The development and evaluation of a web-based diet and diabetes education programme for children with type 1 diabetes

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Abstract

Diabetes education is one of the essential components of standard diabetes care. Rapid advances in technology have made the internet a viable mode for the delivery of educational interventions to young people with type 1 diabetes (T1D). The main purpose of this study was to develop a web-based education programme to assist in diabetes management and to provide support for children with T1D in Malaysia.

The data were collected in three phases using a mix method approach. Participants were children with T1D living in Malaysia (n=64), their parents (n=12), the clinicians (n=3) and Malaysian' children living in Newcastle (n=12). In Phase one, the data were collected using both qualitative and quantitative methods to understand the experiences and challenges which children face living with diabetes and to identify regularly consumed carbohydrate-rich foods. In Phase two, data were gathered by a semi-structured interview and an open-ended questionnaire with healthy children in Newcastle to elicit views and general usability of the programme. In the final Phase, Phase three, children with T1D and their families were recruited and introduced to the programme and guided in its use at home. Semi-structured interviews were conducted with children, parents and clinicians, and the questionnaires were used with children in order to gain participants' views, experiences and acceptance of the system.

Children used the programme for a period of six months. Most children reported using the programme to obtain information about carbohydrate content of the food and drink they consumed and adjusting their insulin accordingly. They also reported they had made changes in their food choices based on the information and knowledge they obtained from the programme. Most of them did not record their blood glucose regularly in the programme. The majority felt confident in managing their diet, insulin, and monitoring their blood glucose, however, a few reported lack of confidence and difficulty managing their diabetes. Clinicians indicated that the programme was feasible to use in the clinic setting to teach and review children' blood glucose and dietary intake, and to support children when they faced any problems related to their diabetes. The clinicians believed that the programme had the most application for children as a self-education and self-management system.

Overall, participants described the programme as useful, accessible and beneficial for managing diet and diabetes. This study demonstrated feasibility of using the web-based education programme. Further research is required to determine the effectiveness of the programme in improving diabetes management of T1D by young people.

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Abbreviations

BG	Blood glucose
CV	Cardiovascular
CVD	Cardiovascular disease
DKA	Diabetes ketoacidosis
DSME	Diabetes self-management education
HbA1c	Glycated haemoglobin
IBCT	Interactive behaviour change technology
ICT	Information and communication technology
ISPAD	International Society for paediatric and adolescent diabetes
M	Mother
MRC	Medical research council
NKS	Nutrition knowledge survey
P	Patient
PDA	Personal digital assistants
PDSMS	Perceived diabetes self-management scale
RIC	Rural internet centre
RCT	Randomised control trial
SCT	Social cognitive theory
SMBG	Self-monitoring blood glucose
T1D	Type 1 diabetes
T2D	Type 2 diabetes
UK	United Kingdom
UMMC	University Malaya Medical Centre
y.o	Year old

Chapter 1 Literature Review

1.1 Introduction

Diabetes is one of the most common non-communicable disease (NCDs). It is one of the top five leading causes of death in most high-income countries and there is substantial evidence that it is epidemic in many economically developing and newly industrialised countries. Diabetes is undoubtedly one of the most challenging health problems of the 21st century (International Diabetes Federation, 2013). Without an effective prevention and management programme, the burden will continue to increase worldwide (International Diabetes Federation, 2013). Type 2 diabetes (T2D) accounts for 85% to 95% of all diabetes cases in high-income countries and may account for an even higher percentage in low- and middle income countries (International Diabetes Federation, 2013). T2D is, therefore, a common condition and a serious global health problem. In most countries, diabetes has increased alongside rapid cultural and social changes: ageing populations, increasing urbanisation, dietary changes, reduced physical activity and unhealthy behaviours (International Diabetes Federation, 2013). Some 382 million people worldwide, or 8.3% of adults, are estimated to have T2D. About 80% of them live in low- and middle-income countries. If these trends continue, it is predicted that by 2035, 592 million people, or one adult in 10, will have diabetes. This equates to approximately three new cases every 10 seconds or almost 10 million per year. The largest increase will take place in the regions where developing economies are predominant (International Diabetes Federation, 2013).

Type 1 diabetes (T1D), less common than T2D, is also on the rise in both rich and poor countries. In most high-income countries, the majority of diabetes in children and adolescents is T1D (International Diabetes Federation, 2013). Worldwide, diabetes is the most common chronic disease in childhood, second only to asthma (Timothy and Nils, 2009). According to the International Diabetes Federation (IDF) T1D is one of the most prevalent endocrine and metabolic conditions in childhood (International Diabetes Federation, 2013). The number of children developing this form of diabetes every year is increasing rapidly, especially among the youngest children (International Diabetes Federation, 2013). About 95% of affected children have T1D, although obesity-related T2D is beginning to appear in teenagers (Timothy and Nils, 2009). Of the estimated 430,000 cases of childhood T1D worldwide, more than one quarter are from southeast Asia (Brink *et al.*, 2007). The demands of this disease imposed on daily life make T1D one of the most challenging medical disorders (Gilbertson *et al.*, 2001). It is very important to get optimal glycaemic control in order to reduce the risk of micro-vascular and macro-vascular complications including retinopathy (eye disease), nephropathy (kidney disease), and heart disease, stroke and various neuropathies (both autonomic and peripheral) (Gilbertson *et al.*, 2001). Good glycaemic control has also been shown to be central to improving quality of life (Hoey *et al.*, 2001). A report from the Children and Young People with Diabetes Working Group claimed that the life expectancy of children with T1D is about 20 years less than for children without the condition, and this reduction is due mainly to cardiovascular disease (Report of the Children and Young People with Diabetes Working Group, 2007).

In T1D, insulin therapy is a life-saving but also lifelong therapy. To maintain health a person with T1D needs to follow a structured self-management plan which includes insulin use and blood glucose monitoring, regular physical activity and a healthy diet (International Diabetes Federation, 2013). In many countries, especially in low-income families, access to self-care tools, including self-management education, as well as to insulin, is limited. This often leads to severe disability and early death in children with diabetes. Many children and adolescents may find it difficult to cope emotionally with their disease. Diabetes can result in discrimination and may limit social relationships. It may also have an impact on a child's academic performance (International Diabetes Federation, 2013). Diabetes also has a psychological impact not only on children but also on their close family members. According to Danne and Kordonouri (2007), poor initial adaptation, depression, anxiety and low self-esteem, predicts ongoing psychological difficulties in children with diabetes (Danne and Kordonouri, 2007). The costs of treatment and monitoring equipment, combined with the daily needs of a child with diabetes, may place a serious financial and emotional burden on the whole family (International Diabetes Federation, 2013).

Results from The Diabetes Control and Complications Trial Research Group (DCCT), showed that it was not easy to achieve optimal glycaemic control in younger populations (The Diabetes Control and Complications Trial Research Group, 1993). According to the recent data from the National Diabetes Audit for England and Wales (2007-2008) more than 80% of children and young people with T1D in the UK do not achieve the National Institute for Clinical Excellence (NICE) glycaemic target criteria of glycated haemoglobin

(HbA1c) of less than 7.5% (NHS The Information Centre for Health and Social Care, 2009). Krone et al. (2009) point out that glycaemic control in UK children is worse than in many other countries in Europe. The reasons for this are not fully established, but are likely to be multi-factorial. Social, economic and healthcare systemic factors along with less intensive glucose and insulin management in the UK may underlie the observed poor glycaemic control (Krone *et al.*, 2009). Managing children with T1D is challenging, due to unpredictable lifestyles, irregular eating patterns, high risk of hypoglycaemia, changing insulin needs, illness, psychosocial aspects associated with age, weight gain and puberty (Danne and Kordonouri, 2007). Youths with T1D transitioning to adolescents (11-14 years) are a particularly vulnerable population compared to youths with T1D at other ages, as they often demonstrate poorer metabolic control, have poor self-management, more social stressors, higher psychosocial distress, and poorer quality of life (Insabella et al., 2007).

To improve diabetes care for the children and young people with T1D there may be a need for an educational programme (Swift, 2009). Education is the keystone for successful diabetes care and is delivered in different ways in different regions and countries (Swift, 2009). Recently, the International Society of Paediatric and Adolescents Diabetes (ISPAD) clinical practice consensus guidelines (2009) have suggested that young children with T1D may be interested in new technologies such as videos, CDs, computer games, text messaging for information, telephone reminders and support (Swift, 2009). Nevertheless, there is little scientific evidence to support widespread use of technologies in managing T1D (National Institute for Clinical Excellence UK (NICE), 2004) and the potential application and utility of such technologies in supporting young people is likely to be, at least in part, culturally specific. To date, as far as the author is aware, standardized and structured educational programmes using information communication technology (ICT) in paediatric diabetes education do not yet exist in Malaysia. The purpose of the current thesis was to develop a web-based diet and diabetes education programme to support the learning of children and adolescents about diabetes management, especially dietary management, and to establish a network of social support. The intention was that this tool could be used by different health care professionals working with children and families of children with T1D (paediatric endocrinologist, diabetes nurse educators and dieticians) allowing the delivery of a standardised dietary education information that could help improve diabetes and dietary management in patients with T1D.

1.2 Diabetes in the childhood population

1.2.1 Definition

Diabetes mellitus is a group of metabolic conditions characterised by chronic hyperglycaemia (high blood glucose) resulting from defaults in insulin secretion, insulin action or both (Craig *et al.*, 2009). Insulin is a hormone produced in the pancreas that allows glucose in the bloodstream to enter into cells and be converted into the energy needed by muscles and tissues to function (Craig *et al.*, 2009). When there is insufficient insulin, the cells start to produce ketones, ultimately causing ketoacidosis (Craig *et al.*, 2009). This can cause coma and eventually death. Inadequate action of insulin on target organs also underlies some of the abnormalities in carbohydrate, fat and protein metabolism observed in diabetes (Craig *et al.*, 2009). Diagnostic criteria for diabetes are based on blood glucose levels and the presence or absence of symptoms (Craig *et al.*, 2009) (Refer to Table 1).

Table 1: Criteria for the diagnosis of diabetes mellitus (ISPAD, 2009; WHO, 1999; reproduced from Craig et al', 2009)

1. Symptoms of diabetes plus casual plasma glucose concentration ≥ 11.1 mmol/L (200mg/dL)*.
   Casual is defined as any time of day without regard to time since last meal.
   or

2. Fasting plasma glucose ≥ 7.0 mmol/L (≥ 126mg/dL)**
   Fasting is defined as no calorie intake for at least 8 hour.
   or

   2-hr post load glucose ≥ 11.1 mmol/L (200mg/dL) during an oral glucose tolerance test (OGTT).
   The test should be performed as described by WHO, using a glucose load containing the equivalent of 75g anhydrous glucose dissolved in water or 1.75g/kg of body weight to a maximum of 75g

*Corresponding values (mmol/L) are ≥ 10.0 for venous whole blood and ≥ 11.1 for capillary whole blood ** ≥ 6.3 for both venous and capillary whole blood.

1.2.2 Diabetes classification

Type 1 diabetes

Type 1 diabetes is caused by an autoimmune reaction, where the body's defence system attacks the insulin-producing beta cells in the pancreas (International Diabetes Federation, 2013). As a result, the body can no longer produce the insulin it needs (International Diabetes Federation, 2013). The mechanism by which this occurs is not fully understood. It usually occurs in children or young adults, however, people of any age can be affected by the disease (International Diabetes Federation, 2013). T1D is insulin-dependent, meaning that treatment with insulin is necessary from the time the disease is first diagnosed (Hanas, 2012). Insulin is given by injection, with syringes increasingly being replaced by insulin pens (Hanas, 2012). Twice-daily injections have been the traditional method of treating diabetes (Hanas, 2012). In general, to provide a more physiological insulin profile, short-acting insulin needs to be given with each meal, and there is also a need for a long-acting insulin (basal insulin) to be given once or twice daily through multiple daily injections (Hanas, 2012). A combination of daily insulin therapy, continuous blood glucose monitoring, a healthy diet, and regular physical exercise can help people with T1D lead a normal, healthy life (International Diabetes Federation, 2013). In the past few decades, the prevalence of T1D has increased. However, the cause of this rise is unknown but might be related to changes in environmental risk factors, early events in the womb, diet early in life, or viral infections (International Diabetes Federation, 2013).

Type 2 diabetes

Type 2 diabetes is the most common form of diabetes. It usually occurs in adults, but is increasingly seen in children and adolescents as well (International Diabetes Federation, 2013). In T2D, the body is able to produce insulin but either this is not sufficient or the body is unable to respond to its effects (also known as insulin resistance), leading to a build-up of glucose in the blood (International Diabetes Federation, 2013). The medication used for treating T2D acts by increasing the body's sensitivity to insulin, or by increasing the release of insulin from the pancreas (Hanas, 2012). Diet, exercise and obesity management are important components when treating T2D (Hanas, 2012). It is rare for insulin injections to be necessary in the early stages of T2D except when there is excessive hyperglycaemia or ketoacidosis at diagnosis (Hanas, 2012). Although T2D is also called non-insulin-dependent diabetes, many people need treatment with insulin at a later stage, in much the same way as people with T1D (Hanas, 2012). There are several important risk factors for developing T2D which are: obesity, poor diet, physical inactivity, advancing age, family history of diabetes, ethnicity and high blood glucose during pregnancy affecting the unborn child (International Diabetes Federation, 2013). In recent years, there has been an increase in the number of people affected by T2D worldwide (International Diabetes Federation, 2013). This rise has been related to economic development, ageing populations, increasing urbanisation, dietary changes, reduced physical activity, and changes in other lifestyle patterns (International Diabetes Federation, 2013).

Monogenic diabetes

According to Hattersley (2009), monogenic diabetes results from the inheritance of a mutation or mutations in a single gene. It may be dominantly or recessively inherited or it may be a de novo mutation and hence a spontaneous case. In children, almost all monogenic diabetes result from mutations in genes that regulate beta-cell function in the pancreas, although diabetes can, rarely, occur from mutations, resulting in very severe insulin resistance (Hattersley *et al.*, 2009). Monogenic diabetes is associated with a strong family history of diabetes, and taking a genetic test should be considered if diabetes is present in several generations of a family (Hanas, 2012). The different types of maturity-onset diabetes of the young (MODY) and neonatal diabetes have been classified into several subcategories. One type of MODY (MODY2) is characterised by a modest increase in blood glucose levels, which often does not require any treatment other than dietary management (Hanas, 2012). Some forms of MODY can be treated successfully with anti-diabetic drugs, while people with other forms of MODY are very likely to require insulin (Hanas, 2012).

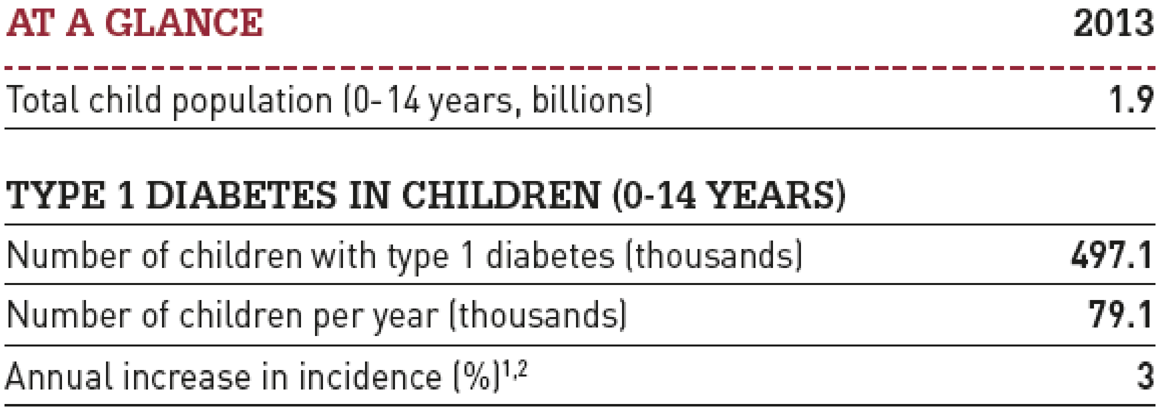
Other forms of diabetes

When the pancreas is affected directly or indirectly by other conditions such as cancer or pancreatitis secondary diabetes can be developed. One of the most common forms of disease-related diabetes is cystic fibrosis-related diabetes (CFRD). Cystic fibrosis results in thick, viscous secretions causing obstruction and damage to the pancreas with progressive fibrosis and fatty infiltration (O'Riordan *et al.*, 2009). In these cases, the dysfunction of the beta cells is not caused by autoimmunity (Hanas, 2012).

1.3 Prevalence of diabetes

The incidence of T1D among children is increasing in many countries (International Diabetes Federation, 2013). Prevalence and incidence figures vary across countries (International Diabetes Federation, 2013). Some 79,100 children under 15 years are estimated to develop T1D annually worldwide (International Diabetes Federation, 2013) (Table 2). Of the estimated 497,100 children living with T1D, 26% live in the European Region, where the most reliable and up-to-date estimates of incidence are available, and 22% in the North American and Caribbean Region (International Diabetes Federation, 2013). Among other International Diabetes Federation (IDF) regions, Europe has the highest number of children with T1D approximately 129,300 (International Diabetes Federation, 2013). The region also has one of the highest incidence rates of T1D in children, with 20,000 new cases per year (International Diabetes Federation, 2013). The United Kingdom, the Russian Federation, and Germany are the top three countries with the highest numbers of young people with T1D (International Diabetes Federation, 2013). Figure 1 shows the number of new cases of T1D in children aged 10-14 years in 2013.

