% and 300% excess costs compared to patients with diabetes and without depression. The excess cost was attributed to the treatment of diabetes.

#### **1.4 Treatment for Depression**

There are various forms of treatment for depression. For example, there are approximately 30 different types of antidepressants that are available to treat depression (Royal College of Psychiatrists, 2015). However, antidepressants often have side effects (Fergusson, 2001). In addition, current evidence also suggests the usage of exercise therapy for the management of

depression (Babyak, 2000). Rimer et al. (2012) conducted a meta-analysis of 28 trials (1,101 participants) that included a comparison of exercise with either a waiting list or placebo to investigate the effect of exercise on depression. The authors concluded that exercise improved the symptoms of depression.

In recent years a vast amount of investigations have been conducted to test the efficacy of psychological treatments in managing depression. Pampallon et al. (2004) conducted a meta-analysis to investigate the impact of combined pharmacotherapy and psychological treatment for depression. Sixteen trials met the inclusion criteria, with 932 patients being randomised to pharmacotherapy alone and 910 to combined treatment. These authors concluded that psychological treatment combined with antidepressant therapy is associated with a higher improvement rate than drug treatment alone. There are various forms of psychological therapies that have been applied to depression management (e.g. guided self-help, cognitive behavioural therapy, counselling, peer (self-help) support, problem solving, interpersonal therapy, psychodynamic psychotherapy, group existential therapy, health education, social support, and relaxation training).

### **1.5 Cognitive Behavioural Therapy for Depression**

Cognitive behavioural therapy is based on the premise that there is a close connection between cognition, emotion, and behaviour. Various meta-analyses and systematic reviews have provided support for the efficacy of cognitive behavioural therapy in treating patients with depression (Gaffan et al., 1995; Gloaguen et al., 1998; Reinecke et al., 1998). The principle of cognitive behavioural therapy states that there is a close connection between cognition, emotion, and behaviour (Rothbaum et al., 2000). Cognitive behavioural therapy aims to enable patients to correct false self-beliefs that can lead to negative moods and behaviours (Rupke et al., 2006). There are various modalities that have been utilised to deliver cognitive behavioural therapy. This form of therapy has been delivered on a one-to-one basis and in groups (Brown et al., 2011). Furthermore, with technological advancement, new delivery modalities have emerged (Farrer et al., 2011; Ruwaard et al., 2009).

In recent years, computerised cognitive behavioural therapy has gained popularity (So et al., 2013; Stallard et al., 2010). Computerised CBT (CCBT) is an intervention that uses the computer to deliver interactive CBT sessions. The program guides a person through the principles of CBT as a therapist would. The interactive program helps the user to understand

and modify their thinking. A good CCBT program will lead a person through the various stages of therapy in exactly the same way a therapist would in face-to-face sessions. An interactive CCBT program can respond to particular circumstances, or problems, and ensure that the training of new ways of thinking and behaving is completed at a pace suited to the patient's individual needs. One of the major advantages of CCBT is the ability to provide more treatment choices for patients and faster access to effective mental health services. CCBT has been effective in treating patients with depression (NICE, 2006).

Cognitive behavioural therapy (CBT) has been effective in treating depressed patients with other co-morbid illnesses, such as coronary heart disease (Freedland et al., 2012; Hambridge et al., 2009), multiple sclerosis (Mokhtari et al., 2008), Parkinson's disease (Dobkin et al., 2007), inflammatory bowel disease (Szigethy et al., 2004), and end-stage renal disease (Cukor, 2007). Recently, researchers have investigated the application of CBT to treat depression among diabetic patients. To date, no studies have systematically assessed the application and effectiveness of cognitive behavioural therapy among depressed diabetic patients.

## **2. Purpose and Aim**

The purpose of this systematic review is to explore the effectiveness of cognitive behavioural therapy for depressed diabetic patients. No previous systematic reviews have been carried out on this topic. The aim of this review is to determine whether CBT interventions are effective in reducing depressive symptoms and improving glycaemic control among depressed diabetic patients.