Table 2: Estimated number of children (0-14 years) with type 1 diabetes worldwide (Source: IDF, 2013)



AT A GLANCE	2013
Total child population (0-14 years, billions)	1.9
TYPE 1 DIABETES IN CHILDREN (0-14 YEARS)	
Number of children with type 1 diabetes (thousands)	**497.1**
Number of children per year (thousands)	**79.1**
Annual increase in incidence (%)[1,2]	3

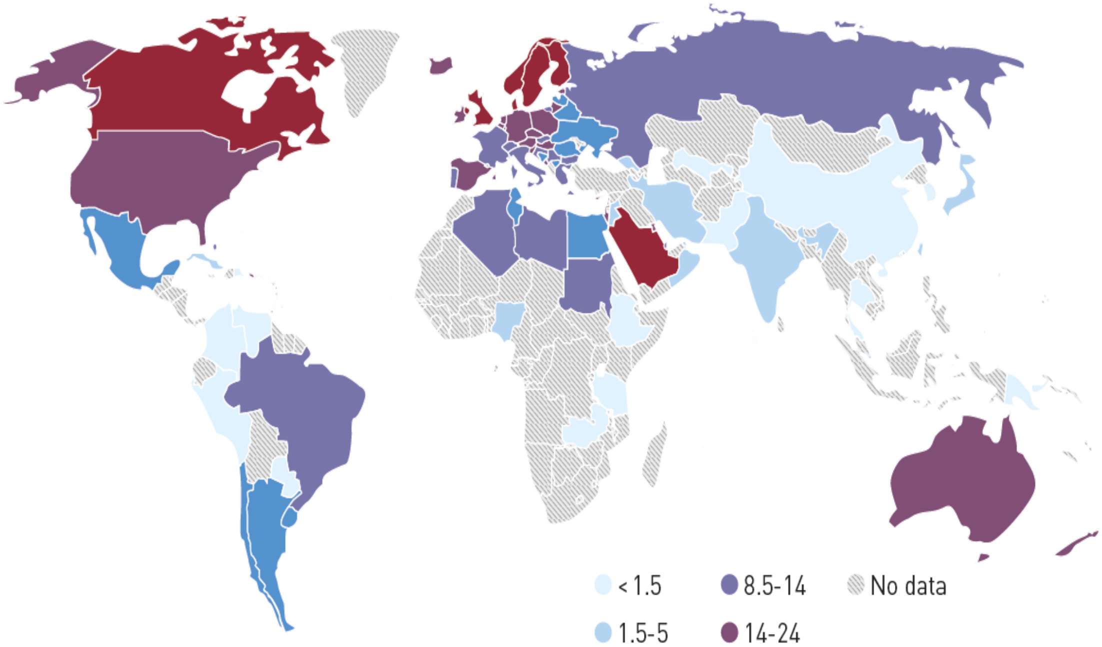


Figure 1: New cases of type 1 diabetes (0-14 years per 100,000 children per year), 2013 Source: IDF, 2013

There are nearly 1.2 million people in Malaysia who have diabetes and an estimated 24,000 people with T1D (Brink *et al.*, 2007). Data from the Diabetes Registry of Malaysia showed that from August 2006 until December 2008 there were 383 cases of diabetes in children aged between 1 and 19 years old (DiCARE, 2006-2008). Of that number, 74% were diagnosed with T1D. The IDF stated that the prevalence of T1D in Malaysia was only 0.3 per 100,000 (IDF Atlas, 2003). This figure is likely to be higher now. Data from the UK show that in 2010 there were 22,000 people in England aged less than 17 years diagnosed with diabetes (Royal College of Paediatrics and Child Health, 2009); of which 97% have T1D. Data from Diabetes UK show that the prevalence of T1D in children in the UK is 100 per 100,000 (Diabetes UK, 2010).

1.4 Glycaemic control

Surveys of glycaemic control from the United Kingdom, Europe, and Australia have consistently demonstrated that many children and adolescents do not achieve good targets for glycaemic control (Mortensen and Hougaard, 1997; Danne *et al.*, 2001; Scottish Study Group for the Care of the Young, 2001; Craig *et al.*, 2002; Cardwell *et al.*, 2005). There is limited information available on glycaemic control in children from Asia. However, data from a study conducted by Maria et al (2007) showed that the mean HbA1c level for children in Asia and the Western Pacific Region was 8.8% (Craig *et al.*, 2002). Data from the National Diabetes Audit for England and Wales stated that in one year (2007-2008) only 17.7% of children from registered centres achieved the treatment target of HbA1c < 7.5%. This suggests that more than four fifths of children do not achieve this target (NHS The Information Centre for Health and Social Care, 2009). In Malaysia, glycaemic control has been found to be unsatisfactory in most children and adolescents. In the annual report from the Diabetes in Children and Adolescents Registry (DiCARE, 2006-2008), it was reported that the median HbA1c was 9.5%. Poor glycaemic control was likely due to the lack of intensification of diabetes therapy, lack of self-monitoring practice and lack of resources to provide diabetes education and activities (DiCARE, 2006-2008).

1.5 Complications

Although the prognosis for diabetes improves with each decade, there is still a considerable risk for long-term diabetes complications (Astrup *et al.*, 2005). The long-term vascular complications of diabetes include micro-vascular and macro-vascular disease. Micro-vascular disease causes retinopathy, nephropathy and neuropathy, while macro-vascular disease causes heart disease and stroke (Hanas, 2012). It is well accepted that development of macro- and micro-vascular complications are related to poor glycaemic control (Hoey *et al.*, 2001). It is therefore important to aim for good glycaemic control from diagnosis (Diabetes Control and Complications Research Group, 1994). The evidence from the Diabetes Control and Complications Trial suggested that a period of poor control can cause lasting damage known as the ‘metabolic memory’ syndrome, even if control later improves. A lower HbA1c reduces the risk but does not remove it completely (Diabetes Control and Complications Research Group, 1994). The risk of developing micro-vascular injury is increased with duration of diabetes in pre-pubertal patients (McNally *et al.*, 1993). This suggest that good glycaemic control is important in all age groups including young people with diabetes (Krone *et al.*, 2009). Figure 2 summarises major complications associated with diabetes.

The International Society for Paediatric and Adolescent Diabetes (ISPAD), has set the target of HbA1c in all age groups to be <7.5% (Rewers *et al.*, 2009). Data from several studies have identified the decreased incidence of complications in many areas with specialised clinics (Bojestig *et al.*, 1994; Rossing *et al.*, 2002; Mohsin *et al.*, 2005). This has occurred over a period of time during which there have been major changes in diabetes management, identification of putative risk factors, and the advent of regular screening for complications (Donaghue *et al.*, 2009). There is no evidence that this is a worldwide occurrence: in areas where health care is not optimal, a greater risk of complications will remain (Donaghue *et al.*, 2009).

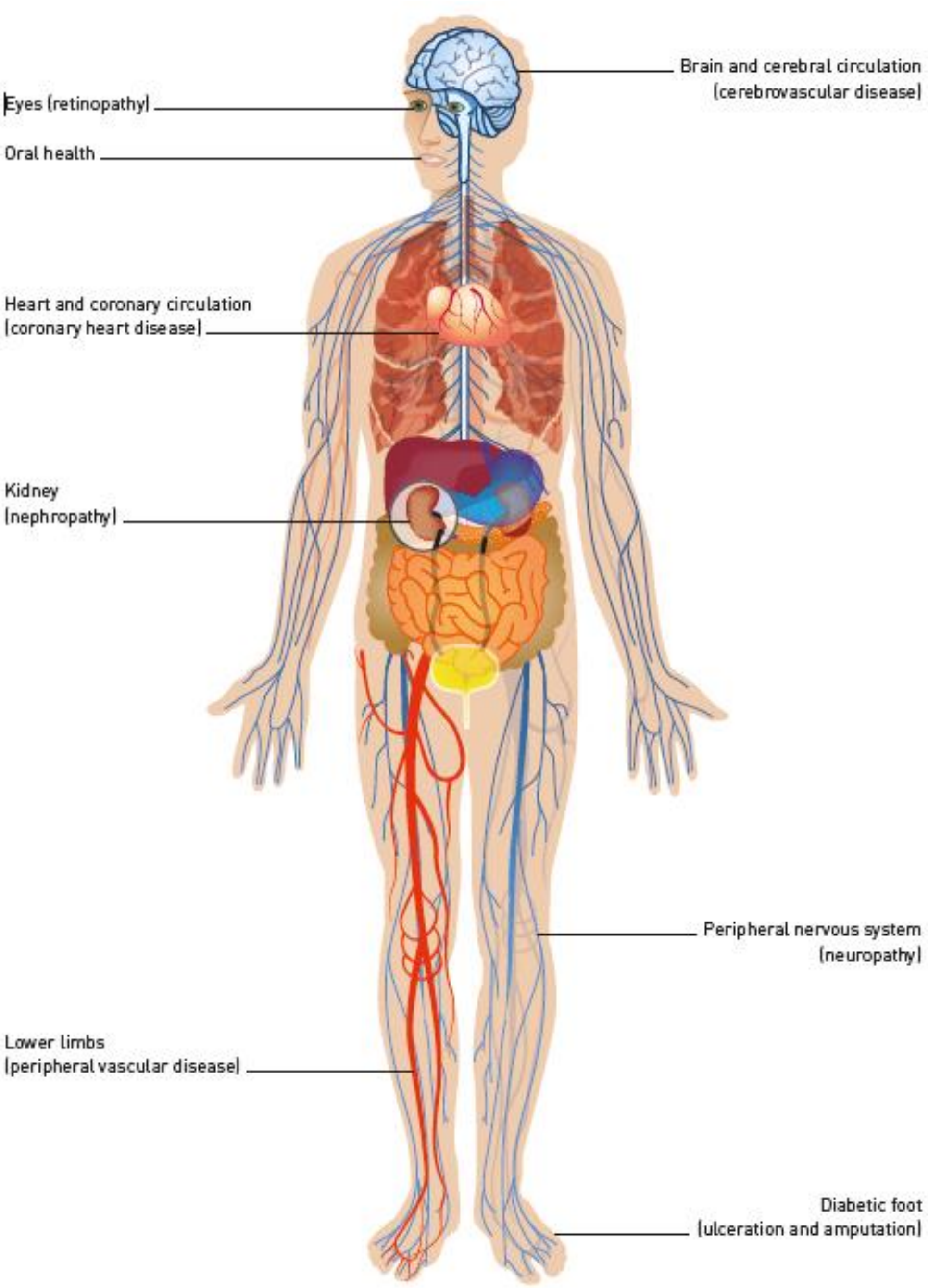


Figure 2: The major diabetes complications (Source: IDF, 2013)

1.6 Diabetes management

Self-management, regular subcutaneous insulin administration for life, together with diet, exercise and lifestyle support plus education are the long-term treatment for T1D (Krone *et al.*, 2009). The main objective of diabetes management is to achieve and maintain good glycaemic control and prevent the occurrence of complications (Glastras et al., 2005). Glycaemic control, which is directly linked to complication rates, is monitored by the measurement of HbA1c, which reflects the mean blood glucose level over the period 2 to 3 month (Glastras *et al.*, 2005). The microvascular and neuropathic complications of diabetes can be reduced by lowering the level of HbA1c (Diabetes Control and Complications Research Group, 1994).

It is generally accepted that in order to effectively manage diabetes, education about components of management including blood glucose monitoring, insulin replacement, diet, exercise, and problem solving strategies must be delivered to the patient and their family ('Erratum: American Diabetes Association: Standards of medical care in diabetes-2006 (Diabetes Care (2006) 29, SUPPL. 1, (S4-S42)),' 2006). The American Diabetes Association (ADA) has published standards regarding diabetes management in children ('Erratum: American Diabetes Association: Standards of medical care in diabetes-2006 (Diabetes Care (2006) 29, SUPPL. 1, (S4-S42)),' 2006) and self-management education (Mensing *et al.*, 2005). Key points are that management should involve a physician-coordinated team of professionals and should recognize the interaction between parent and family, physician, and other members of the health care team. Individual factors (age, schedule, culture, family dynamics, developmental stage, and physiological differences related to maturity) should be considered when developing a treatment plan. The goal for glycaemic control is to self- monitor and to achieve an HbA1c measure as close to normal as possible in the absence of hypoglycaemia. Severe or frequent hypoglycaemia indicates the need to modify treatment regimens, including setting higher glycaemic goals. Since hypoglycaemia is more of a concern in children, the optimum glycaemic goals for children are set according to age and are higher in younger children (Couch *et al.*, 2008).

1.6.1 Self-monitoring blood glucose (SMBG)

Glycaemic control can be assessed by measurement of HbA1c (Rewers *et al.*, 2009). There are several factors which should be taken into consideration when assessing glycaemic control in children such as frequency of hypoglycaemia, type of treatment, patient's age and quality of life (Rewers *et al.*, 2007). It has been suggested that for children, the target should be the lowest HbA1c without severe hypoglycaemia while preventing longer duration of hyperglycaemia and episodes of diabetic ketoacidosis (DKA) (Rewers *et al.*, 2007). This can only be achieved by frequent self-blood glucose monitoring (Rewers *et al.*, 2009). Unfortunately, guidelines on the frequency of monitoring are not given in the ISPAD Clinical Practice Consensus Guideline 2006-2007. However, frequency of SMBG is associated with the quality of glycaemic control, therefore, the importance of regular testing, recording and review of the results is highlighted (Rewers *et al.*, 2007). Improvement of HbA1c in children with T1D is related to the frequency of SMBG. This is thought to be because of both better insulin adjustment for food consumed and an improved ability to quickly correct out-of-target glucose values (Rewers *et al.*, 2009). In addition, early detection of lower glucose values prior to symptomatic hypoglycaemia may allow correction with a decreased risk of overcorrection and resultant hyperglycaemia (Rewers *et al.*, 2007).

1.6.2 Insulin management

The administration of insulin is the initial treatment of T1D (Voltarelli *et al.*, 2007). Patients with T1D have an absolute insulin deficiency and will die from ketoacidosis without insulin replacement (Voltarelli *et al.*, 2007). Silverstein et al. (2005) reported that the management of children and adolescents with T1D has undergone many changes over the past decade which involved broad use of insulin analogues, basal bolus regimens and continuous subcutaneous insulin infusion (CSII) (Silverstein *et al.*, 2005a). In the United Kingdom, data on the use of insulin regimens are not readily accessible (Krone *et al.*, 2009). Data from The Diabetes in Children and Adolescents Registry, Malaysia, reported that only one third of the children were treated with an intensive regimen (more than 3 injections a day), and most children are treated with conventional therapy (less than 3 injections a day) (DiCARE, 2006-2008).

The clinical effectiveness of insulin management continues to be a matter of debate. In the Hvidore Study Group on Childhood Diabetes, two cross-sectional surveys in 21 paediatric diabetes centres from 19 countries in Europe, Japan, North America and Australia were under taken. No improvement in mean HbA1c (8.6% in 1995, 8.7% in 1998 and 8.6% in 2005) was observed across all centres even with the introduction of newer insulin, increased implementation of basal bolus insulin and increased use of continuous subcutaneous insulin injection (CSII) and intensive insulin regimen (Mortensen and Hougaard, 1997; Danne *et al.*, 2001; de Beaufort *et al.*, 2007). Only two centres did show significant improvement in glycaemic control. In one of these centres (in Denmark), improvement in insulin regimen coincided with improved patient education, written patient information, increased number of diabetes nurses and weekly staff meetings, suggesting that all of these factors are necessary to improve overall treatment and achieve adequate metabolic control (Dyrløv *et al.*, 2000). Indeed, numerous studies have shown that in the absence of intensified comprehensive patient education, poor glycaemic control could result even with multiple insulin injections. Conversely, intensive consistent education, together with adjusted food intake, appropriate adjustments of insulin doses and with twice daily insulin injection might help improve metabolic control (Dorchy *et al.*, 1997; Nordfeldt and Ludvigsson, 1997; Dorchy, 2006).

1.6.3 Diet management

It is well recognised that medical nutrition therapy, which consists of nutrition education and counselling which is intended to help people with diabetes achieve optimal blood glucose control, should be individualized (Mehta *et al.*, 2009). Meal planning strategies for T1D emphasize the relationship between prandial insulin dose selection and the anticipated amount of carbohydrate to be so consumed (Mehta *et al.*, 2009). Education can help people to balance and adjust their food choices according to their activity and insulin levels, avoid and treat hyperglycaemia and hypoglycaemia, and adjust meal patterns when feeling ill (Waldron, 2005). Both the source and the amount of carbohydrates in food affect blood glucose levels and insulin response (Waldron, 2005), and meal planning strategies for T1D generally assist patients in understanding the relationship between prandial insulin dose selection and the anticipated amount of carbohydrate to be consumed (Mehta *et al.*, 2009). In general, many factors influence the postprandial blood glucose (BG) response to foods:

composition, starch structure, particle size and cooking methods all influence carbohydrate absorption rate from the small intestine and the resulting postprandial response (Waldron, 2005). Therefore, pre and postprandial BG testing provides important information on the absorption of carbohydrate as part of a mixed meal, and both children and their parents benefit from learning to interpret BG test results and adjust insulin accordingly (Waldron, 2005).

Since the 1980s, evidence has suggested that T1D in young people accelerates atherosclerosis compared with young people without diabetes (Waldron, 2005). This implicates high HbA1c as an independent risk factor in the development of premature atherosclerosis and increased risk of a cardiovascular (CV) event (Waldron, 2005). Studies of young people are limited, but Valsania and colleagues reported advanced atherosclerotic lesions in young people with T1D compared with their non-diabetic peers (Valsania *et al.*, 1991). Therefore, education should include dietary recommendations that improve CV risk factors such as reducing total fat intake and promoting an increased intake of foods containing mono and polyunsaturated fats and reduced intake of saturated and trans fatty acids. Education should also recommend appropriate energy intake for children and adolescents, and regular weight assessment to prevent children and young people becoming overweight (Swift, 2009). Monitoring food choices provides information on dietary changes and helps guide dietary messages (Swift, 2009). The ADA and the International Society of Paediatric and Adolescent Diabetes (ISPAD) suggest that, in combination with the best glycaemic control that could be achieved, the nutritional medical therapy should try to prevent and treat the risk factors leading to vascular complications, by controlling body composition, blood lipids and blood pressure (Aslander-van Vliet *et al.*, 2007). In children, medical nutrition therapy should be provided at diagnosis and reviewed annually to ensure normal growth (Silverstein *et al.*, 2005a).

1.7 Diabetes education intervention in childhood

Educational methods and research into diabetes are important for improving clinical practice (Clement, 1995; Lorenz *et al.*, 1996; Mensing *et al.*, 2005; Silverstein *et al.*, 2005a) and have become a national priority and responsibility of each nation or state (Department of Health (2003); Diabetes UK and Dept of Health, 2005; Lange *et al.*, 2007). Several studies have revealed that intensification of management reduces micro-vascular complications and that intensification needs effective diabetes self-management. In order to be effective, it needs regular and high levels of educational input and persistent support (Diabetes Control and Complications Research Group, 1994; Clement, 1995; Lorenz *et al.*, 1996; ADA Position Statement, 2003; Mensing *et al.*, 2005; Lange *et al.*, 2007). It has been suggested that education is key to diabetes care and structured self-management education is key to a successful outcome (ISPAD Consensus Guidelines 2000).

Educating and supporting patients in managing their daily life with chronic diseases like diabetes mellitus is an important goal of therapy today (Visser *et al.*, 1989). The aim of diabetes patient education is to make patients knowledgeable about the disease, build a positive attitude, and make him or her an active partner in therapy. Diabetic patients need to understand the importance of nutrition, physical activity, self-monitoring of blood and urine, and/or taking medication ('Supplement 1. American Diabetes Association: clinical practice recommendations 2000,' 2000). However, the most relevant objectives are most often prevention of acute and late complications, diabetic foot care, effective insulin regimens and new recommendations for diet and exercise ('Supplement 1. American Diabetes Association: clinical practice recommendations 2000,' 2000). Diabetes patient education programmes have been shown to significantly improve control of the disease and enhance quality of life (Burton and Connerty, 1998). This can be achieved through a global approach to the patient (Maldonato, 1995). It is widely believed that a patient who is educated about his or her health related problem, will have better adherence to treatment plans and have improved health outcomes (Thakurdesai *et al.*, 2004).