## **3. Methodology**

### **3.1 Search Strategy, Data Sources, and Search Terms**

A systematic literature search was performed using Ovid, CINAHL, EMBASE, PubMed, PsycINFO, Web of Science, and Cochrane Library databases for published articles (from 1995–2011). The search was performed between August 2012 and December 2012. The results obtained from the searches were screened to identify studies that met the inclusion criteria of this review.

The search terms used were:

- Diabet\* *or*
- Diabetes *or*
- Diabetic

AND

- Cognitive therapy *or*
- Behaviour therapy *or*
- Behaviour therapy *or*
- Cognitive behavioural therapy *or*
- Cognitive behavioural therapy *or*

AND

- Depression
- Depressive

### **3.2 Study Selection Criteria**

Inclusion criteria were set out to identify studies for this review. All publications that met the inclusion criteria were included regardless of the study design. Studies included had to fulfil all criteria set out below:

- **Participants**

Depressed diabetic patients (types 1 & 2). Studies of adults and adolescents (13–16 years old) with mild to moderate depression were included in this review. Mild to moderate depression is defined with the Becks Depression Inventory (Beck et al., 1961) score of 1–28.

- **Interventions**

Included studies had evaluated CBT interventions aimed at depressed diabetic patients. This review included studies that used CBT only as a sole form of treatment.

- **Types of outcome measures**

Studies that reported depressive symptoms and glycaemic control were included in this review.

Studies that focused on postnatal depression, bipolar disorder, depression with psychotic symptoms or current major depression, or serious suicidal thoughts did not fall under the scope of this review. Published studies that used cognitive behavioural therapy in combination with other forms of intervention, such as exercise prescription, pharmacological intervention or holistic treatments, were excluded from this review.

A bibliographical search was conducted on studies identified to retrieve additional studies that met the inclusion criteria of this review.

### **3.3 Study Selection**

The electronic database search identified 136 studies. A bibliographic search was also conducted on identified studies. In total, 141 studies were identified. Fifty-two studies were excluded based on the title alone. The remaining 89 abstracts were reviewed. A further 76 papers were excluded for failing to meet the inclusion criteria of this review. The remaining 13 papers were subjected to a full article review. Five studies met all of the inclusion criteria of this review (**Figure 1**).

### **3.4 Data Extraction**

A data extraction sheet was developed based on the Cochrane Handbook for Systematic Reviews of Interventions, Version 5.1.0. Data was extracted by the main review author and checked by an independent reviewer. Information was extracted from each included study on: (1) type of intervention (whether there was sufficient detail, such as the format of CBT intervention, session details, duration), (2) study design (i.e. randomised controlled trial, quasi-experimental, case series), (3) number of participants, (4) results on HbA1c (i.e. whether a significant decline for HbA1c was found), (5) results on depressive symptoms (i.e. whether a significant decrease in depressive symptoms was found), and (6) other significant findings (i.e. whether any other significant findings were found). The data extraction is presented in **Table 1** below:

### **3.5 Methodological Quality Assessment**

The quality of the studies was assessed by two reviewers: the author and an independent reviewer. Disagreements were resolved through discussion. Two reviewers (JK & PK) reviewed all of the papers based on the criteria below:

- Description Criteria
  - Eligibility criteria specified
  - Description of intervention
  - Long-term follow-up (>6 months post-intervention)
  - Similar baseline data
- Internal Validity Criteria
  - Randomisation performed
  - Method of randomisation performed
  - Blind assessment reported
  - Drop-out rates reported
- Statistical Criteria
  - Power analysis conducted
  - Point estimates and measure of variability

One point was allocated for each item of the methodology quality if the study fulfilled the criteria. If the study did not fulfil the criteria, zero marks were allocated. Total methodology quality scores were then summed up. Studies could get a maximum of 10 points. Studies scoring above 6 points were classified as being of a high quality. Studies scoring 4 points and below were classified as being of a low quality.

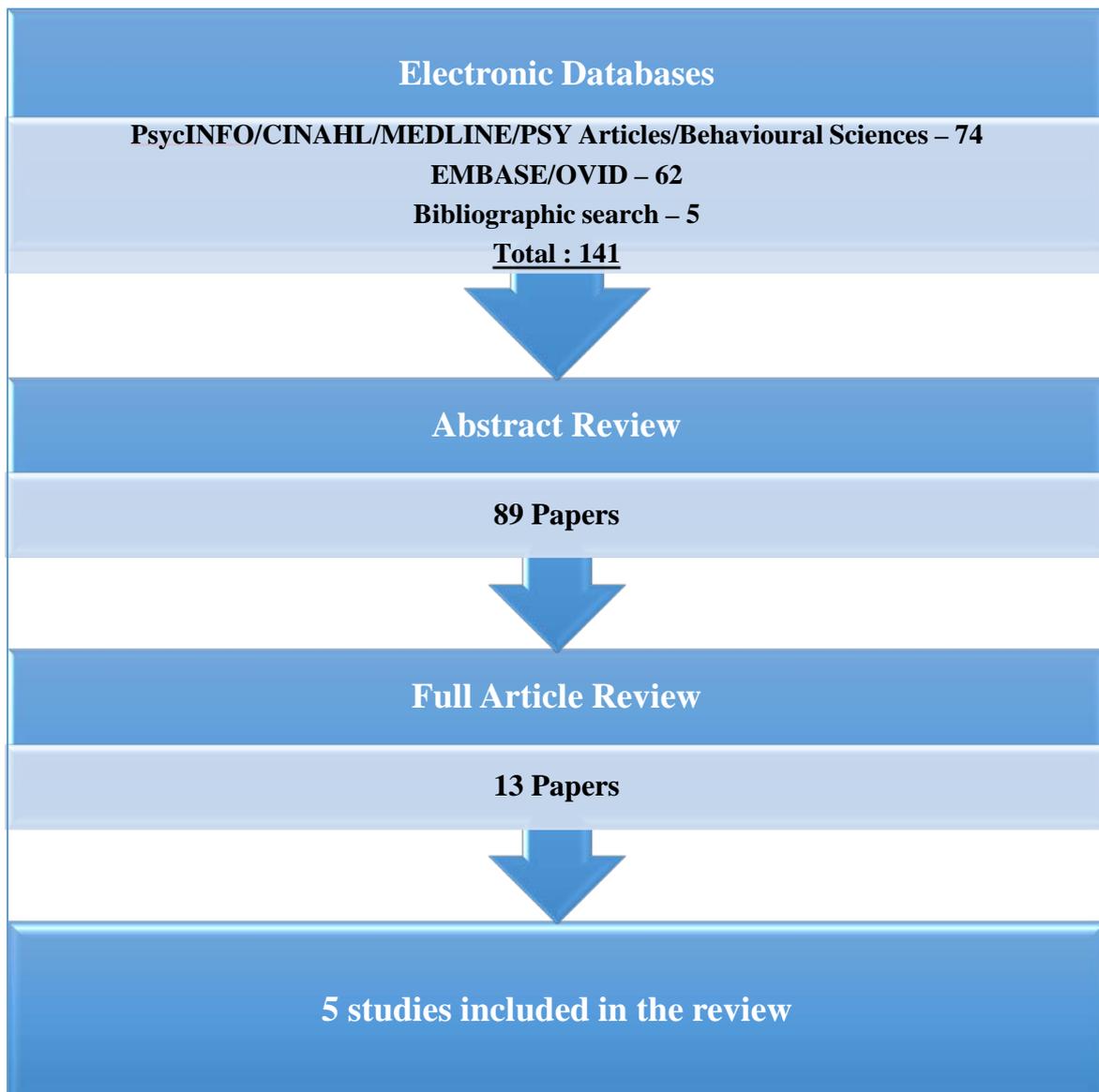
Authors	Intervention	Study design	N	Decline in HbA1c	Decline in depression symptoms	Other significant findings
Rosello et al. (2006)	<b>12-session group CBT intervention</b> Intervention integrates educational and discussion segments to provide the adolescents with information about coping with depression and diabetes, as well as an opportunity to address concerns and questions. Various strategies are used to facilitate discussion, including games, role-playing exercises, group discussion, and worksheets. Each session follows a basic format of: 1) a week in review; 2) review of weekly mood rating scales, blood glucose monitoring, and home practice assignments; 3) summary of previous session; 4) presentation of new material; 5) group discussion and exercises; and, 6) home practice assignment or exercise.	Quasi-experimental design	11	Not significant	Depressive symptoms decreased significantly (p .0005)*	Self-concept (p .0001)** Self-efficacy for diabetes (p .0005)*
Bastelaar et al. (2011)	<b>Web CBT</b> Participants individually went through eight consecutive lessons that provided written and spoken information and videos on depressed diabetic patients explaining how they learned from the course. Coaches (certified health psychologists) provided feedback on homework assignments on working days. Feedback was, to a large degree, standardised and consisted of a concise, constructive reply to the CBT techniques that are meant to help patients to understand and apply the CBT skills in daily practice.	Randomised control trial	255	Not significant	Depressive symptoms decreased significantly (p .0001)**	Emotional distress (p .0001)** Clinically significant improvement (p .0001)**