In order to effectively manage diabetes, education around components of self-management such as blood glucose monitoring, insulin replacement, diet, exercise, and problem solving strategies must be delivered to the patient (Gage *et al.*, 2004). Education is important both at diagnosis, where there is usually no knowledge base and the patient and their family are given the basic skills for controlling the disease, and throughout the patient’s lifetime, with ongoing attention to self- management skills, screening and prevention of complications, and to new developments in these areas (Gage *et al.*, 2004). Diabetes self-management education (DSME) is considered an integral component of care and is recommended at diagnosis and thereafter (Mensing *et al.*, 2005). DSME helps people with diabetes initiate effective self-care when first diagnosed and also helps people maintain effective self-management as diabetes presents new challenges and as treatment advances become available (Mensing *et al.*, 2005). In children, education must take into account that younger children will require adult supervision. As children mature, it is expected that they take on more responsibility for their own monitoring and care. DSME helps patients optimize metabolic control, prevent and/or manage complications, and maximize their quality of life in a cost effective manner (Mensing *et al.*, 2005).

There are several types of educational interventions, for example didactic education, computer games, board games, cognitive behavioural therapy and telephone calls (Couch *et al.*, 2008). The aim of educational interventions is to improve metabolic control, reduce complications, gain skills in self-management and to improve quality of life (Couch *et al.*, 2008). In 2008, Couch and co-workers conducted a systematic review to determine the effectiveness of diabetes education on metabolic control, diabetes-related hospitalization, complications, knowledge, quality of life and other psychosocial outcomes for children with T1D and their families. In that review, 80 studies were identified from 1980 until 2003. The mean age of study participants ranged from 2.7 to 16 years. The studies' interventions were heterogeneous and included cognitive behavioural therapy, family therapy, skills training and general diabetes education. There were inconsistent results in terms of the effect of education intervention on HbA1c, health service utilization, short-term complications, knowledge, self-management and psychosocial outcome. They concluded that due to heterogeneity of reported diabetes education interventions, outcomes measured, and duration of follow-up, there was insufficient evidence to identify a particular intervention that is more effective than standard care to improve diabetes control or quality of life or to reduce short-term complications. However, they suggested educational interventions were successful in improving various psychosocial outcomes such as social support, coping and self-efficacy.

1.7.1 Technologies in diabetes

According to Piette (2007), the most complex problems faced by health care providers include how to coordinate diabetes services across providers and how to provide effective support for self-management between outpatient visits (Piette, 2007). Diabetes educators and care managers have been a core resource in the vision for reshaping services so that they prevent, rather than just treat, patients' diabetes-related complications (Piette, 2007).

Unfortunately, care management programmes and diabetes education services often struggle with staffing shortages, limited funding, and competing time demands (Piette, 2007). Even under the best of circumstances, clinicians cannot provide the day-to-day support that many people with diabetes need to proactively address self-management problems (Piette, 2007). As a consequence of both resource constraints and acute care-oriented health systems, providers often spend their time only with patients who are either newly diagnosed, in crisis, or the most assertive in advocating on their own behalf (Piette, 2007). To meet the growing need for diabetes care given these realities, health systems must take a broader approach that views patients' care in the context of their social network, culture and community (Fisher *et al.*, 2005).

Interactive behaviour change technology (IBCT) is one potential resource for improving the effectiveness of diabetes management programmes given the very real limits on funding and staffing time (Glasgow *et al.*, 2004). IBCTs include the use of hardware and software to promote and sustain behaviour changes (Glasgow *et al.*, 2004). Personal Digital Assistants (PDA), patient-centred web sites, automated telephone calls, DVDs, and touch screen kiosks have all been used to deliver IBCT (Glasgow *et al.*, 2004). In 2007, Piette published a paper in which he described how IBCT can assist patients and their clinicians in monitoring changes in health and self-care needs, support patients' attempt to make behaviour changes by promoting health and effective self-care, and enhanced communication between patients and potential supports for their disease management (Piette, 2007). Some IBCTs are designed to assist patients in being more independent; thus patients can improve their self-management without assistance from their health care team (Piette, 2007). For example, resources such as electronic medication reminders, meters that provide longitudinal records of patients' glycaemic control, and PDA-based calculators to monitor intake of various nutrients may assist patients with self-regulation and serve as important cues to action (Piette, 2007).

Computers and the internet have emerged as an incredible resource for enhancing communication, and the advantage of many IBCTs is that they can strengthen the potentially critical communication linkages that are shown in Figure 3 (Piette, 2007).

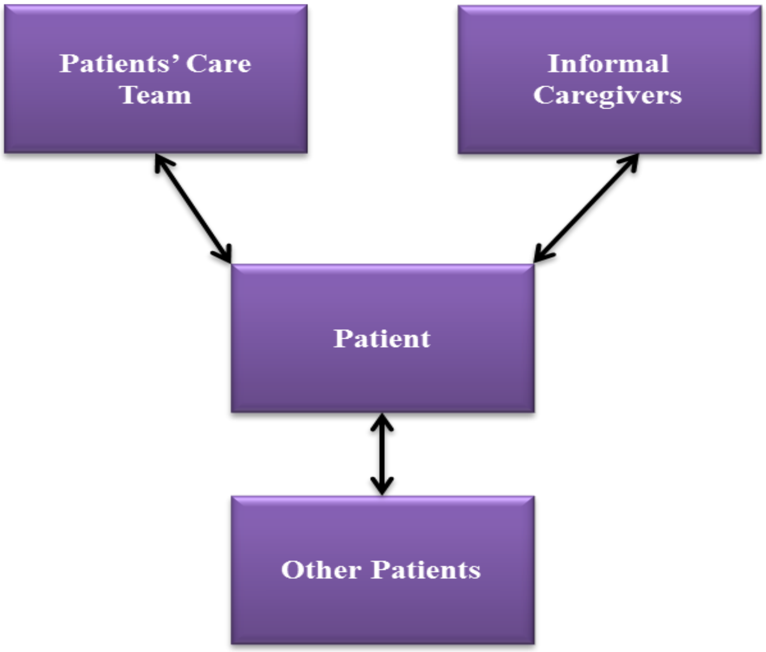


Figure 3: Communication links that could be targeted by Interactive Behaviour Communication Technology (IBCT)

Much of the research on IBCT has focused on improving communication between patients and their care teams using services that allow clinicians to review patients' status and deliver educational messages between face-to-face visits (Balas et al., 2004). Other IBCTs have sought to build connections between patients, often using internet chat and e-mail to enhance mutual support (Balas et al., 2004). Several reviews of IBCT applications to improve chronic illness care have been published, and these generally have been positive (Balas et al., 2004). Balas et al. (2004) reviewed the literature and found that computerized educational programmes improve diabetic patients' diet and metabolic indicators (Balas *et al.*, 2004). Other reviews, including one by the Cochrane Collaboration, have concluded that IBCTs can improve end-users health-related knowledge, perceptions of social support, self-care behaviours, and clinical outcomes (Murray *et al.*, 2005; Dorr *et al.*, 2007; Young *et al.*, 2007). Several studies have shown that chronically ill patients can and will use IBCTs such as automated telephone calls or email to provide valid information about their status over extended periods of time when this information is linked to follow-up by a nurse or nutritional counsellor (Friedman *et al.*, 1996; Piette *et al.*, 2001; Tate *et al.*, 2001; Tate *et al.*, 2003). In each of these randomized trials, researchers demonstrated important improvements in patients’ self-care, physiological outcomes (including weight, glycaemic control, and blood pressure), and even mortality risk.

One question that needs to be asked, however, is whether the user will continue using this service and perhaps continue to improve self-care. Previous studies have reported that fifty percent reductions in log-on to health web sites over less than one year and dropout rates higher than 90% over less than one year have also been observed (Piette, 2007). One study suggests that behavioural intervention programmes delivered over the internet may reach those who need them the least (Verheijden *et al.*, 2007). In another study, Wu et al (2005) found that only 26 of 58 patients used the internet to enter self-care data and communicate with their clinicians over 3 months, and only 4 continued using it after 3 years (Wu *et al.*, 2005). Several studies have reported that most web-based programmes simply do not provide services that are accessible and useful to many patients, particularly those who do not own a computer, speak languages other than English, or have health literacy deficits (Engl *et al.*, 1998.; Bull *et al.*, 2005; Glasgow, 2007). In addition, the benefits of these technologies are not equally distributed across patients. Many patients already have the resources they need to effectively manage their illness and may receive little benefit from the type of support possible through IBCT. At the opposite extreme are patients with problems such as an unstable residence or other serious psychosocial needs who lack the basic resources to take advantage of this additional support (Piette, 2007).

Despite this concern, these technologies are still useful for certain reasons. IBCT has the potential to reach patients who are poorly served by standard outpatient diabetes care. If appropriately designed, IBCTs can deliver diabetes education and monitoring of a consistently high quality across patients, clinicians, and health systems and may alleviate the pressure on a patient’s care team to provide all of the services a patient might require during brief outpatient encounters (Piette, 2007). IBCT can be available to patients where and when they need help and can link patients with resources (e.g. other people with diabetes) that would not be easily accessible without these tools. In short, IBCTs may improve diabetes care through not only increasing patients’ access to the types of services available from their health care team but also by providing completely new resources for helping them cope with their self-care challenges (Piette, 2007). If appropriately designed and delivered, patients with a variety of socio demographic characteristics, including patients with limited functional health literacy or English proficiency, will use IBCT as part of their diabetes care (Schillinger *et al.*, 2008). IBCT may be of greatest benefit to the large number of patients with an interest and basic capacity to improve their diabetes care but who need the additional support for self-monitoring and self-management information that IBCT can provide (Piette, 2007).

Information technology makes it possible for learners to be networked and participate in learning tasks, thus greatly enhancing social interactions, and sharing of learning experiences and resources in a very convenient way (Lubis *et al.*, 2009). Information technology can also facilitate and accelerate monitoring, assessment, and feedback processes in a very fast and efficient way (Lubis *et al.*, 2009). The Malaysian government has introduced various initiatives to facilitate greater integration of information and technology (ICT) to enhance the effectiveness of education and training programmes. Malaysia ranks 17th in the top 25 countries of internet users (Lubis *et al.*, 2009). The growth of ICT users in Malaysia over the last five years was over 60 per cent increasing the number from 3.7 million to about 6 million users (Lubis *et al.*, 2009). Rapid advances in technology and access to the internet have made the internet not only a viable mode for the delivery of educational interventions, but a platform that can be widely disseminated and reach diverse children and adolescents with T1D. Access to the internet is becoming increasingly available nationwide and has risen to its highest level ever, with 93% of youth using the internet regularly (Grey *et al.*, 2012). The internet therefore, represents an efficient way to deliver educational interventions for diverse adolescents with T1D (Grey *et al.*, 2012). Although the number of internet programmes for paediatric diabetes education is limited, they show promise in improving outcomes as shown in Table 3

Table 3: Study intervention on paediatric diabetes using Interactive Behaviour Communication Technology (IBCT)

Author	**Methods**	**Patients' characteristics**	**Details of Interactive Behaviour Change Therapy (IBCT)**	**Intervention group**	**Outcome measures**	**Results**
1. Brown 1997 (Packy & Marlon)	RCT 2 arms: intervention versus control	59 children with diabetes aged 8 to 16. Intervention group n=31 Control group n=28	Interactive computer program in video game format. Information about self-care is provided in the form of multiple choice quizzes and behaviour change support is provided through role playing within the game.	Received in home access to a video game system and the video game Packy & Marlon to play on it for a period of 6 months Received in home access to a video game system and entertainment video game to play on it for a period of 6 months	Self-efficacy, social support, knowledge score, diabetes self-care rating scale, HbA1c, number of urgent care visit.	Knowledge score ↑in intervention group. Social support ↑in intervention group. Self-efficacy ↑ in intervention group. Diabetes self-care rating scale better than control group. HbA1c ↓ in intervention group. HbA1c ↑ in control group.
2.Horan 1990 (DISC)	RCT 2 Arms: Intervention versus Control	20 adolescents aged 12 to 19 with type 1 diabetes for > I year. Intervention group n=10 Control group n=10	A microcomputer based system giving in home access via a provided computer terminal. DISC contains 3 components. Information is provided via factual and applied diabetes education; behaviour change support is provided via goal setting; and problem solving functions and facilities for reviewing self-monitored, blood glucose, exercise, diet, emotional stress.	Used the computer at home for a period of 15 weeks, spending 7 weeks on diabetes education model and focusing on the goal setting and problem solving module for the last 8 weeks. Received conventional diabetes education via an education booklet	Applied diabetes knowledge score, behaviour change exercise, diet, insulin, emotional stress, physical stress, weight, hormones, alcohol and drugs	Applied diabetes knowledge score improved in intervention group ↑. A higher proportion of participants in the intervention group had changed their exercise behaviour compared to control group.

Author	**Methods**	**Patients' characteristics**	**Details of Interactive Behaviour Change Therapy (IBCT)**	**Intervention group**	**Outcome measures**	**Results**
3.Franklin VL et al. 2006 (Sweet Talk)	RCT 3 Arms	126 children and adolescents aged 8-18 with type 1 diabetes	Sweet Talk is a motivational support network, using text messages through a mobile phone, to deliver behavioural intervention to support patients. Sweet Talk, a text messaging support system designed to enhance self-efficacy, facilitate uptake of intensive insulin therapy and improve glycaemic control. Goal setting at clinic visits was reinforced by daily text messages from Sweet Talk software system containing personalized goal specific prompts and messages tailored to patients' age, sex and insulin regimen.	Conventional insulin therapy (CIT) plus usual care and access to emergency hotline. Conventional insulin therapy and the Sweet Talk plus usual care plus goal setting at clinic. Intensive insulin therapy (IIT) received carbohydrate counting education and Sweet Talk plus goal setting at clinic.	HbA1c, self-efficacy, self-reported adherence.	HbA1c did not change in patients on conventional therapy with or without Sweet Talk, 10.3 (1.7) vs 10.1 (1.7), but improved in patients on intensive therapy and Sweet Talk 9.2 (2.2), P< 0.001. Sweet Talk was associated with improvement in diabetes self-efficacy (conventional therapy 56.0 (13.7), conventional therapy plus Sweet talk 62.1 (6.6), P = 0.003 Improvement in self-reported adherence (conventional therapy 70.4 (20.0), conventional therapy plus Sweet Talk 77.2 (16.1), P = 0.042
4.Graue et al. 2005	RCT 2 Arms: Intervention versus Control	83 adolescents aged 11-17 with type 1 diabetes Intervention group n= 45 Control group n= 38 Diabetes duration (ranged 1-16 years)	The program focused on three main aspects: patient experience and peer support, parental experience and family functioning, and knowledge of diabetes. The patients were randomized to an intervention group (structured educational and counselling program) or a control group (traditional care).	The intervention group was invited to 15 months program comprising group visits and computer assisted consultation. The education and counselling process was aimed at providing adolescents with information, re-education and support in	HbA1c, Child-health questionnaire (CHQ-CF87) and Diabetes quality of life questionnaire (DQOL)	HbA1c End of intervention (-) 0.35 (1.59) vs (+) 0.09 (1.19) NS, *p* = 0.15 24 months after study start (-) 0.37 (1.52) vs (-) 0.08 (1.31) NS, *p* = 0.15 No significant difference between two groups. There were significant age by randomization group interactions for diabetes-

				relation to individual needs. The control group was offered traditional out-patient consultation.		related impact (P = 0.018), diabetes related worries (P = 0.004), mental health (P = 0.046) and general behaviour (P = 0.029). Intervention was effective in older adolescents (13-14 years old).
5.Mulvaney et al. 2010 (YourWay)	RCT 2 Arms Intervention versus Control	52 adolescents aged 13-17 with type 1 diabetes Intervention group (n= 34) Control group (n= 18)	Your Way is an internet-based program to improve adolescent problem solving, self-management, and glycaemic control. Intervention component were designed based on based on learning, social cognitive and self-determination theories. During 11 weeks, six multimedia stories depicted psychosocial barriers to self-management and approaches to coping and problem solving. Participants were prompted twice to complete problem solving cycles for personal barriers to self-management. Other activities included personalized homepage, multimedia presentations on the steps of problem solving and how to use the website, social network via a peer forum, social comparison of their responses compared with other adolescents, help from a problem solving expert and weekly email that encouraged participants. Participants had no interaction with diabetes clinician or parents through the website.	Intervention groups received usual care plus internet based problem solving and self-management support. Control group received usual care.	Problem solving, self-management, HbA1c.	The intervention group HbA1c remained constant 9.1 (1.9) vs 9.1 (1.8) pre and post intervention. Control group showed worsening values 8.2 (1.2) vs 8.5 (1.3) pre and post. P = 0.27 Problem solving improved by intervention group 3.5 (0.5) vs 3.6 (0.5) pre and post Control group 3.4 (0.6) vs 3.3 (0.7), P = 0.23. Self-management adherence improved compare to control group. Intervention 3.7 (0.4) vs 3.9 (0.4) Control 3.7 (0.4) vs 3.7 (0.5), P = 0.02). The stories were rated as highly relevant and realistic.

Author	Methods	Patients' characteristics	Details of Interactive Behaviour Change Therapy (IBCT)	Intervention group	Outcome measures	Results
6.Gerber et al. 2007 (STYLE)	Cross sectional study	19 adolescents aged 19 to 26 with type 1 diabetes and type 2 diabetes.	STYLE is an online program consisting diabetes education, goal setting exercises with individualized feedback, role playing, group discussion, empowerment activities and communication skills training to improve interaction with health professionals. Program also contained 'Ask the expert' segment for participants to consult psychologist, patient advocacy expert and social worker.	Each week a diabetes educator introduced a new educational module, with an activity and feedback form. Discussion board monitored by diabetes educator to provide encouragement, discuss clinical and logistic problem and prevent sharing of misinformation regarding diabetes management among participants. They also received encouragement and computer use reminder from diabetes educator.	Comments and feedback, time spent on modules, usage patterns using the software.	Participants accessed the program 4,445 times, discussion board received greatest activity (2,256 total posted and read message). Participants used the program most frequently at night, with an overall gradual decline in computer use over 6 month period. Social (emotional) support was dominant theme for discussion board followed by informational support and exchanged of stories. After end of intervention, 12 subjects (63%) attended individual or group feedback session. Half of subjects felt that the modules were very easy or easy to complete. 8 of 12 subjects (67%) reported trouble completing module activities due to work, school and family commitments, 12 (100%) participants indicated the modules very helpful. 10 (83%) stated they experienced greater control of their diabetes.

						83% participants felt comfortable discussed diabetes with doctors. Three (25% participants stated STYLE improved communication with their providers.
7.D.B. Nicholas et al. 2012	Mixed method evaluation study. RCT: 2 Arms Experimental group versus control group.	31 adolescents aged 12 to 17 with type 1 diabetes. Control groups n = 16 Experimental group n = 17	Online education and support website for adolescents with type 1 diabetes comprised three integral components: diabetes based information, interactive learning activities and discussion topics relevant to adolescents. Module included self-care, transitional issues, dealing with bullying, diabetes management strategies, managing difficult situations and constructive relationship formation.	Experimental participants discussed module-based topics in an online forum. Online peer-to-peer dialogue was moderated by social worker experienced in paediatric diabetes. Moderator conveyed weekly topics for discussion and invited participant dialogue during ‘quiet times’ in the forum.	Children’s inventory of social support (CISS) before and after intervention. Post intervention qualitative interviews with experimental group. Open ended questions addressing perceived impacts of website use, facilitator and barriers to participation, process that fostered or limited beneficial outcomes, and usefulness of website as diabetes education and social support.	Participants described personal benefit from online intervention. The website was viewed as a resource for health information, peer support and the normalization of diabetes. Participants stressed the critical need for information and emotional support that directly relates to key areas of struggle for youth with diabetes, such as dietary and treatment information, and support for dealing with bullying. Pre-post intervention scores of CISS indicated post-intervention gains approaching significance at 5% alpha level, in awareness of relationships with others outside of participants family (P = 0.052) Computer problems, busyness, difficulty logging, loss of usernames or password were the reason for less participation.