Georgiades et al. (2007)	<b>16 CBT sessions</b> Delivered in small closed-end groups (five to eight participants) led by one of four psychologists. The treatment was based on the well-validated model of cognitive therapy originated by Beck and colleagues and adapted to address themes specific to the management of diabetes.	Quasi-experimental design	90	Not significant	Depressive symptoms decreased significantly (p .0001)**	Not applicable
Lustman et al. (1998)	<b>10 CBT sessions</b> Delivered in small closed-end groups. CBT group received 1 hour of treatment weekly for 10 weeks from a licensed psychologist who had been the principal cognitive therapist in an early empirical trial of CBT. In addition, patients received a diabetes education programme which covered a variety of diabetes self-care topics.	Randomised control trial	51	Significant decrease found (p .0005)*	Depressive symptoms decreased significantly (p .0001)**	Not applicable
Gonzalez et al. (2004)	<b>10–12 CBT sessions</b> Individual cognitive behavioural therapy for adherence and depression	Quasi-experimental design	5	Significant decrease found (p .0005)*	Depressive symptoms decreased significantly (p .0001)**	Diabetes self-care (p .0001)**

**Table 1: Data Extraction**

## 4. Results

The electronic database search identified 136 studies. A bibliographic search was also conducted on identified studies. In total, 141 studies were identified. Fifty-two studies were excluded based on the title alone. The remaining 89 abstracts were reviewed. A further 76 papers were excluded for failing to meet the inclusion criteria of this review. The remaining 13 papers were subjected to a full article review. Five studies met all of the inclusion criteria of this review (**Figure 1**).



**Figure 1: Article selection process**

#### **4.1 Overview of Studies Included**

Three studies were conducted in the USA (Lustman et al., 1998; Gonzalez et al., 2004; Georgiades et al., 2007) and one study was conducted in Puerto Rico (Rosello et al., 2006). Bastelaar et al. (2011) conducted their research in Amsterdam. The total pooled sample size comprised 412 patients. Patients ranged from 13 years old to 70 years old.

Three studies (Lustman et al., 1998; Gonzalez et al., 2004; Bastelaar et al., 2011) focused on type 2 diabetes patients. One study (Georgiades et al., 2007) focused on type 1 and type 2 diabetes patients. One study (Rosello et al., 2006) focused on adolescents with type 1 diabetes.

## **4.2 Hierarchy of Research Design**

Two studies (Lustman et al., 1998; Bastelaar et al., 2011) were randomised controlled trials and the remaining two studies (Georgiades et al., 2007; Rosello et al., 2006) were quasi-experimental studies. Gonzalez et al. (2004) conducted a case series in which an intervention was administered to a small sample (N = 5) of participants. Both of the randomised controlled studies stipulated the randomisation technique used.

## **4.3 Quality Assessment of Studies**

Two independent reviewers rated the quality of the papers (**Table 2**). None of the studies fulfilled all of the quality assessment criteria. However, both of the randomised controlled trials scored 9. The study by Georgiades and colleagues (2007) scored 7 points. Two studies (Rosello et al., 2006; Gonzalez et al., 2004) demonstrated poor methodology quality. These studies merely scored 3 and 4 points, respectively. Due to the heterogeneous nature of the studies and the results reporting style, it was not possible to conduct a meta-analysis on the data obtained.

Assessment criteria	Gonzalez et al (2004)	Rosello et al (2006)	Bastelaar et al (2011)	Georgiades et al (2011)	Lustman et al (1998)
<b>Description Criteria</b>					
Eligibility Criteria Specified	√	√	√	√	√
Description of Intervention	√	√	√	√	√
Long term follow-up (> 6 months post intervention)				√	√
Similar baseline data	√		√	√	√
<b>Internal validity Criteria</b>					
Randomization performed			√		√
Method of randomization performed			√		√
Blind assessment reported			√		√
Drop-outs rates reported		√	√	√	√
<b>Statistical Criteria</b>					
Power analysis conducted			√	√	
Point estimates and measure of variability		√	√	√	√
<b>TOTAL</b>	<b>3</b>	<b>4</b>	<b>9</b>	<b>7</b>	<b>9</b>

**Table 2: Methodology quality**

### **Depressive measures**

A range of measures was used across the studies in order to assess depression among diabetic patients. Four studies (Lustman et al., 1998; Georgiades et al., 2007; Gonzalez et al., 2004; Rosello et al., 2006) utilised the Beck Depression Inventory (BDI; Beck et al., 1961). Rosello and colleagues did not find a significant difference in BDI scores. Lustman et al. (1998) and Georgiades et al. (2007) found a significant decrease in BDI scores ( $p < 0.001$ ) from baseline levels to follow-up after the CBT intervention. Gonzalez and colleagues (2004) found that

BDI scores were slightly less responsive, with one patient showing an increase. Another patient in this study showed no change from pre- to post-assessment. The three remaining patients reported decreases on the BDI.

Gonzalez et al. (2004) used an additional depressive measure which was completed by the clinicians. The clinicians involved in this study completed the Montgomery–Asberg Depression Rating Scale (MADRS; Montgomery and Asberg, 1979), which is a structured 10-item questionnaire. This measure was utilised to measure specific symptoms of depression and to provide a rating of severity of depression over the last seven days. All patients experienced a decrease in their MADRS score between the baseline and post. Georgiades and colleagues (2007) also used an additional measure. These researchers utilised the 17-item Hamilton Depression Scale (HAM-D; Hamilton, 1960). The HAM-D measurement of depression demonstrated reductions from the baseline to follow-up after CBT intervention ( $p < 0.001$ ).

Bastelaar et al. (2011) utilised the Dutch validated version of the Centre for Epidemiological Studies Depression Scale (CES-D). This is a self-report screening instrument which measures the frequency with which participants have experienced specific symptoms of depression within the preceding week. The outcome of this randomised control trial indicated that the CBT group had a lower level of depressive symptoms at 1-month follow-up ( $d = 0.29$ ,  $p < 0.001$ ). Rosello et al. (2006) utilised the Children’s Depression Inventory (CDI). This is a 27-item self-rated symptom-oriented scale suitable for school-aged children and adolescents (Kovacs, 1992). The outcome indicated that depressive symptoms significantly improved after the intervention ( $p < .05$ ).

### **HbA1c**

All papers reviewed included this measure. However, only two papers found significant findings. In the case series conducted by Gonzalez et al. (2004), findings indicated that all patients except for one experienced a decrease in HbA1c between the baseline and post-intervention. Two patients experienced a decrease in HbA1c from above 7 to below 7, which is the treatment goal for most patients. Lustman and colleagues (1998) found that post-treatment HbA1c levels were not different in the CBT and control groups, but 6-month follow-up mean HbA1c levels were significantly better in the CBT group than in the control group (9.5% compared with 10.9%;  $P = 0.03$ ). Georgiades and colleagues (2007) determined

HbA1c using ion exchange HbA1c performance liquid chromatography, a methodology that measures only the A1c fraction of glycohemoglobin (reference range: 4.3% to 6.0%). Baseline tests were conducted in a clinical laboratory that met the requirements certified by the National Glycohemoglobin Standardization Program. To obtain comparison data, patients measured fasting blood glucose before breakfast for a 7-day period before each hospital visit. The patients were given an Accu-Chek Complete meter system (Roche Diagnostics, Indianapolis, Indiana) and they were instructed in its proper use. The data were downloaded into a computer for analysis, and the mean fasting blood glucose level was calculated as the average of the fasting measurements completed within a week of each clinic visit. There were no significant changes in glycaemic control post-intervention.