Author	Methods	Patients' characteristics	Details of Interactive Behaviour Change Therapy (IBCT)	Intervention group	Outcome measures	Results
8. Rami et al. 2006 (VIE-DIAB)	A randomized crossover study Intervention group (n=18) versus Control group (n=18) and switched group after 3 months	36 adolescents aged 10 to 19 with type 1 diabetes. Duration diabetes > 1 year.	VIE-DIAB is a telemedical (TM) support program. Patients were instructed to measure at least four blood glucose values per day. They were advised to send their data (date, time, blood glucose, carbohydrate intake and insulin dosage) every time they measured a blood glucose value or at least once daily. VIE-DIAB collects and process data on blood glucose value, insulin dosage, carbohydrate intake and additional notes received from mobile phone services (SMS, GPRS, WAP) or password-protected internet connection. Patients were received an automatically generated SMS or personalized message with more specific advice based on their blood glucose target. Advised were conducted by two diabetologists.	One group started using the VIE-DIAB system (TM) and weekly advice for 3 months, and then switched to the routine scheme with a daily written protocol (paper diary, PD) and a clinical visit after 3 months (TM-PD group). The other group started with their PD and switched thereafter to TM (PD-TM group). During the PD-TM phase no additional contact scheduled to or from the clinic. 3 months with TM and another 3 months with conventional support and paper diary	HbA1c at 0, 3 and 6 months, complications (severe hypoglycaemia and diabetic ketoacidosis (DKA)) and patient satisfaction survey	HbA1c improved during the TM phase while deteriorated during the PD phase. TM-PD group: HbA1c (%, median range): 9.05 (8-11.3) at 0 month, 8.9 (6.9-11.3) at 3 months and 9.2 (7.4-12.6) at 6 months. PD-TM group: HbA1c 8.9 (8.3-11.6), 9.9 (8.1-11), and 8.85 (7.3-11.7). P<0.05. Severe hypoglycaemia and DKA was similar in both groups: no severe hypoglycaemia but two events DKA, one during TM phase and one during PD phase. Overall satisfaction was good. The patients mainly criticized the additional workload and GPRS access problems.

Author	**Methods**	**Patients' characteristics**	**Details of Interactive Behaviour Change Therapy (IBCT)**	**Intervention group**	**Outcome measures**	**Results**
9.Grey M et al. 2012 (TEENCOPE) versus Managing diabetes.	A randomized control trial.	A total of 300 youth aged 11-14 with type 1 diabetes will be recruited for 2.5 years.	TEENCOPE is an internet coping skills training program. It is focus on the coping skills of problem solving, social skills training, cognitive behaviour modification, assertive communication, stress reduction, and conflict resolution. Each session is interactive and takes 30 min to complete. Upon completion of session, response to interactive aspects will be posted on a personal profile so that participants will be able to access each other's responses and learn from each other. At the end of each lesson, participants will be asked to practice the new coping skills and to share experiences on a discussion board. A moderator will provide feedback to participants to promote positive coping skills and assure that postings are appropriate.	Participants will be randomized to TEENCOPE or the internet diabetes education program. Both programs consist of 5 weekly, interaction sessions that participant complete asynchronously. They will be allowed to access the intervention sites for approximately 3 months. After 12 months data collection will be completed and participants will encourage to crossover and complete the alternate program. The difference between the Managing diabetes (as control) and TEENCOPE websites are in the contents (Diabetes education versus coping skills) and in the use of virtual role model in TEENCOPE. TEENCOPE allowed participants to obtain feedback from peers as well as professionals, while Managing diabetes has no interaction and no discussion board.	Data will be collected at baseline, 3,6,12 and 18 months. Primary outcomes are metabolic control, quality of life and family conflict. Secondary outcomes include stress, coping, self-efficacy and social competence plus usage, satisfaction and cost.	In progress.

The revolutionary advances in interactive technology can increase the scope and impact of health promotion programmes (Bandura, 2004). Long term success can be maintained by social support and guidance during early periods of personal change (Bandura, 2004). Interactive computer assisted feedback provides a convenient approach for informing, enabling, motivating, and guiding people in their efforts to make lifestyle changes. Feedback can be personalized and adjusted based on participants' efficacy level, the unique impediments in their lives, and the progress they are making. Individualized printed communications, telephone counselling and linkage to a supportive social network are examples of feedback forms (Bandura, 2004). Several key priorities in the care of young adults with diabetes have been proposed. First, to develop a strong relationship that will ensure continued follow-up to promote change in self-care behaviour and second, to work in partnership with the patient to establish treatment goals that will foster a sense of success, self-efficacy, and engagement in self-care (Bandura, 2004).

1.8 Theory based interventions

Effective public health intervention and chronic disease management programmes help people maintain and improve health, reduce disease risks, and manage chronic illness (Rimer and Glanz, 2005). Unfortunately, some of the health programmes and initiatives are unsuccessful (Rimer and Glanz, 2005). Programmes which are based on a clear understanding of targeted health behaviour and the environmental context in which they occur are able to achieve the desired outcomes (Rimer and Glanz, 2005). Behaviour change theory can play a critical role throughout the programme planning process. In order to be effective, an intervention must be theory- and evidence-based. Theory gives planners tools to design and evaluate health behaviour and health promotion interventions based on understanding of behaviour. The use of theory ensures that the relevant behavioural determinants are targeted by applying the appropriate behaviour change techniques (Rimer and Glanz, 2005).

Golley et al. (2010) reviewed the literature from the period 1998 until 2008 and examined the behaviour change theory underpinning interventions to improve children's weight related nutrition intake or activity pattern. The most common theories used were behavioural learning theory, social cognitive theory and health education model (Golley *et al.*, 2010). The majority of these studies also used the behaviour change techniques classified by Abraham and Michie (2008) for the intervention in order to make sure the relevant behavioural determinants were targeted. Abraham and Mitchie (2008) developed and validated a comprehensive taxonomy of 26 behaviour change techniques with standard definition used in behaviour change intervention (Abraham and Michie, 2008.) Table 4 summarizes the most prevalent theories, focus and key concepts.

Table 4: Summary of the most prevalent theories, focus and key concepts (Rimer and Glanz, 2005)

	Theory	**Focus**	**Key concepts**
Individual level	***Health Belief Model***	Individual's perceptions of the threat posed by a health problem, the benefits of avoiding the threat, and factors influencing the decision to act.	Perceived susceptibility Perceived severity Perceived benefit Perceived barriers Cues to action Self-efficacy
	Stages of Change Model	Individual's motivation and readiness to change a problem behaviour	Pre contemplation Contemplation Decision Action Maintenance
	Theory of Planned Behaviour	Individual's attitudes toward a behaviour, perceptions of norms, and beliefs about the ease or difficulty of changing	Behaviour intention Attitude Subjective norm Perceived behavioural control
	Precaution Adoption Process Model	Individual's journey from lack of awareness to action and maintenance	Unaware of issue Unengaged by issue Deciding about acting Deciding not to act Deciding to act Acting Maintenance
Interpersonal Level	***Social Cognitive Theory***	Personal factors, environmental factors, and human behaviour exert influence on each other	Reciprocal determinism Expectation Self-efficacy Observational learning Reinforcements
Community Level	***Community Organization***	Community-driven approaches to assessing and solving health and social problems	Empowerment Community capacity Participation Relevance Issue selection Critical consciousness
	Diffusion of innovations	How new ideas, products, and practices spread within a society or from one society to another	Relative advantage Compatibility Complexity Observability
	Communication Theory	How different types of communication affect health behaviour	Media agenda setting Public agenda setting Policy agenda setting Problem identification

The use of behavioural change theory in the design of a computer based education programme is important in order to ensure the success of this approach (Peng, 2009). Many recent behavioural interventions have drawn heavily upon Social Cognitive Theory (SCT) (Bandura, 2004). Social cognitive theory states that health behaviours are influenced by self-efficacy, or the belief in one's ability to perform actions that will influence outcomes, which, in turn, is influenced by goal setting and social support. This can lead to changes in knowledge for improved health or health behaviours, affective parameters and self-efficacy. The combination of enhanced self-efficacy with motivation and knowledge may enable adolescents and young adults to change their health behaviours, which in turn, may change some clinical outcomes (e.g. HbA1c) (Bandura, 2004).

Self-efficacy is a focal determinant because it affects health behaviour both directly and through its influence on other determinants. Efficacy beliefs influence goals and aspirations. The stronger the perceived self-efficacy, the higher the goals people set for themselves and the firmer their commitment to them. Self-efficacy beliefs shape the outcomes people expect their efforts to produce. Those of high efficacy expect to realize favourable outcomes. Those of low efficacy expect their efforts to bring poor outcomes. Self-efficacy beliefs also determine how obstacles and impediments are viewed. People of low efficacy are easily convinced of the futility of effort in the face of difficulties. They quickly give up trying. Those of high efficacy view impediments as surmountable by improvements of self-management skills and perseverant efforts. They stay the course in the face of difficulties (Bandura, 2004). Most of the models or theories of health behaviour are concerned only with predicting health habits; they do not describe how to change health behaviour. Social cognitive theory offers both predictors and principles on how to inform, enable, guide and motivate people to adopt habits that promote health and reduce those that impair it (Bandura, 1997). This theory describes a dynamic, on-going process in which personal factors, environmental factors, and human behaviour exert influence upon each other (Rimer and Glanz 2005).

1.8.1 Children as an informer and user

Over the past fifteen years, there has been a proliferation worldwide of research on the technology design process with children (Druin, 2002). Nowadays it is more common that children have long term involvement in the design process, not only as a tester and user but also as an informer and designer. Druin (2002) has a set taxonomy for the role of children in the design process. In this conceptualisation, there are four main roles that children can play in the design of their technology as a user, tester, informer and design partner. As users, children may be able to play with the technology and tell or show the designer what they like and do not like about it. However, there is generally very little room for revision of the technology. Meanwhile, as a tester, children can test the technology in the early phases of the design process. The advantage is that designers can gather input from the children earlier in the design and development process. As informers, children can be called at any time during the design process and as a designer partner children are considered to be equal participants in the design process with the adult designer (Druin, 2002).

1.9 Rationale for the study

My Diabetes is a web-based diet and diabetes education and support programme that aims to improve self-efficacy and self-management skills. Self-management for diabetic patients is the skill to manage dietary intake, insulin injection and monitoring blood glucose. The E-learning in this programme component will give instructions and help children and adolescents to use and improve their skills in dietary management and enhance their self-efficacy. My Support Group component contains support from diabetic peers who will act as role models and motivators. The interaction with the health care professionals (HCP) will reinforce the use of and improve self-efficacy skills and self-management. The development of components will also be facilitated by social cognitive theory. Social cognitive theory is used because only this theory emphasises the relationship of self-efficacy beliefs, social/environmental factors and behaviours which other theories do not include. All of these factors directly and indirectly promote behaviour changes and may assist children and adolescents to improve self-management of diabetes, thereby ameliorating clinical outcomes. For the development of this web programme, children will be involved as an informer, tester and end user. This study will develop a web-based diet and education programme and support system for children with T1D in UMMC, Malaysia. The system will include various components including the *'Diabetes diary'*, *'E-learning'*, *'E-consultation'* and the *'Forum'*.

Based on the literature review, consultation with experts in Malaysia, and observation during seminars and conferences in Malaysia and international conferences, this is the first web-based diet and diabetes education and support programme which aims to assist children and adolescents to improve diet and diabetes self-management in Malaysia. This programme is intended to support the education programme in the paediatric endocrine department in the University Malaya Medical Centre (UMMC), Malaysia. As a clinical dietician with 15 years of experience working with children and adolescents with diabetes in UMMC, there are several problems that have been identified in the paediatric endocrine department, UMMC, Malaysia which this system would help to address.

1. There is a lack of health care professional (HCP) staff in the paediatric diabetes team, for example Paediatric endocrinologists and doctors, nurse educators and also clinical dieticians. Priority is given to educating newly diagnosed patients, and not all follow-up patients can be seen again for re-education and reinforcement due to time constraints. Follow-up is every 3 months therefore patients have many things to discuss and so consultation times are sometimes more than one hour for each patient. By using this web-based programme, the HCP will be able to provide diabetes information and support for self-care management between outpatient visits. Children and adolescents will be able to seek information and education at anytime and anywhere without needing to wait until their outpatient visit and consultation day.
2. There is no standardised education tool for dietary management for patients with T1D. Individual HCP use their own educational tools for teaching and counselling. This leads to inconsistencies, for example, they may give conflicting information about the number and timing of blood glucose tests (before and after meals versus only before meals), inconsistent dietary advice (count only carbohydrate versus consider impact of glycaemic index and macronutrients on carbohydrate availability and absorption rate).
3. The patients will be given paper-based education tools by the HCP during consultation. However, not all patients keep these education tools. Some patients may lose the tool and are therefore unable to use information for managing their diet or diabetes, and they will request new ones. A web-based programme may make the information more consistent, reliable and accessible.
4. Currently HCP and patients use the Atlas of food exchanges and portion size book developed by Suzana et al (2009) to obtain information about carbohydrate content

of foods in Malaysia. However, this book contains insufficient information about common foods, snacks and drinks consumed by children and adolescents in Malaysia. In addition, patients or their family must purchase this book.

5. When parents and patients have a problem related to diabetes, they will call a doctor or HCP to seek advice. By using this web programme, parents and patients will be able send their question to their HCP and have it answered more promptly.
6. Some patients do not bring their paper-based food and blood glucose monitoring diary to the clinic for their appointment. Therefore, the HCP is not able to adjust the insulin or diet accordingly. By using the web programme, HCP are able to obtain patient's data via the computer and internet.
7. Once the website is completed, maintenance will take less effort and it will be cost effective and easy to update. The content of the website can be updated regularly with less cost involved.
8. Most of the children and adolescents with T1D do not meet or know other children and adolescents with the same problem even though they have been treated in the same hospital. They only meet each other during the diabetic camp organized by the UMMC paediatric department. However, not all of them have the opportunity to attend. This web-based programme will be developed with a facility for social networking for the children and adolescents to share their experiences and information, and support each other.

Considering these problems and acknowledging the need for evidence-based treatment strategies in children and adolescents with T1D, an education and support programme for children and adolescents aged 10-14 years was developed. Although online education provides an informative and supportive environment and is a popular alternative to traditional methods limited research has been conducted in this area in Malaysia. In line with Vision 2020, Malaysian's health care is to be transformed. The emergence of internet technology has encouraged hospitals in Malaysia to take advantage of this technology to restructure their operation. UMMC is one of the hospitals in Malaysia implementing Hospital Information Technology (HIS) in their operation. By applying this technology it is hypothesised that it will increase patient interaction and satisfaction, improve workforce effectiveness, and maximise their infrastructure investment. By developing this web-based programme it may potentially improve and support the patient education programme in UMMC. This education programme is the first web-based diet and diabetes education and support programme for paediatric patients with T1D in the UMMC.

1.9.1 Research project, aims and objectives

This project will be conducted in three Phases (See Figure 7, 20 & 21 for Study flow chart & Work plan for each phase)

1. Phase One –Establishing the requirements of children and adolescents with T1D in Malaysia
2. Phase Two –Testing the feasibility of a web-based diet and diabetes education and support system with Malaysian children in Newcastle, United Kingdom
3. Phase Three –Evaluation of the web-based programme in Malaysia (a cross sectional feasibility study)

The study design is based on the MRC Framework (2008) and will include the development and feasibility process (Figure 4). A randomised control trial of effectiveness and implementation is beyond the scope of this PhD study and will be considered for future work.

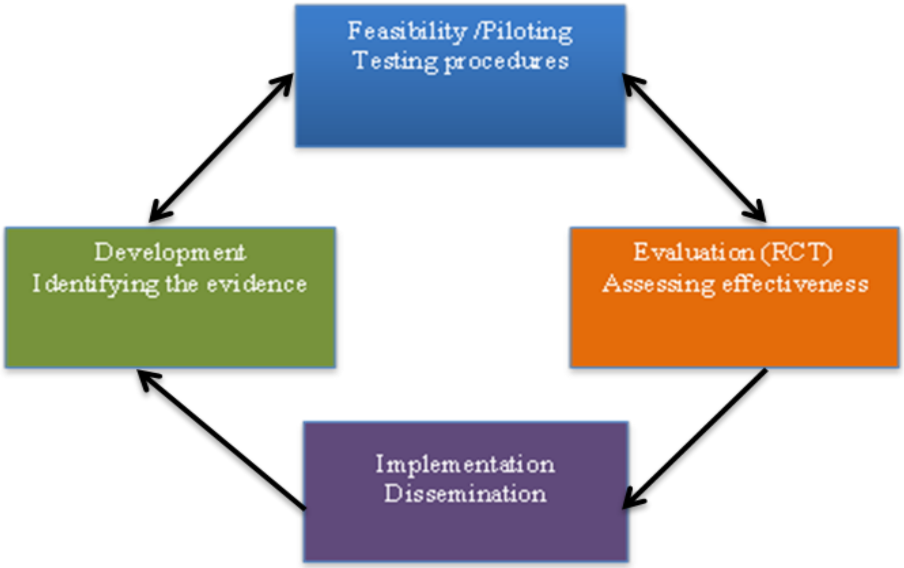


Figure 4: Key elements of the Medical Research Council (MRC) framework of complex intervention studies

Aims and objectives

This study has one primary aim and one secondary aim

Primary aim

To develop a web-based diet and diabetes education programme to improve dietary management of children and adolescents with T1D in UMMC, Malaysia and provide facility for a social network of support.

Secondary aim

To evaluate the impact of this programme on children and adolescents' nutrition knowledge, dietary intake and self-efficacy in management of their T1D.

Objectives

1. To establish the requirements of children and adolescents living with T1D in Malaysia, for a web-based diet and diabetes education programme.
2. To design and develop educational components and other components of the web-based diet and diabetes education programme.
3. To test the general usability and acceptability of the web-based diet and diabetes education programme with non-diabetic Malaysian children and adolescents living in Newcastle.
4. To evaluate the impact of this programme in improving dietary management, nutrition knowledge and self-efficacy of children and adolescents with T1D in UMMC, Malaysia.
5. To test the general usability and acceptability of the programme with children and adolescents with T1D and their parents in UMMC, Malaysia.
6. To test the acceptability and usability of the programme among HCP to teach and support their children and adolescents with T1D in UMMC, Malaysia.