In the study conducted by Rosselló et al. (2006), glycosylated HbA1c levels were obtained at pre- and post-intervention. HbA1c provides a measure of glycaemic control for the previous 2–3 months. Values above 8% are classified as being an indicator of inadequate or poor metabolic control. There were no significant changes in glycaemic control post-intervention. Bastelaar and colleagues obtained HbA1c data from patients' medical charts via their treating physician. There were no significant changes in glycaemic control post-intervention.

### **Other measures**

Some studies included in this review included other outcome measures. For example, Bastelaar et al. measured diabetes-specific emotional distress using the Dutch version of the Problem Areas in Diabetes (PAID) Scale (Snoek et al., 2000). A significant treatment effect was found for PAID ( $p < .01$ ). Rosselló and colleagues used various other outcome measures. These authors used the Hopelessness Scale for Children (HSC), which is a 17-item scale designed to measure cognitions of hopelessness defined as negative expectations about oneself and the future (Kazdin, French, Unis, Esveldt-Dawson, and Sherick, 1983). They also utilised the Self-Efficacy for Diabetes Scale (SED), which is a 35-item scale designed to measure the self-perception or expectations of competence, power and resources for successful management of type 1 diabetes (Grossman, Brink, and Hauser, 1987). In addition, these authors also assessed diabetes self-care behaviours using the Summary of Self-Care Activities (SSCA), which is a self-report instrument used to measure adherence to diabetes treatment (Schafer, Glasgow, McCaul, and Dreher, 1983), and the Piers–Harris Children's Self-Concept Scale (PHCSCS), which consists of 79 items to be answered “yes” or “no”

(Piers and Harris, 1984). The outcome of this study indicated a significant treatment effect for self-efficacy for diabetes ( $p < .05$ ) and self-concept ( $p < .01$ ).

### **CBT intervention**

Although all studies included in this review were CBT interventions, the nature of the interventions was not homogenous. Two studies used individual-session CBT (Bastelaar et al., 2011; Gonzalez et al., 2004), while three other studies used group-session CBT (Lustman et al., 1998; Georgiades et al., 2011; Rosello et al., 2006). Among the studies that delivered individual sessions, one was delivered face-to-face; one study used a web delivery method (Bastelaar et al., 2011). Moreover, the duration of the intervention also varied from one study to another, ranging from eight sessions to 16 sessions. The delivery of the therapy session also varied. For example, in the study conducted by Lustman et al. (1998), sessions were delivered by one psychologist. Georgiades et al. (2011) had a team of four psychologists, although sessions were led by one psychologist. In the study conducted by Gonzalez et al. (2004), sessions were delivered by a group of professionals, including a psychologist, a nurse educator, and a dietician.

The content of the CBT interventions also varied vastly. Lustman et al. (1998) did not provide details of the content covered in their intervention. Georgiades and colleagues provided participants with training regarding information processing biases (i.e. mood congruent interpretations of events) on behaviour and affect. Participants in this study were taught to take an empirical approach to cognitions, whereby thoughts were evaluated against substantive objective information and alternative explanations for events were articulated. In addition, participants received guidance in communication, problem-solving, and goal-setting skills. Rosello and colleagues (2006) also trained patients on how thoughts affect mood. In addition, patients in this study learned about planning pleasant activities, time management, and goal setting. Patients were also trained on establishing social support networks, communication skills, and assertiveness.

Bastelaar and colleagues (2011) included stress and relaxation techniques, physical activity, anti-rumination techniques, and relapse prevention within their CBT intervention. Gonzalez et al. (2004) used cognitive behavioural therapy intervention for adherence and depression (CBT-AD). Within this intervention, patients were trained on monitoring blood glucose levels and tracking dietary and physical activity behaviours that influence glucose levels. Within the CBT intervention, patients were also taught problem-solving skills and provided

relaxation training such as diaphragmatic breathing and progressive muscle relaxation. Given the heterogeneous application of cognitive behavioural therapy in the studies included in this review, it is impossible to establish a best-practice model of delivery.