1.9.2 Research questions

1. Is the web-based diet and diabetes education programme practical for use by children and adolescents with T1D at home as a diabetes self-management, education and support programme?
2. Is the web-based education programme able to improve nutrition knowledge, dietary intake and self-efficacy of children and adolescents with T1D?
3. Is the web-based education programme practical for use by HCP in the clinic to monitor and support their patients?

Chapter 2 Methods

2.1 Research design and mix methods research

In 2009, Creswell (2009) published his book wherein he defined research design as: *“research designs are plans and the procedures for research that span the decisions from broad assumptions to detailed methods of data collection and analysis”* (Creswell, 2009). According to him, there are three types of research design including qualitative, quantitative and mix methods. Creswell (2009) in his book states *“mixed methods research is an approach to inquiry that combines or associates both qualitative and quantitative forms. It involves philosophical assumptions, the use of qualitative and quantitative approaches, and the mixing of both approaches in a study”* (Creswell, 2009). Creswell and Plano Clark (2007) further defined mixed methods research by stating that it is not simply a process of collecting and analysing both qualitative and quantitative data, but that it includes the use of both approaches in tandem so that the overall strength of a study is greater than either qualitative or quantitative research (Creswell and Plano Clark, 2007).

According to Bowling (2009), “*the complementary use of combined qualitative and quantitative designs was relatively common before the development and increasing use of statistics, and is again increasing in popularity”* (Bowling, 2009). *“As well as using different methods to complement each other (drawing on the strengths of each method, on the basis that each have different weaknesses and strengths), there have long been advocates of the use of what has generally been termed ‘triangulated methods’ (in order to minimise research bias and enhance the validity of the results by testing the consistency of findings obtained by different methods)”* (Bowling, 2009).

Mixed methods research offers the potential to obtain a deeper understanding of people and events (Bowling, 2009). Sandelowski (2009) also highlighted that in order to broaden the scope of their research and deepen insights to their studies, most of the researchers used the mixed method technique (Sandelowski, 2000). In his 2012 text, Creswell suggested the use of both quantitative and qualitative data to provide a better understanding of the research problem than either type by itself. This is because often one type of research (qualitative or quantitative) is not sufficient to address the research problem or answer research questions(Creswell, 2012).

This current study used a type of mixed method known as the convergent parallel design. In this design, quantitative and qualitative data were collected concurrently, analysed the two data sets separately and mixed the two databases by merging the results during interpretation (and sometimes during data analysis). The purpose of the convergent parallel design was to obtain a more complete understanding from two databases and corroborate results from different methods. Figure 5 shows the convergent parallel design (Creswell, 2012).

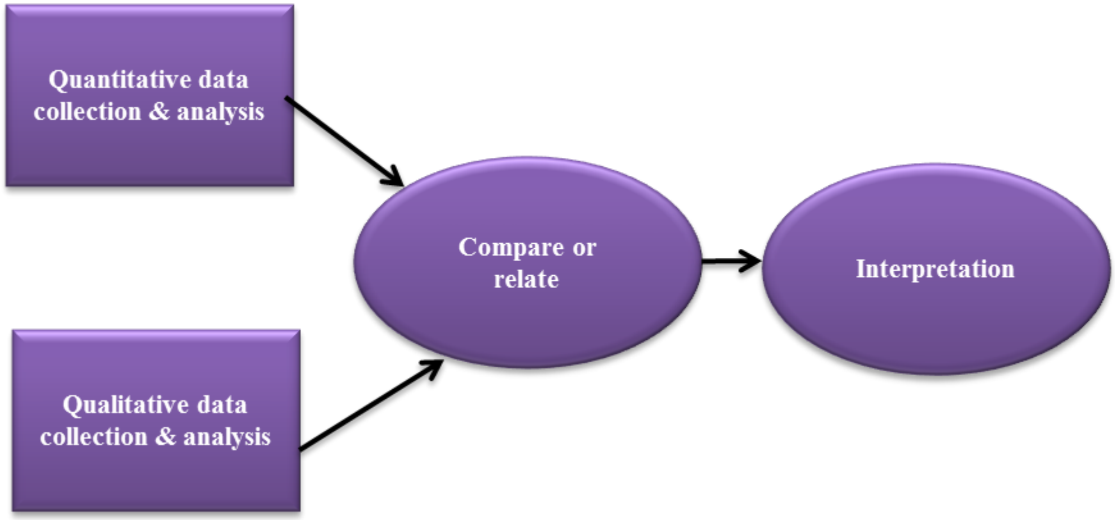


Figure 5: The convergent parallel design

The reason for the use of mixed methods research in the current study is to obtain detailed information about the experiences, challenges and problems the children and adolescents with T1D face when managing their diabetes and what information and support they need to better manage their diabetes. In addition it was used to examine whether the support and information given by *'My Diabetes'* is able to improve diabetes self-management. Quantitative data was collected to support the data obtained using a qualitative approach. The data was collected in three phases. Phase one included the collection of both qualitative and quantitative data; Phase two collected qualitative data only and Phase three collected both quantitative and qualitative data.

2.1.1 Qualitative research approach

Qualitative research is a type of educational research in which the researcher relies on the views of participants; asks broad, general questions; collects data consisting largely of words (or text) from participants; describes and analyses these words for themes; and conducts the inquiry in a subjective, biased manner (Creswell, 2012). Other authors describe qualitative research as a field of inquiry used to gain insight into people's beliefs, attitudes, behaviours, culture, or lifestyle (Morse and Field, 1995).

In health care research, particularly diabetes research, qualitative methods help clinicians to answer questions that quantitative research may not be able to answer, such as exploring patient's motivation, perceptions, and expectations (Morse and Field, 1995). Understanding experiences, beliefs, attitudes, and behaviours is crucial to clinical care because these areas have a profound effect on perception of health, health-seeking behaviour, and adherence to treatment. Furthermore, qualitative research can play a role in generating hypotheses for quantitative research, providing insights that can be used to help interpret the findings of quantitative research, and enabling patients and clinicians to say, in their own words, what matters to them and why (Patton, 1990; Morse and Field, 1995).

2.1.2 Quantitative research approach

In his introduction to quantitative research, Creswell (2012) defines quantitative research as a type of educational research in which the researcher decides what to study; asks specific, narrow questions, collects quantifiable data from participants (a large number of participants); analyses these numbers using statistics; and conducts the inquiry in an unbiased, objective manner. It generally involves collecting numerical data that can be subjected to statistical analysis (Creswell, 2012).

2.2 Qualitative and quantitative data collection

This section describes both the qualitative and quantitative data collection strategy employed in this study.

2.2.1 Qualitative data collection

In order to collect the qualitative data, an observation study was conducted during Phase one, while semi-structured interviews and open-ended questions method were used in Phase two and semi-structured interviews in Phase three of the study.

Observational study

According to Bowling (2009), observation of behaviours, actions, activities and interactions is a tool for understanding more than what people say about (complex) situations, and can help to comprehend these complex situations more fully. It can be participatory or non-participatory, structured and quantitative (with a checklist, categories to check, rating scales) or unstructured and qualitative (direct recording of events and stories as they occur) (Bowling, 2009). In social science, the definition of observation is not limited to ‘watching’ but extended to the direct gathering of information by the researcher using the senses, generally both sight and hearing (Bowling, 2009). In addition to that, observation is a research method in which the researcher systematically watches, listens to and records the phenomenon of interest (Bowling, 2009).

In the current study, observing education sessions was deemed beneficial as it allowed the researcher to gain an understanding of the attitudes, behaviour, experiences, challenges and problems that the children and adolescents face living with diabetes. Further, observational study allows us to identify factors that support or interfere with effective diabetes care. With this deeper understanding of the existing problem, we can design an intervention which is appropriate to the children’s and adolescents’ needs. Observation was conducted during phase one of the study among children and adolescents with T1D in Malaysia.

Field Notes

Because of the weakness of human memory, field notes were made in which the researcher took notes based on her observations. These notes contain detailed summaries of events and behaviour and the researcher’s initial reflections on them. The notes specified key dimensions of whatever is observed or heard (Bryman, 2012). As noted by Bogdan and Biklen (1982), field notes are a written account of the things that the researcher hears, sees, experiences, and thinks in the course of collecting or reflecting on data in a qualitative study (Bogdan and Biklen, 1982) and for a successful qualitative study there is a need for detailed, accurate, and extensive field notes (Morse and Field, 1995).

Interviews

Bowling (2009) points out that an interview includes the collection of data through talking to respondents (interviewees) and recording their responses. The interview may be conducted face-to-face or by telephone (Bowling, 2009). Interviews were conducted during the Phase two and Phase three of this study. In Phase two, interviews were conducted among Malaysian non-diabetic children and adolescents living in Newcastle, while in Phase three, interviews were conducted among Malaysian children and adolescents with T1D living in Malaysia and their parents. In Phase three interviews were also conducted among clinicians involved with the care of children and adolescents with T1D.

Face-to-face semi-structured interviews were carried out among children and their parents in Newcastle and in UMMC, Malaysia. The UMMC interviews were conducted while the researcher was travelling to Malaysia for data collection. The advantages of face-to-face interviews are: interviewers can probe fully for responses and clarify any ambiguities; more complicated and detailed questions can be asked; more information of greater depth can be obtained; body language and facial cues can be picked up; inconsistencies and misinterpretations can be checked; there are no literacy requirements for respondents; questions in structured schedules can be asked in predetermined order; response rates are generally higher with friendly interviewers than for questionnaires which are sent through the post or telephone interviews (Bowling, 2009). Open-ended questions were included in the questionnaire so that respondents were able to provide their opinions in full on more complex topics (Bowling, 2009). They also provided rich and quotable material which enlivens research reports. Normally for topics which are largely unknown or complicated open-ended questions were used (Bowling, 2009).

Telephone interviews were carried out among HCP in UMMC, Malaysia. It was not possible for the researcher to carry out face-to-face interviews while the researcher was in Malaysia as the majority of HCP were busy with their clinics and one HCP was attending a conference abroad. In view of this, telephone interviews were conducted when the researcher was back in Newcastle.

Open ended-questions (Feedback)

A feedback form was located at the end of each component of the web programme. This feedback form was a blank field for free text writing. This form used two open-ended questions, first: “How would you improve this section”? and second: “Any other comments”? The feedback form was designed in such a way that it allowed children and adolescents the freedom to express their views in response to the question asked without any influence or clues from the researcher. This feedback form was used to gather facts about children and adolescents experiences and challenges in using the web-based education programme. In 2008, Ballou published a paper in which she stated “The open ended-question does not provide answer categories” (Ballou, 2008). The respondent who is asked this type of question formulates the answer and gives the response in his or her own words (Ballou, 2008). The feedback regarding experiences using the web programme was gathered from Malaysian children and adolescents living in Newcastle.

2.2.2 Quantitative data collection

The quantitative data collection was undertaken during Phase one and Phase three of the study. For the purpose of quantitative data collection, food diary data were collected during Phase one and questionnaires were used during Phase three among children and adolescents with T1D in UMMC, Malaysia.

The Perceived Diabetes Self-management Scale (PDSMS)

The Perceived Diabetes Self-Management Scale (PDSMS) developed by Wallston et al (Wallston *et al.*, 2007), was administered with permission from Dr Kenneth A. Wallston. The PDSMS consists of eight items to measure how confident the patient is in managing their glycaemic control well, also known as self-efficacy. The responses to the items were rated on a five-point likert scale, which ranged from 1 (strongly disagree) to 5 (strongly agree). Four of the items were reverse-scored because “strongly agree” in these items reflected low perceived competence. The total scores ranged from 8 to 40 with higher scores indicating a greater level of confidence in self-managing diabetes. All participants were asked to complete the PDSMS at baseline and at six months. Participants were asked to rate how confident they were in managing their diabetes. Data were collected pre and post intervention to identify any changes in their self-efficacy after using the web-based programme.

“Self-efficacy is defined as one’s perceived confidence in his or her ability to perform a behaviour in a prospective situation. An example of diabetes self-efficacy is an adolescent’s confidence in adhering to his or her diabetes regimen under a wide range of conditions, such as on holidays or at social gatherings”. “Diabetes self-efficacy has been shown to positively correlate with metabolic control among adolescents (Grossman *et al.*, 1987)”. “For patients with T1D self-efficacy it is essential for them as they are required to carry out self-management tasks such as daily insulin injections, self-monitoring of blood glucose, following a balanced diet as well as regular exercise in order to control their diabetes (Glasgow *et al.*, 1999)”.

Type 1 Diabetes Nutrition Knowledge Survey (NKS)

The Type 1 Diabetes Nutrition Knowledge Survey (NKS) was developed by Rovner et al (Rovner *et al.*, 2012). The NKS is an American validated tool consisting of 23 items. It was specially developed for youth with T1D to assess both general nutrition (for example healthful choices and label reading) and diabetes specific (example carbohydrate counting and glycaemic response to foods) nutrition knowledge. The NKS was developed by a multidisciplinary team consisting of a paediatric endocrinologist, paediatric diabetes nurses, a nutrition scientist, registered dieticians, certified diabetes educators and a behavioural scientist. Item content was designed to reflect constructs typically addressed in diabetes nutrition education and relevant to disease management and general health. The NKS contained 4 domains 1: Healthful eating (6 questions); 2: Carbohydrate counting (7 questions); 3: Blood glucose response to food (3 questions) and 4: Nutrition label reading (7 questions). The researcher substituted three of the answers for three of the questions from the American product to Malaysian local products. The permission to substitute and to use the questionnaire was obtained from one of the authors, Dr Tonja R. Nansel. Data were collected at baseline and at six months post intervention to identify any improvement in nutrition knowledge after using the web-based programme.

Dietary intake

The 3-day food diary method allowed for both assessment of individual diets and identification of commonly consumed carbohydrate-rich foods. The diaries used were bespoke, being compiled exclusively for use in this project, owing to the need for the language to be adapted to Malaysian English, and for the insertion of appropriate pictures and examples accurately reflecting the typical Malaysian diet. The diaries contained instructions on how to complete and record food and drink consumed during the study. The participants were asked to record all food and drink consumed over a three day period, of which one day should be a weekend day. Where possible, participants were asked to record food weights or household measures, cooking methods, and brand names.

Chapter 3 Establishing children requirements in Malaysia (Phase one)

3.1 Introduction

This chapter presents the preliminary research which informed the development of the web-based education programme. It begins by stating the aims and objectives of this phase of the research, followed by a description of the research methods used. A detailed description of the sample population, data collection and data analysis are also given. This chapter concludes with a discussion and limitations of the study.

3.2 Aims

To establish children’s (age 10-16 years) requirements for an education programme; to understand the children’s experiences, attitudes, challenges and problems related to their diabetes; to identify regularly consumed foods and their portion sizes and the information which needed to be included in the education programme.

3.2.1 Objectives

1. To conduct an observation study in order to understand the attitudes, experiences, problems and challenges which children face living with diabetes and in managing diabetes.
2. To collect dietary data from up to thirty Malaysian children with T1D, using 3-day food diaries, followed up with interviews to clarify information contained therein.
3. To use these data to identify regularly consumed foods and their portion sizes and to ensure a full range of these foods are included in the development of the education programme to improve diet and diabetes management.

Data were collected in two ways:

1. Observation
2. 3-days food diaries

3.3 Observation study (Qualitative method)

3.3.1 Aim & objective

The focus of this observation was to explore the attitudes, experiences, challenges and problems children face living with diabetes and managing diabetes in their everyday lives and to identify what they actually do.

3.3.2 Eligibility

Children aged 10-16 years old with a diagnosis of T1D, who participated in a diabetes camp from 14th to 16th December 201l in Pangkor Island, Perak, Malaysia were eligible to take part in this study.

3.3.3 Sample selection and recruitment

Thirty three children with T1D (58% females, 42% males) participated in this camp. The mean age was 13.2 years ± 2.3 with a range from 10 to 16 years old. Participants were from three Hospitals; UMMC, Ipoh Hospital and Taiping Hospital. Approval for the camping programme was obtained from the three institutions and written informed consent was obtained from children's parents for both participation in the camp and the research (Appendix 1).

3.3.4 Data collection

Data were collected from the 14th to 16th of December 2011 in Pangkor Island. Observations were conducted during education sessions. Notes were taken by the researcher during the activities. The diabetes camp was organised by the Paediatric Department, UMMC with support from the Malaysian Diabetes Association. This camp gives children and adolescents with diabetes an opportunity to participate in a safe and fun medical education experience together with their peers with diabetes. The camp lasted for three days, two nights and the children participated in many activities including swimming, team games, arts and crafts, aerobic dance and education sessions. Camp facilitators were paediatric endocrinologists, medical doctors, dieticians, social-workers, and diabetes educators. Children were divided into five groups and year 1 diabetes educator students from UMMC were assigned into each group and were present with the children at all times. Every day participants were required to attend an education session. Education sessions were divided into four topics: Insulin management, monitoring of blood glucose, diet management and exercise, which were delivered by experienced Paediatric diabetes consultants, a dietician and a sports medicine doctor. Before teaching participants the education topics, facilitators asked questions of the participants to establish what they had learned so far, their experiences and how they managed their diabetes.

The researcher undertook between one to two hour periods of observation during each education session. The researcher observed how the participants performed the tasks and answered the questions given to them by facilitators. The tasks and questions were related to diabetes self-management including insulin injections, diet management and blood glucose monitoring. The researcher was interested in how participants managed their diabetes and what their information, communication and support needs were in relation to it. The researcher noted whether participants helped each other during any activities.

3.3.5 Data analysis

Qualitative data from the field notes was analysed using a system of coding and framework analysis. After repeated reading and immersing in all collected data, a general picture was obtained (familiarize the data). At first, exact words of text that express key ideas or concepts were highlighted. The researcher identified codes anticipated from the literature (e.g. effect of diabetes in life) and codes that emerged from the data (identify thematic framework). Then the researcher applied the codes to the dataset. Various codes were merged and categorized based on their relationship and similarity. Finally, four major themes were identified through analysis of the data. The themes were classified as: knowledge; effect of diabetes; coping with the disease and regimen adherence and social support.

Framework analysis

According to Srivastava and Thompson (2009), framework analysis allows the users to either collect all the data first and then analyse or analyse some of the data during the collection process (Srivastava and Thompson, 2009). All the collected data is sifted, charted and sorted in accordance with key issues and themes throughout the analysis stage (Srivastava and Thompson, 2009). This involves a five step process as shown in Figure 6

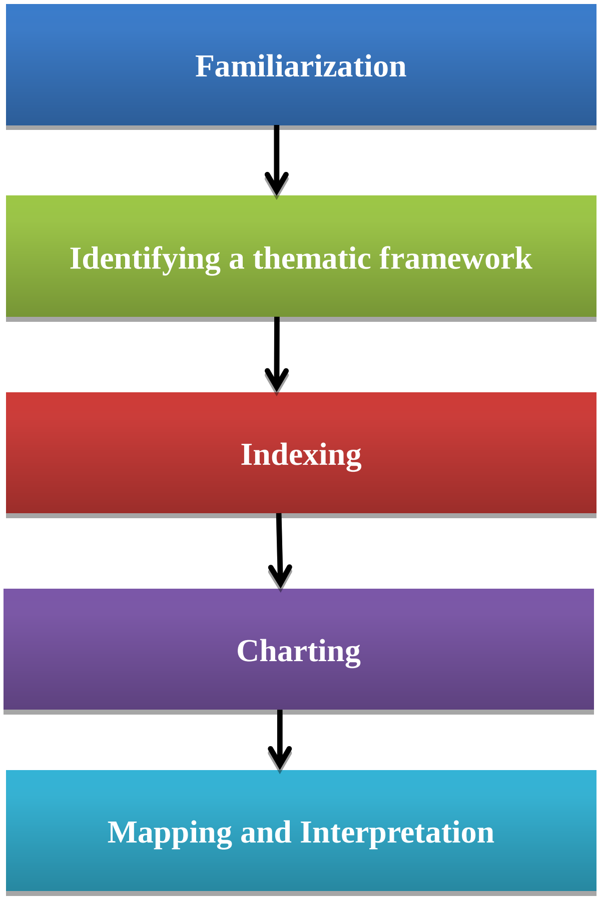


Figure 6: Framework analysis

a. Familiarisation

Familiarisation refers to the process during which the researcher becomes familiarised with the transcripts of the data collected (i.e. interview, observation or field notes) and gains an overview of the collected data (Ritchie and Spencer, 1994). This involves listening to tapes and re-reading field notes or transcripts until the researcher is closely familiar with them in their entirety (Green and Thorogood, 2004).

b. Identifying a thematic framework

The second step is to develop a coding scheme (Green and Thorogood, 2004). This stage occurs when the researcher recognises emerging themes or issues in the data set. The key issues, concepts and themes that have been expressed by the participants now form the basis of a thematic framework that can be used to filter and classify the data (Ritchie and Spencer, 1994).

c. Indexing

The process of applying codes to the whole data set in a systematic way is called indexing (Green and Thorogood, 2004).

d. Charting

This step involves rearranging the data according to this thematic content, either case by case, or by theme (Green and Thorogood, 2004). This means that the data is lifted from its original textual context and placed in charts that consist of the headings and subheadings that were drawn during the thematic framework, or from prior research (Ritchie and Spencer, 1994).

e. Mapping and interpretation

This final step involves the analysis of the key characteristics as laid out in the charts. This analysis should be able to provide a schematic diagram of the event/phenomenon thus guiding the researcher in their interpretation of the data set (Ritchie and Spencer, 1994).

3.3.6 Results

Observation during the education sessions also provided the opportunity to recognise problems faced by participants in relation to their diabetes management. Four major themes were identified through analysis of the data. The themes were classified as: knowledge; effect of diabetes; coping with the disease and regimen adherence and social support.

Theme 1: Knowledge

Most of the participants had insufficient knowledge especially on diet management. During the diet management education session, the majority had difficulties reading food labels. When asked by the dietician about the carbohydrate content of the selected food display, most of them struggled to give the correct answer.

Even I got diabetes for 4 years, I still don't know how much of carbo in this noodle (Boy, 12y.o).

I do know how to read this (Food label) (Girl, 14y.o).

My dietician teach me, but I don't remember (Girl, 13y.o).

At the insulin management education session, when asked by the doctor about how often they monitor their BG, some of them did not monitor their BG regularly, for them frequent monitoring did not give assurance of good BG control.

I do not know why we need to check sugar many times? My sugar stills the same (Boy, 11y.o).

I only check sugar two times a day, all the same even you check more (Girl, 15y.o).

In the camp, every morning participants were required to perform aerobic exercise led by the sport medical doctor. The researcher noticed that most of the participants did not check or monitor their BG levels before and after exercise. They only checked when told by their facilitator. They did not realise or have knowledge that it was important to check BG before and after exercise. A few participants were not allowed to join in the session due to very low blood glucose before starting the exercise. However, one participant still insisted they wanted to continue with the exercise. Due to that, one of the facilitators needed to teach him how to reduce his insulin dose in order to improve his blood sugar before he continued to exercise. A few of the participants had low blood glucose after exercising and did not know how much carbohydrate they needed in order to increase their BG back to an acceptable level. They had low knowledge about dietary management for hypoglycaemia (low blood glucose level).

Theme 2: Effects of diabetes in life

The majority of the participants stated that diabetes had had an impact on their daily life such as diet and family routine. Many reported that the whole family wanted to consume the same diet.

My parents did not buy sweet foods at home because I cannot eat (Girl, 13y.o).

All my family must eat the same diet (Boy, 11y.o).

A few of them mentioned that at the time of first diagnosis, their mother needed to wake them up at midnight each night to check their blood sugar.

Every midnight my parent will wake me up to check my sugar (Girl, 13y.o)

Some of them did not obtain permission from parents to go to parties due to their diabetes.

My mother do not allowed me go to birthday party, if I want to go I will bring my own food (Girl, 14y.o)

1 am not allow to go to any party because of food and I also do not want to go (Girl, 15 y.o).

On the final day in the camp, when everybody wanted to celebrate the birthday of one of the participants and eat cakes bought by one of the facilitators, it was observed that one girl 11 years old cried because she had been told by her mother not to eat any sweet foods.

Theme 3: Coping with the disease and regimen adherence

Some of the participants who attended the camp stated that they were not confident and still struggled to manage their diabetes. In some cases, mothers either shared responsibility with their children or took control of their child's management following diagnosis.

I am 11, but my parent still do injection for me, I'm afraid to do myself (Girl, 11y.o).

My mother need to do everything for me, I still not confident to do it myself (Girl, 11y.o)

I am not confident to do finger prick to check my blood sugar (Boy, 10y.o).

When I was first diagnosed, they had to do everything for me, but know I am 12, doctor told me I need to do myself (Girl, 14y.o).

Some of the participants injected insulin themselves and monitored their blood sugar with parental supervision. During the diabetes camp, they demonstrated the correct injection technique in front of the facilitator and the other participants.

Theme 4: Social support

Some of the participants indicated that they needed support from the clinician, especially when their parents were not capable of helping them to manage their diabetes.

Sometimes we need help to manage our diabetes, we need to call doctor (Boy, 12y.o).

My mother will called doctor if we still do not know what to do (Boy, 14y.o).

3.3.7 Discussion

Knowledge

The findings from the observational study provide essential information about children's experiences with diabetes and the problems they face in managing their diabetes on a daily basis. Most of the difficulties were knowledge based. Most of the participants had problems dealing with foods, had trouble reading food labels, and found it difficult to identify the carbohydrate content especially of cooked and mix-meals. Many were also unaware of the reason frequent blood glucose monitoring is recommended or of the correct injection technique. The majority of participants did not possess sufficient knowledge or skills to care for themselves effectively. There are similarities between the lack of knowledge expressed by participants in this study and those described by Chaney et al (Chaney *et al.*, 2011). In this study conducted among 21 adolescents with T1D aged 13-19 years old in order to establish adolescents views on a diabetes education programme, they found that most of the participants had insufficient knowledge or skills to achieve optimal control of their diabetes. A previous study conducted by Spiegel et al (2012) demonstrated that adolescents with T1D (aged 12 to 18 years) do not accurately count carbohydrates and commonly either over or underestimate carbohydrate grams in a given meal (Spiegel *et al.*, 2012) which is similar to the result of the current study.

According to Auslander et al (1991) children and adolescents with higher knowledge levels have better metabolic control compared with those with lower knowledge levels (Auslander *et al.*, 1991). As Hanson et al. (1987) states knowledge has also been linked to adherence to treatment, which is related to metabolic control (Hanson *et al.*, 1987). Coates and Boore (1996) proposed that a lack of knowledge can be one of many reasons for diabetes mismanagement (Coates and Boore, 1996). However, O’Neil et al (2005) suggested that knowledge alone does not predict metabolic control (O'Neil *et al.*, 2005). Other researchers point out that knowledge is believed to be one of several variables affecting metabolic control (Coates and Boore, 1996; Grey *et al.*, 1999). Auslander et al. (1991) suggested that because of the complexities involved in diabetes management, children need knowledge and skills as a beginning step towards compliance with diabetes regimen and metabolic control (Auslander *et al.*, 1991).

Effects on patients and family (family adaptation)

Diabetes also had an impact on participant’s family life. Parents created new family routines following diagnosis and changed their lifestyle, to cope with the demands of the diabetes regimen. In the current study, T1D had positive effects for some families with the whole family following a healthy diet and this result was consistent with other studies (Mellin *et al.*, 2004; Herrman, 2006). The results also indicated that parents, especially mothers, have greater involvement in participants’ diabetes management and provide supervision during their children’s diabetes management. Previous research indicated that adolescents with T1D reported that encouraging support from parents was helpful in managing their condition (Guthrie, 2001). Parental involvement and support for young people with T1D is also related to metabolic control. Moreover, according to Berg et al. (2007) when mothers and children collaborate in their coping efforts, negative emotions about their experience with T1D were reduced (Berg *et al.*, 2007). Conversely, if the mother was less involved or hostile, poor metabolic control occurred (Jaser and Grey, 2010; Wiebe *et al.*, 2011). In 2012 Scholes et al (2013) demonstrated that participants with high HbA1c levels seemed to have less family support and involvement in T1D care than those with low HbA1c (Scholes *et al.*, 2013), a pattern also seen in other studies (Hsin *et al.*, 2010; Wiebe *et al.*, 2011).

Self-efficacy

Self-efficacy is defined as one's confidence to take action to achieve a specific goal (Iannotti *et al.*, 2006). Evidence shows that self-efficacy has an important role in health behaviour in adolescents and children, especially those with chronic diseases such as T1D (Johnston-Brooks *et al.*, 2002). Furthermore, patients with T1D, if they have a strong sense of self-efficacy, have better adherence to diabetes management, better diabetes self-management, better glycaemic control and finally better quality of life (Johnston-Brooks *et al.*, 2002). In this current study, we found that some of the participants had low self-confidence. They depended on their parents for managing their diabetes. This finding is in agreement with Spencer et al (2013) in their study conducted among 20 adolescents with T1D aged 13-16 years, which showed that some adolescents in their sample depended on their mother for insulin injections or some part of their diabetes management (Spencer *et al.*, 2013). Several studies suggested that adolescents with low self-efficacy were more likely to have worse glycaemic control compared to those with high self-efficacy. One of the studies conducted in Taiwan among 52 Taiwanese adolescents with T1D aged 12-20 years old, demonstrated that participants with higher self-efficacy have a higher probability of reaching target diabetes control (Chih *et al.*, 2010). However, in the current study we did not assess the relationship between self-efficacy and blood sugar control.

Support

Positive relationships, support and assessment from healthcare teams are important (Chisholm *et al.*, 2007; Guo *et al.*, 2011; Keough *et al.*, 2011). They play a vital role in helping young people become responsible for self-management and motivated to maintain glycaemic control (Anderson, 2010). Healthcare providers should help young people assume self-management responsibilities at the appropriate time (Cameron *et al.*, 2008) and according to individual needs (Price *et al.*, 2011). Health professionals are supposed to provide knowledgeable expertise and skills to the children and their parents. Their role involves encouraging competence through the development of skills, knowledge and attitudes, and translating this into behaviour through reflection with the adolescents about their experiences (Fraser and Greenhalgh, 2001). Findings from this study showed that some of the participants were still struggling with their diabetes self-management and they required continuing support from the clinician in addition to their parents. One qualitative study was conducted among 14 young people aged 11-22 years living with T1D, in order to explore whether participants with different levels of metabolic control have different perceptions about their lives and disease. In that study they found that most of the participants believed that positive relationships with physicians were vital for optimal T1D management (Scholes *et al.*, 2013).

In the diabetes camp, some participants exchanged personal mobile contact numbers so that they could communicate and share their experiences after the camp. Some participants had increased confidence at the end of the camp as a result of seeing that some of their peers were able to perform diabetes management tasks such as correct injection technique and monitoring their blood glucose. This finding was similar to other findings which showed that support from others with T1D was important so that they can share experiences and challenges in managing their diabetes (Scholes *et al.*, 2013). This support can be obtained from attending a diabetes camp or if this is not possible by establishing a support group via a website or other means of connecting with others. Teamwork between adolescents, parents, peers and health professionals is essential to facilitate adolescents' development of capabilities and independence (Scholes *et al.*, 2013). In conclusion effective interventions can assist young people with T1D to better manage their disease. It is essential to provide an education and support system which can enhance their self-efficacy and self-management especially with regard to dietary management, how to read food labels and identify carbohydrate content and to provide support in the event of any problems.

3.3.8 Strengths and limitations

This study has several limitations. Participant numbers were small, thus it is possible that those who did not attend the diabetes camp could have different care and management, experiences and needs. Consideration must also be given to the fact that behaviour and attitudes of participants may be different outside the camp when their parents and relatives were around. The responses given during the education sessions may be affected by their cognitive maturity and ability to express themselves verbally, the children's answers may be influenced by the facilitator. However, the observation study was of great benefit for understanding more about attitudes, experiences, challenges and problems they face in managing diabetes.

3.4 Dietary data

The overall aim of this study was to contribute to the development of the dietary component of a web-based education programme for Malaysian children and adolescents with T1D. The 3-day food diary method was used to collect dietary data. The 3-day food diary method allowed for both assessment of individual diets and identification of commonly consumed carbohydrate foods. The diaries used were modified, being compiled exclusively for use in this project and contained appropriate pictures and examples which accurately reflect the typical Malaysian diet. The diaries contained instructions on how to correctly record dietary intake. The participants were asked to record all food and drinks consumed over a three day period, of which one day should be a weekend day. Where possible, they were also required to record food weights or household measures, cooking methods and brand names. An example of an uncompleted food diary can be found in (Appendix 3).

3.4.1 Objectives

- To collect dietary information from up to 30 Malaysian children with T1D, using 3-day food diaries, followed by interviews to clarify information contained therein.

- To use these data to identify regularly consumed foods and their portion sizes, with a focus on foods with carbohydrate content to be included in the web-based diet and diabetes education programme.

3.4.2 Eligibility

To be eligible to take part in this study, all children had to be diagnosed with T1D and aged 10 to 16 years old.

3.4.3 Sample selection and recruitment

Twenty eight children were approached, via their parents, to ask if they would give informed consent to complete a 3-day food diary. Nineteen of these children with T1D were scheduled to attend the diabetes camp, while the remaining nine children were scheduled to attend a routine appointment at the diabetes clinic at UMMC. Parents were called to inform them about the study. If they agreed to participate, an information sheet about the study (Appendix 2), consent form (Appendix 1) and also food diary (Appendix 3) were sent to them by post. All participants were sent the 3-day food diaries between seven and eleven days before the camp or clinic appointment to allow sufficient time for completion. The consent and assent forms were required to be signed by parents and also the children themselves, and brought with them either on attendance at the diabetes camp, or at the clinic appointment, along with their 3-day food diaries.

3.4.4 Data collection

Dietary data was collected in the form of a 3-day food diary. The data collection took place at various locations in Malaysia over an 8-day period. Participants who attended a Diabetes Camp on 14-16th December 2011 at Pangkor Island, Perak and those who attended a Paediatric Diabetes Clinic on 13th, 20th December 2011 in UMMC, Kuala Lumpur were invited to participate in this study. During the diabetes camp and clinic day, children were interviewed by the researcher in order to clarify foods, gather more detailed information, and ensure all foods consumed during the 3-days period were included. This method was therefore appropriate for these participants, as both the camp and the clinic provided the opportunity to conduct these interviews.

The interviews were aided by use of two food atlases, the Young Person Food Atlas (Foster *et al.*, 2010), and the Malaysian Atlas of Food Exchanges and Portion Size (Suzana *et al.*, 2009a); these were used to clarify portion size where no weight or household measure approximation had been recorded. The participants were asked to estimate what proportion of the portion size shown on the picture they had consumed and the appropriate amount was recorded. All dietary records were checked by two researchers for accuracy and completeness. Further clarifications were sought from the respondents in cases where the food records were incomplete or filled in incorrectly. Energy and macronutrient intakes were calculated for each day, and the average of the three days calculation was taken in the final statistical analyses. The dietary intakes of the participants were analysed using the Malaysian food database (Tee *et al.*, 1997). Dietary quality was reported for macronutrient intakes (carbohydrate, fat and protein) as mean percentages of energy and gram for fibre. All statistical analyses were conducted using IBM Statistical Package for Social Sciences (SPSS) version 21.

3.4.5 Results

Participants' characteristics

Nineteen Malaysian children (73% females, 27% males) took part in the study and completed 3-day food diaries. Mean age was 12.9 ± 2.5 years old and mean diabetes duration was 6.1 ± 4.5 years. All were on basal-bolus injection therapy and mean HbA1c was 10.2 ± 2.6%. The Table 5 below illustrates some of the main characteristics of participants.

Table 5: Participant characteristics (Phase one)

Number of participants	**19**
Number of male participants	*5 (27%)*
Mean (SD) age in years	*12.9 (2.5)*
Mean (SD) number of years since diagnosis	*6.1 (4.5)*
Mean (SD) HbA1c	*10.2* (2.6)*

**Normal value for HbA1c < 7.5 mmol/L (Rewers et al., 2009)*

Macronutrient intake and fibre intake

The macronutrient profile of the participants was compared against ISPAD (International Society of Paediatric & Adolescence Diabetes) recommendations (Smart *et al.*, 2009b), which are also the Malaysian national recommendations. The results are shown in Table 6

Table 6: Mean (SD) macronutrient intakes (as a percentage of contribution to overall energy intake) and fibre intake compared to ISPAD and Malaysian guidelines

Nutrient	Recommendation (ISPAD) & Malaysian Guidelines	Participants (n=19)
% of energy from carbohydrate	*50-55*	*51.0 (6.8)*
% of energy from fat	*30-35*	*33.0 (5.1)*
% of energy from protein	*10-15*	*16.0 (2.9)*
Fibre (gram)	*20-25*	*9 (2.6)*

As can be seen from the Table 6, the mean percentage of energy from carbohydrate and fat met the current nutrient recommendations. It is also apparent from Table 6 that the mean percentage of energy from protein was slightly higher than the International and Malaysian recommendation.

Fruit and vegetable intake

The Malaysian dietary guideline is also the same as the World Health Organisation recommendation of five servings of fruits and vegetables a day, equivalent to 400 gram (*Malaysian Dietary Guidelines*, 2010). The mean intake of the participants in our sample was 104 gram or 1.8 servings of fruits and vegetables per day, well below the recommendation. None of the participants achieved an intake of fruits and vegetables equal to 400gram on any of the days of recording (Table 7).

Table 7: Mean daily intake (gram) ± SD of fruit and vegetables consumed

Nutrient	Recommendation by WHO & Malaysia (gram)	Mean Intake (gram)
Fruit & Vegetables	*400*	*104 (73.8)*

Sources of carbohydrate

Table 8 presents the estimated mean daily nutrient intake consumed by participants in this study. Only a small number of participants consumed healthy sources of carbohydrate such as wholegrain breads and cereals, legumes (peas, beans and lentils) and low fat milk. Daily fibre intake was 9 gram which was very low compared to the ISPAD guidelines of 20-25 gram per day. Whole grain, legumes and low fat milk intake were also insufficient at less than half serving a day. Only two (10%) participants consumed one serving of wholegrain product per day from brown rice and wholemeal bread. Three (16%) of the participants consumed one serving of legumes from dhal and bean products a day. Seventeen (89%) participants consumed whole milk products. The intake of sugar from sweet food and drinks less than one serving a day. (Refer to appendix 4 for serving size of fruit, vegetable, legumes, whole grain and low fat milk).