## **5. Discussion**

Five studies were included in this review, which evaluated the effectiveness of CBT for treating depressed diabetic patients. No previous systematic reviews have been carried out on this topic. This review found that the quality of two studies reviewed was not optimal. The results reveal diversified application of CBT for depressed diabetic patients. Studies included in this review employed various methodological designs. A meta-analysis was not conducted because of the heterogeneous nature of the studies. It was challenging to draw a definitive conclusion on the effectiveness of CBT for depressed diabetic patients due to this issue. Because of this, the results were presented in a narrative form. This narrative review enabled a comparison and overview of the findings, whereby facilitating an assessment of the effectiveness of CBT for depressed diabetic patients.

In summary, all studies reported that cognitive behavioural therapy had a positive impact on depressive symptoms. However, only two studies found an improvement in HbA1c. One study also demonstrated that CBT interventions improved self-efficacy for diabetes and self-concept. As depression among diabetic patients does contribute towards a poorer quality of life, improvement in depressive symptoms could possibly cause an improvement in quality of life. Depressed diabetic patients have demonstrated non-adherence to the diabetes treatment regimen and self-care behaviour. Improvements in depressive symptoms might not reflect directly on the HbA1c improvement, but could possibly cause an improvement in adherence to the diabetes treatment regimen and self-care behaviour.

There are various aspects of diabetes management, such as managing the relationships between food, physical activity, medications, self-monitoring of blood glucose, blood pressure, regular retinal screening, and targeting goals tailored to individual needs, e.g. around foot care, weight loss, injection techniques, and managing acute complications such as hypoglycaemia and hyperglycaemia. Therefore, the lack of glycaemic control could be attributed to diabetic management factors that were not addressed within the CBT

intervention. Poor glycaemic control could also be attributed to poor knowledge and understanding of diabetes management. Only one study (Lustman et al., 1998) provided diabetes education to patients. It is possible that an improvement in HbA1c was not observed across the studies because patients still had a poor knowledge of diabetes management.

### **Review Limitations**

Studies included in this review reported various methodological issues. For example, only one study had long-term follow-up of more than six months. Thus, it is difficult to establish if the impact of CBT interventions was maintained for a longer period of time. Only two studies included in this review observed a significant decrease in the HbA1c level. Among these two studies, one had long-term follow-up. All studies that did not find a significant decrease in the HbA1c level did not have long-term follow-up. It is possible that not enough time had elapsed between HbA1c assessments to detect a significant change. Furthermore, most studies reviewed had small sample sizes. Consequently, the generalisability of the findings of these studies is uncertain. Only two studies reviewed were a randomised control trial. Due to the lack of a control group in three studies, it is hard to ascertain whether improvement in depressive symptoms was due to cognitive behavioural therapy or improved overtime without intervention. Furthermore, all studies utilised various self-reporting measures, e.g. Beck Depression Inventory, Problem Areas in Diabetes (PAID) Scale, and the 17-item Hamilton Depression Scale. The usage of self-reporting measures elevates the possibility of social desirable bias.

### **Implications for Future Research**

This review clearly highlights the need for more controlled studies with longer-term follow-up to ascertain with certainty the effectiveness of CBT for depressed diabetic patients. In addition, the cost-effectiveness of this therapy as a treatment option for depressed diabetic patients also needs investigation.

In recent years, computerised cognitive behavioural therapy (CCBT) has been used to treat depression. One of the major advantages of CCBT is the ability to provide more treatment choices for patients and faster access to effective mental health services. One study investigated the application of computerised CBT. More research is being published on

CCBT for depressed diabetic patients. Further research on the effectiveness of tailored computerised cognitive behavioural therapy for depressed diabetic patients is needed.

## **6. Conclusion**

This review highlights the need for more studies that focus on cognitive behavioural therapy for depressed diabetic patients. Depression among diabetic patients is a major public health concern. Therefore, it is pivotal to conduct high-quality research to establish the best psychological treatment option to address this issue.

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