Table 8: Estimated daily nutrient intake (mean ± standard deviation and servings per day) of food consumed by participants

Nutrient	**n=19**
Calorie	*1673 (1013.6)*
% Carbohydrate	*51 (6.8)*
% Protein	*16 (2.9)*
% Fat	*33 (5.1)*
Fruit & Vegetable (gram)	*104 (73.8)*
Fibre (gram)	*9 (2.6)*
Sweet food (serving)	*0.5 (0.6)*
Whole grain (serving)	*0.2 (0.4)*
Legumes (serving)	*0.4 (0.6)*
Low fat milk (serving)	*0.1 (0.3)*

Commonly consumed foods and portion sizes

Table 9 lists the 13 most commonly consumed foods and portion sizes. Foods were included in the list if there were more than ten instances of individual servings. Boiled white rice and white bread, which are low in fibre content, were more frequently consumed by participants than brown rice and wholemeal bread.

Table 9: The most frequent consumed food (> 10 servings) and portion sizes

Food	Frequency	Range of portion sizes (gram)
Boiled white rice	*51*	*54 – 250*
Apple	*19*	*57 – 115*
Fried Chicken	*18*	*69 – 207*
Milo (Cocoa based drink)	*18*	*5 – 30*
Dahl	*17*	*13 – 180*
Boiled cabbage	*16*	*4 – 107*
Tea	*15*	*150 – 250*
Full cream milk	*15*	*75 – 250*
Fried rice	*15*	*35 – 191*
White bread	*14*	*29 – 87*
Bee Hoon (Noodle)	*13*	*21 – 200*
Fried egg	*12*	*60 – 120*
Low fat milk	*12*	*5 – 30*

3.5 Discussion

The findings demonstrate that apart from protein where intake was slightly higher than recommended, the percentage of energy from carbohydrate and fat were adequate according to current recommendations. The participants in this study consumed 33%, 51% and 16% of energy intake from fat, carbohydrate and protein respectively. However, this finding was not consistent with other studies (Mayer-Davis *et al.*, 2006) with children with diabetes aged 10-15 years old and children and adults aged 10-22 years old who were found to consume more than 35% of calories from fat. While the finding from other studies (Lodefalk and Aman, 2003; Wilson and Smith, 2003; Overby *et al.*, 2007; Pais *et al.*, 2010) found participant intakes fell within the recommended ranges for all macronutrients. Although the results from this study differed from some published studies as mentioned earlier, it was consistent with the study conducted by Zalilah et al (2006). In this study which was conducted among 618 non-diabetic Malaysian school children aged 11-15 years old they were found to consume 32-34%, 51-53% and 14-16% of energy intake from fat, carbohydrates and proteins respectively (Zalilah *et al.*, 2006), suggesting that the diet of this sample of Malaysian children with diabetes was similar in composition to that of non-diabetic Malaysian children. However, data from the Malaysian Adult Nutrition Survey (MANS) found that the macronutrient intakes of Malaysian adults was somewhat different, at 28%, 59% and 14% for fat, carbohydrate, and protein, although it noted that younger groups tended to have a greater contribution of energy from fat (Mirnalini *et al.*, 2008).

Although the percentage of carbohydrate was within the recommended range, the type of carbohydrates did not meet the international guidelines. ISPAD Clinical Practice Consensus Guidelines, 2009 for children with diabetes (Smart *et al.*, 2009b) suggested that dietary recommendations for children with diabetes are based on healthy eating recommendations suitable for all children and adults and therefore the whole family should consume more fruits, vegetables, fibre, whole grains, and low fat dairy. However, there are no specific recommendations for numbers of servings of whole grains products, fruits, vegetables and low fat dairy for the T1D children based on ISPAD consensus guidelines. In the current study, the mean intake of whole grains, fruits and vegetables and low fat diary was 0.2, 1.8 and 0.1 servings per day respectively. The most commonly consumed carbohydrate foods were white rice and white bread which are low in fibre. The only whole grain foods consumed by this sample were brown rice and wholemeal bread. The majority of the participants consumed full cream milk products instead of low fat milk. The present findings seem to be consistent with other research which found that children with diabetes consumed an inadequate intake of whole grains, fruits and vegetables (Mayer-Davis *et al.*, 2006; Overby *et al.*, 2007).

The SEARCH study conducted in the United States with a sample of 1511 youth with T1D aged 10-22 years indicated that the mean intake of fruit and vegetables was only one and a half servings a day and for wholegrain products less than one serving a day (Mayer-Davis *et al.*, 2006). A study conducted among Norwegian children and adolescents aged between 12 and 13 years found average fruit and vegetable consumption to be 2.7 servings per day (Overby *et al.*, 2007). The results of current study also indicated that participants' mean fibre intake was lower than recommended. There were similarities between the low fibre intake in this study and that described by Overby et al (Overby *et al.*, 2007). In their study, participants' fibre intake did not reach the amount recommended in the ISPAD guidelines (Smart *et al.*, 2009b). Diabetic patients are recommended to eat a high fibre diet to improve blood glucose control. Studies conducted by Buyken et al (1998) and Overby et al (2007) showed the association between a high fibre diet and decreased HbA1c levels (Buyken *et al.*, 1998; Overby *et al.*, 2007). The studies conducted by Overby et al. (2007) among 550 children and adolescents with type 1 diabetes (aged 2-19 years old) found that adolescents with a low intake of fibre had higher HbA1c (Overby *et al.*, 2007). This is an important finding, as there is a growing body of evidence to support the theory that the incidence of non-communicable diseases and other health outcomes are associated with the diet. The World Health Organisation recognises that diets which are relatively high in fruits, vegetables, and fibre, are likely to decrease the risk of cardiovascular disease and certain cancers, while diets high in fat, salt, and sugar, are likely to increase adult risk factors for high blood pressure and dyslipidaemia, particularly when combined with physical inactivity (Nishida *et al.*, 2004; Brunner *et al.*, 2007).

There are no specific recommendations for numbers of servings of sweetened beverages or other sweets and snacks except to the extent that these foods should be restricted in the interest of glucose control and weight management for youth with diabetes, especially those with T2D (Mayer-Davis *et al.*, 2006). In the current study, approximately half a serving of sweet foods and sweet drinks per day was reported among participants. While a study by Mayer-Davis et al (2006) found the intake of sweet snacks among their participants was one serving a day (Mayer-Davis *et al.*, 2006). A possible explanation for the low intake of high sugar foods might be that youth with diabetes believed that sweet foods might contribute to poor blood glucose control. Studies done by Overby et al (2007) show that participants who had optimal blood glucose control had a lower intake of added sugar and sugar sweetened soft drinks, plus a higher intake of fruits and vegetables (Overby *et al.*, 2007). While a study by Rickard et al (2001) found no differences in glucose control between a diet with or without sucrose. The effects on glycaemia following consumption of different types of carbohydrate are debated. The ISPAD recommended that no more than 10% of energy should be derived from sucrose, but acknowledge that isocaloric amounts of sucrose and starch have the same effects on glycaemia, while a study by Rickard et al. (2001) also found no difference in glycaemic response between two diets based on mixed-meals, one of which contained twice the amount of sucrose than the other (Rickard *et al.*, 2001). A review by Buccino et al. (2004) also found mixed evidence. Several studies reported improved HbA1c levels in diets rich in foods that were low glycaemic index (GI), high fibre, and unrefined carbohydrate, findings that were contradicted in one study. This review also found no evidence that sucrose causes an abnormal glycaemic response, and therefore no reason why advice should be given for sucrose to be avoided (Buccino *et al.*, 2004).

3.6 Strengths and limitations

According to Burrows et al. (2010) the most accurate method of collecting dietary data collection in children is to use a 24-hour recall conducted over at least a 3-day period, with the multiple-pass interview method, and with parents used as proxies for the children. In order to choose which method would be suitable for this study, practicalities had to be considered, and the fact that there was only a short time window of 2 weeks to collect all data. This resulted in the conclusion that 3-day food diaries were the best option. The 3-day food diary allows collection of intake over 3 days (2 weekdays and one weekend) with only one interview. To conduct 24-hour recall for a 3-day period would not have been practical. There are some strengths and limitations of using the food diary method. By using a food diary, participants are able to record their intake at the time of consumption so there is no need for them to memorize all the food, and all eating occasions are recorded in real time. A detailed description of foods is provided which enhances the accuracy of diet coding. This method is suitable for the assessment of foods eaten regularly. Unfortunately, it is time consuming and poses a relatively high burden on the participant who must record their food and drink intake for three days. Children may alter their diet to make it easier to record their intake or to cover poor eating habits or when parents are not around (McPherson *et al.*, 2000; Burrows *et al.*, 2010). Consequently, the reliability of a 3-day food diary depends on the motivation and understanding of the children and parents.

A particular strength of this study is that food photographs were used to clarify portion sizes at the dietary interview. The young person's food atlas (secondary) has been validated for use with children, and has been shown to facilitate good estimation of portion sizes in children of all ages, with more accurate estimations than when trying to estimate portion sizes with photographs designed for use with adults (Foster *et al.*, 2008; Foster *et al.*, 2009). The small sample size in this study has to be considered a limitation: nineteen children completed food diaries within the short research trip to Malaysia. The data provide some information about the diet of Malaysian children with T1D, however, all the participants involved in this study lived in the Klang Valley which is one of the largest metropolitan areas in Malaysia which has better access to healthcare and food availability. The diet might be different from children residing in more rural areas with less access to all the facilities. The small sample size in this study may not represent the true picture of dietary intake of children with diabetes in Malaysia. Nevertheless, to our knowledge, this was the first study investigating the dietary intake of children with T1D in Malaysia. The overall aim of this dietary study was to contribute to the development of the dietary component of a web-based education programme for Malaysian children with T1D and not to undertake extensive study of diet of children with T1D. The sample sizes was small but it achieved the aims of the dietary study.

3.7 Conclusion

These studies give information about participants attitudes, experiences, problems and the challenges they face in managing their diabetes and their dietary intake. From these we can conclude that children with T1D in UMMC need an effective Malaysian diabetes education programme that not only provides them with information about dietary management but also social support so that they can seek advice and motivation at anytime and anywhere without needing to wait until their follow-up day at the clinic. From this study we were able to identify types of foods commonly consumed by children with T1D and the portion size of these foods. Results reported herein indicate a clear need for improvement in the dietary intake of children with T1D in UMMC. The diets of the children in this sample are not conducive to contributing to the long-term good health and education needs to be effective in order to change this. Malaysian children with T1D would benefit from eating more fruits, vegetables and wholegrain products and choosing low fat dairy products instead of high fat dairy products. Eating more fruits and vegetables, and more whole grain products, would potentially improve glycaemic control, improve overall health, and reduce longer term risk factors for non-communicable disease.

This study provides us with information about what topics should be included in the diet and diabetes education programme. Information that is needed includes:

1. Encouragement to eat more high fibre foods (such as grains, fruits and vegetables)
2. Sources of carbohydrate and different types of carbohydrate
3. Sugary foods (how frequent and the amount they can consume)
4. Frequently consumed foods, their portion size and carbohydrate content.

In addition special attention should be given to fat and saturated fat recommendations for children with T1D because they are at increased risk of cardiovascular disease, and there is evidence that atherosclerosis can be well-established by adolescence (Berenson *et al.*, 1998; Jarvisalo *et al.*, 2002). All of this information was included in the E-learning section and food library section of the web programme. The diet and diabetes web-based education programme will provide not only education but also social support to enhance children’s self-efficacy and self-management especially with regards to diet management which they cannot obtain from ordinary web sites and traditional pamphlet and booklet education programmes.

Chapter 4 Design and development of the web programme ('My Diabetes')

4.1 Introduction

The design and development of *"My Diabetes"* web-based diet and diabetes education programme followed three main phases. Phase one consisted of several parts. First: To establish children's and adolescents' requirements of an education and support programme (part one A). Second: To design the web database and the various components (part one B) and third: To establish the education component (part one C). Figure 7 shows the work plan of phase one of the study. Part one A was discussed in chapter two of the thesis, and in this chapter I will focus on the process of designing the web database and its components (part one B) and establishing the education component (part one C).

4.2 Theory-based nutrition interventions

Nutrition interventions, especially behaviour-based interventions, have been shown to be effective in triggering dietary behaviour change among children and adolescents (Nader *et al.*, 1999). In addition, these behavioural changes have been shown to be maintained over time (Nader *et al.*, 1999). Designing a successful nutrition education programme for children and adolescents requires a systematic approach that combines knowledge of determinants of behaviour with efficacious strategies and an evaluation plan (Hoelscher *et al.*, 2002). Based on a review of 43 studies, Lytle concluded that a number of elements contributed to the effectiveness of nutrition interventions for children and adolescents including; a behavioural focus, incorporation of instructional strategies that are based on appropriate theory, adequate dose (amount of education required to stimulate positive behaviour change), peer involvement; self-assessment and feedback, environmental interventions to complement behavioural lessons, and community involvement (Lytle, 1995).

According to Lytle (1995), although the knowledge-attitudes-behaviour model has been used for many school-based interventions, it has not been shown to be particularly effective for school-aged children (Lytle, 1995). The goal of a knowledge-based nutrition programme is to enhance the knowledge, skills, and attitudes of the target population regarding broad nutritional issues. As a result, this model has been successful in increasing

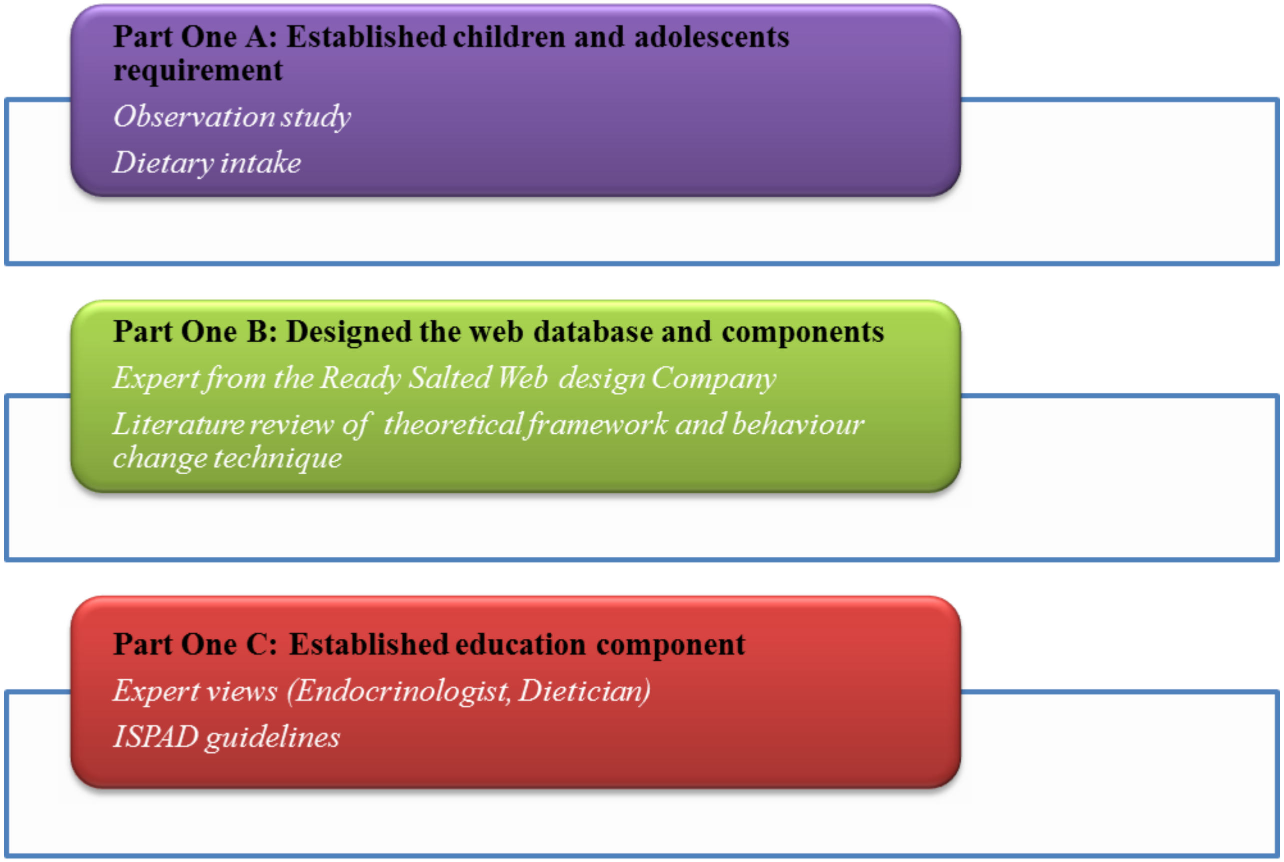


Figure 7: Work plan of the design and development of the web-based diet and diabetes education programme (Phase One)

knowledge among children and adolescents but has not been particularly effective in changing nutrition-related behaviours (Lytle, 1995). A few studies showed that compared with knowledge-based programmes, interventions that have a behavioural focus tend to be more successful in producing behaviour change (Lytle and Achterberg, 1995; Bartholomew *et al.*, 1998) . The goal of a behaviourally-focused health promotion programme is to enhance health through reduction of risk factors. Theory-driven interventions, on the other hand, emphasize specific, desired behaviours as well as the motivators and behavioural skills necessary to engage in these behaviours (Hoelscher *et al.*, 2002). Theory-based nutrition programmes aim to achieve a number of educational outcomes including: changes in specific behaviours such as increasing fruit and vegetables or reducing the amount of fat in the diet, as well as changes in specific behavioural skills necessary to engage in these behaviours (Hoelscher *et al.*, 2002). According to Hoelschar et al (2002), the most successful nutrition programmes are behaviourally-focused and target other behaviours in addition to dietary behaviour (Hoelscher *et al.*, 2002).

Numerous theories have been used to describe or predict health behaviours and to design and evaluate behaviour change programmes. Health behaviour theories (for example: Social Cognitive Theory, Theory of Planned Behaviour and Health Belief Model) are helpful for interpreting dietary behaviours among young people (Cerin *et al.*, 2009) and evidence suggests that theoretically-based interventions are more effective in changing behaviour than non-theoretical approaches (Abraham and Michie, 2008; Anderson-Bill *et al.*, 2011). Theory-based interventions that impact behaviour related to nutrition can provide the basis for understanding factors related to dietary choices (Baranowski *et al.*, 1997a; Baranowski *et al.*, 1998).

The most dominant theory used in the development of programmes for children and adolescents has been Social cognitive theory (SCT) (Hoelscher *et al.*, 2002). SCT provides a reciprocal model in which behavioural or personal factors, as well as environmental influences interact continuously. SCT has been particularly effective for developing nutrition education programmes for children and adolescents (Hoelscher *et al.*, 2002). Because children are often not completely in control of their behaviour, their environment needs to be taken into consideration when designing nutrition interventions. Using SCT, both individual behaviours and the environment are proposed to influence behaviour

(Hoelscher *et al.*, 2002). Anderson et al (2000, 2001, 2007) and Winett et al. (2007) in their papers reported that SCT is commonly used in nutrition education interventions. They also suggested that outcome expectancy (good or bad consequences expected to result from the behaviour), self-efficacy (one's confidence in one's ability to perform the behaviour), self-regulation (ability to regulate action pertaining to behaviour), and social support (emotional support from family and friends to perform the behaviour) were key to behaviour change (Anderson et al., 2000; Anderson et al., 2001; Anderson et al., 2007; Winett et al., 2007). There was also empirical evidence that self-regulatory skills are particularly important for regulating food choices in college students and that self-efficacy, outcome expectations, and social support were associated with maintenance of healthy dietary patterns during the college years (Strong et al., 2008).

Several researchers have also recommended the use of SCT in nutrition education (Sims, 1987; Glanz and Eriksen, 1993). The SCT has been used as the foundation for nutrition interventions in school-based settings with good results (Perry et al., 1990). Several studies showed that interventions targeting SCT variables produce promising results in modifying behaviours, including dietary behaviours in college students (Sallis et al., 1999; Schnoll and Zimmerman, 2001; Rovniak et al., 2002; Suminski and Petosa, 2006). Furthermore, according to Via et al (1999), diabetes self-management education programmes often incorporate behaviour change theories such as SCT (Via and Salyer, 1999). The SCT has been used to predict adherence to certain diabetes-related outcomes, such as diet adherence, exercise, and self-monitoring of glucose (Hays and Clark, 1999; Glasgow et al., 2002). Components of SCT include expectancies, such as beliefs and self-efficacy, and incentives or reinforcement, which include perceived value of the outcome (Bandura, 1986). Bandura's Social cognitive theory (SCT: 1986) provides a useful framework for explaining why people acquire and maintain health behaviours. It has been used extensively to guide interventions targeting a variety of health behaviours, across a range of population groups (for example children, adolescents and adults) (Baranowski *et al.*, 1997b).

Bandura (1986) proposed that behavioural, personal, and environmental factors interact to explain and predict changes in behaviour. Bandura called these relationships "reciprocal determinism", meaning that, as the three components interact, a change in one will produce changes in the other components (Bandura, 1986). Environmental influences such as family support and create opportunities, introduce barriers, teach skills, and provide reinforcement for behaviour change. Personal factors, such as perceived self-efficacy and outcome expectancies, on the other hand, provide direct causal influences on behaviour and are used to interpret information from the environment. Behaviour itself, once enacted, can modify beliefs and directly influence the environment through mechanisms such as meeting new friends who support the behaviour (Bandura, 1986). Specific behavioural theories should be chosen as a framework for the nutrition education intervention. The choice of theory or theories to be used depends on numerous factors such as: the overall goals of the programme, the programme population, and previous evidence that supports the application of a theory to the problem (Hoelscher *et al.*, 2002). Theories that can be applied to children and adolescent populations include those that take into account environmental influences, peer relationships, and skill development (Hoelscher *et al.*, 2002).

From the study conducted in part one A (establish children and adolescents' requirements), we found that children and adolescents with T1D had low self-efficacy and knowledge to manage their diabetes. In order to enhance self-efficacy and self-management skills we used behaviour change techniques from SCT. Using SCT (Bandura, 1986), a model was developed to improve self-management skills especially dietary management skills in children and adolescents with T1D (Bandura, 1986). Bandura (1986) proposed that behaviour, personal factors, and environmental factors interact to explain and predict changes in behaviour. The proposed model includes two environmental factors (Web-based nutrition education and social support), two personal factors (Self-efficacy and knowledge) and a single behaviour factor (Dietary management).

Social support (environmental factor) from family, health care professionals and peers with diabetes was used to provide support, teach skills, facilitate problem sharing and knowledge in order to improve dietary management skills among children and adolescents with type 1 diabetes. Nutrition education is an important tool in modifying eating behaviour and has been shown to have an important impact on self-efficacy, knowledge and dietary management. While personal factors such as self-efficacy are considered important determinants of behaviour change (dietary management). Knowledge is considered necessary but not sufficient to induce behaviour change and often needs to be combined with self-efficacy.

Figure 8 shows the model framework for the development of a web-based diet and diabetes education programme based on the model proposed by Bandura (1986).

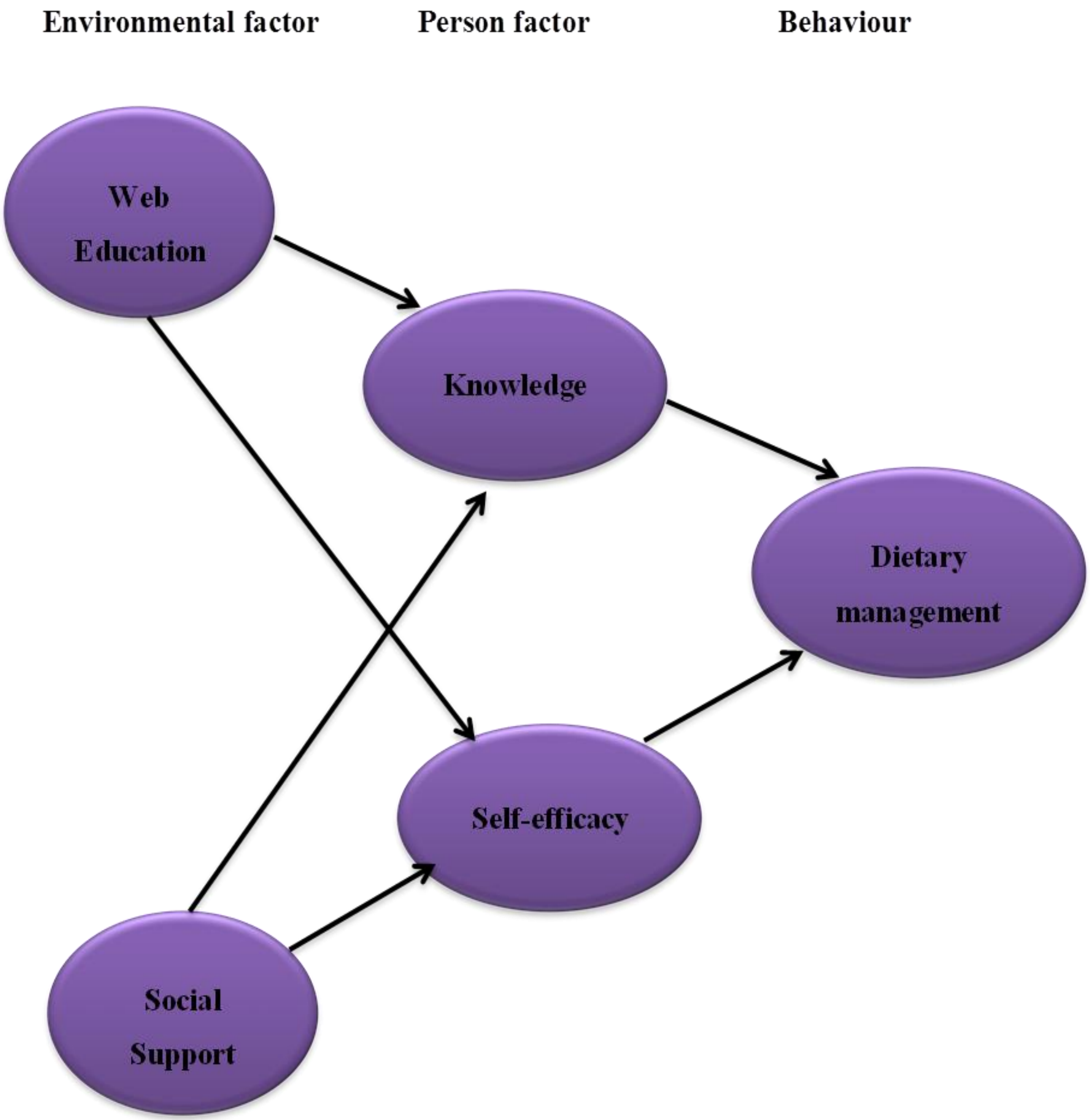


Figure 8: Model framework for the development of a web-based diet and diabetes education programme based on a model proposed by Bandura (Bandura, 1986)

4.3 Part One B: Designing the web database and the components

4.3.1 Needs assessment

The first step in planning effective interventions is knowledge of the problem and the population at hand, both of which can be gained through a thorough needs assessment. In general, assessment of the needs of a population can be accomplished by conducting a literature review, reviewing previously collected data, or assessing baseline data collected specifically for the proposed project (Hoelscher *et al.*, 2002). Data for the project can be drawn from a variety of sources and can be in the form of quantitative data such as dietary intake, or qualitative data which includes focus groups and structured interviews (Hoelscher *et al.*, 2002). Collection of data specific to the intervention will produce the most relevant information. However, in many cases this is not possible due to cost and time limitations. In that case, the researcher needs to rely on data previously collected, such as dietary information from national surveys or similar studies (Hoelscher *et al.*, 2002). Once a thorough needs assessment has been done, the overall goals and objectives for the study must be selected. Goals are general, overarching statements that direct the intervention. Objectives are aims that specify how the general goals will be achieved. For example, if current data show that adolescent girls consume inadequate amounts of fruits and vegetables, a nutrition education intervention may be developed with the goal of increasing fruit and vegetable consumption in adolescent girls. The objectives of the study may include statements such as “Adolescent girls will increase their consumption of fruit by 2 servings per day” (Hoelscher *et al.*, 2002).

In the current study, data collected from part one A, qualitative data (observation) and quantitative data (dietary data) showed that children and adolescents with type 1 diabetes faced a number of challenges in managing their diabetes and dietary intake (Part one A was discussed detailed in chapter two). Results indicated that children and adolescents require an effective Malaysian diabetes education programme that not only provides information about dietary management but also provides social support so that they could seek advice and motivation at anytime and anywhere without needing to wait until their next visit to the clinic. The internet can be an efficient way to promote healthy behaviours in children and adolescents because they generally have access to internet, are accustomed to web-based instruction, and find the modality acceptable (Suminski and Petosa, 2006).

“My Diabetes” is a web-based diet and diabetes education programme that was designed for use by both children and adolescents with Type 1 diabetes and health care professionals involved in their care. Its purpose is to engage and empower patients in self-management with particular focus on dietary management. For the health care professionals the purpose of the system is to assist them in teaching, monitoring and supporting their patients. This web programme contains four components or site features. The *‘E-Learning’* feature educates patients on diabetes and dietary management and contains information on the nutrient content of foods and beverages available in Malaysia. The *‘Diabetes Diary’*, the *‘Forum’* and *‘E-Consultation’* are secure online systems that allow patients to record blood glucose, report dietary intake and send enquires to selected health care professionals. Patients were able to discuss their diabetes-related issues with other patients in a secure environment, while health care professionals monitored or reviewed patient-entered data, provided tailored advice on diet to meet specific individual needs, as well as answering any diabetes- or dietary-related questions.

“My Diabetes” is a secure online system that requires a username and password for the user to log on and browse through the programme. All children and adolescents’ data were protected, and only health care professionals involved in the project were able to monitor their records. However, the *‘Forum’* component and the *‘My Stories’* section could be seen by all users. All four components or features were included in the programme based on children’s and adolescents’ requirements and needs. The finding of what children and adolescents required from the education programme was obtained from part one A of the study conducted among children and adolescents in Malaysia (please refer to chapter two). The system requirement for the website is presented in Table 10. Meanwhile Table 11 shows the different features and components of web-based diet and diabetes education programme based on SCT and behaviour change techniques suggested by Abraham and Michie (Abraham and Michie, 2008).

Table 10: System requirements for the website

Design/ application	Description	Findings from literature/Guidelines/Part One A study
Attractive	The design of the website will look modern and youth orientated. It will be easy to use breaking down barriers and assisting in the research aims. The use of colour in the interface helps highlight important information and can be used to guide users to important information. The use of colourful and bright photos aims to attract user attention.	Colour chosen in designing can affect perception and cognition and therefore can improve understanding and enhance learning process. Children prefer to use attractive combinations of colours (Boyatzis and Varghese, 1993).
Easy to use	The structure and layout of the website will assist the user in navigating to the key areas of the system. The design of the website, especially the homepage is key to ensuring that the user will find the information they require quickly. The site will feature a search box throughout the website with built in dictionary, again ensuring the young target audience can easily find information	Navigation must be simple for users to understand and easy to learn. Web pages that are attractive, intuitive, and functional will encourage users to return (Cook and Dupras, 2004). The search function should be easy to use and allow for users to be successful when searching. Provide a box (entry field) for entering search terms that is at least 35 to 40 characters wide (U.S. Department of Health and Human

		Services, 2006).
Motivating	Windows conventions are followed regarding the design and layout of the menu bar through which users can select modules, open other resources and quit the programme. A navigation control panel containing a list box for sub-topic selection and other tools for navigation is present on every page.	The page layout should help users find and use the most important information. Important information should appear higher on the page so users can locate it quickly. The least used information should appear toward the bottom of the page. Information should be presented in the order that is most useful to users (U.S. Department of Health and Human Services, 2006).
Open source	The My Diabetes (working title) website will be built in an open source content management system (CMS) allowing the administrator to update all website content and allowing all amendments to be made internally for example text or images (rather than outsourcing) By using an open source CMS, new functionally can be added or developed in the future and can be widely supported by the web community. With the website CMS being managed internally and content being editable via any web browser the updates can take place at any time. This will save time and money on future running costs.	
Slick and run on any platform	The website will have a slick user interface which will be fast loading and work on PC, Mac, IPad, IPhone and any other mobile device.	

Multimedia animation	Multimedia and animation will be used in order to motivate users and to help consolidate their knowledge and understanding of diabetes and its dietary management. Animation clips to illustrate the physiological processes of diabetes, and promote a greater understanding where dense text explaining the same processes is less easy to follow. Flash animated graphics added for food library, food label, diabetes symptoms and protein sections.	Multimedia refers to the simultaneous use of text, sound, video (with or without sound), slideshow (with or without narration), images, animation and more. Multimedia improves satisfaction with the learning experience and enriches the teaching (Cook and Dupras, 2004).
Text easy to read and consistent look	Text is easy to read, large enough and clear on the background in order to hold the user’s attention. Each page of textual content looks the same, and hypertext contents pages within each sub-topic are consistent. Text is 14 point and the font consistent within context.	Use at least 12-point font. Research has shown that fonts smaller than 12 points elicit slower reading performance from users (U.S. Department of Health and Human Services, 2006).
E-Learning	A page with information about dietary and diabetes management and online food library. Comprehensive material about type 1 diabetes and dietary management. Objective: As well as informing users of general information the website will feature an updatable database of images and breakdowns of carbohydrate exchanges, providing a great online resource for the patients. The E-learning side of the site is open for patients and clinicians only.	Website interventions were found useful in educating children about their health, improving self-efficacy, improving knowledge, social support and diabetes self-management (refer to chapter: literature review). Patients have problems dealing with foods, trouble reading food labels, and find it difficult to identify carbohydrate

		content of food (Finding from Part One A).
Diabetes Diary E-Consultation The Forum	The other main functionally of the site that the patients/users access is password protected (Diabetes Diary, the Forum and E-consultation). Only patients/users and their clinicians are able to monitor his/her own data. The main admin will create user accounts for clinicians. Clinicians can then create specific secondary user accounts for the patients. For clinicians the site acts as an online reference point and communication tool. Diabetes diary Children and adolescents will be able to record their blood glucose results and dietary intake in the diary. It can provide children with tailored information and personally adapted feedback from clinicians about their current dietary intake and blood glucose profile. Objective: Diabetes diary (password protected) which enables patients to record and monitor their own data. E-Consultation E-Consultation is a platform for interaction between patients and clinicians. They are able to seek advice and feedback from clinicians. This page contains a send button which children and adolescents can click and post questions to the clinician. Objective: To facilitate contact between children and clinicians.	E-Consultation/My Diary Some patients had low self-efficacy. They were struggling with their diabetes management. They required continuing support from clinicians in addition to their parents (Finding from Part One A). The Forum Some of them exchanged personal mobile contact numbers so that they could communicate and share their experiences (Finding from Part One A). Some of them increased their self-confidence at the end of the camp after seeing that their peers were able to perform some of the diabetes management tasks such as correct injection technique and monitoring their blood glucose (Finding from Part One A).

	The Forum/discussion board The Forum or discussion board is an online discussion site. Users can hold conversations in the form of posted messages. They differ from chat rooms in that messages are often longer than one line of text, and are at least temporarily archived. Users can read and send in contributions to the discussions. Previous contributions are stored. Objective: To enhance the possibility to share knowledge and give support to communication between all of the participants.	

Table 11: Features or components of the website, behaviour change technique used and illustrated theoretical frameworks

Features of the website	Aspects of the feature	Tasks	Outcomes	Behaviour change technique (Abraham and Michie., 2008) & Social Cognitive Theory
1. My diabetes diary ***-Glucometer diary***	Children and adolescents will be able to record their blood glucose results in the diary.	Children are encouraged to enter their blood glucose value into the glucometer diary every day.	It will assist patients, parents and HCP in monitoring changes in health and self-care needs.	**Prompt self-monitoring of behaviour and self-monitoring of behaviour outcome** The person is asked to keep a record of a specified behaviour(s) i.e. in diary
-Diet diary	Children and adolescents will be able to record their diet intake in the diary.	Children are encouraged to enter their diet intake into the food diary three times a week	It will assist patients, parents and HCP in monitoring changes in health and self-care needs. It may improve diet intake.	**Prompt self-monitoring of behaviour and self-monitoring of behaviour outcome (SCT)** The person is asked to keep a record of a specified behaviour(s) i.e. in diary

2. E-learning ***-Introduction on diabetes*** ***-Diet management*** ***-Insulin Management*** ***-Blood glucose monitoring***	There is information on what is T1D, diabetes complications and diabetes symptoms, healthy eating, carbohydrate counting and healthy snacks. Future plan Future plan	Children and adolescents will use the information as a guide for them to eat healthy food, and take adequate amount of food based on their insulin dose. They can choose different types of healthy snacks to eat during snack time.	This might improve children's knowledge and help them to manage their diabetes. This might improve self-management skills especially diet management skills.	**Provide instruction on how to perform the behaviour** Telling the person how to perform a behaviour and/or preparatory behaviour. **Provide information on consequences** Information about the benefits and costs of action or inaction, focusing on what will happen if the person does or does not perform the behaviour.
-Food library	This library will contain more than 100 photos of main dishes, desserts, snacks, ready foods, and drinks normally consumed by children and adolescents in Malaysia with carbohydrate**,** sugar and energy contents.	Children and adolescents will use the information as a guide to match their carbohydrate and insulin dose.	This might improve children's ability to match the carbohydrate and insulin and might help to control their blood glucose. This might improve self-management skills.	**Provide instruction on how to perform the behaviour** Telling the person how to perform a behaviour and/or preparatory behaviour.

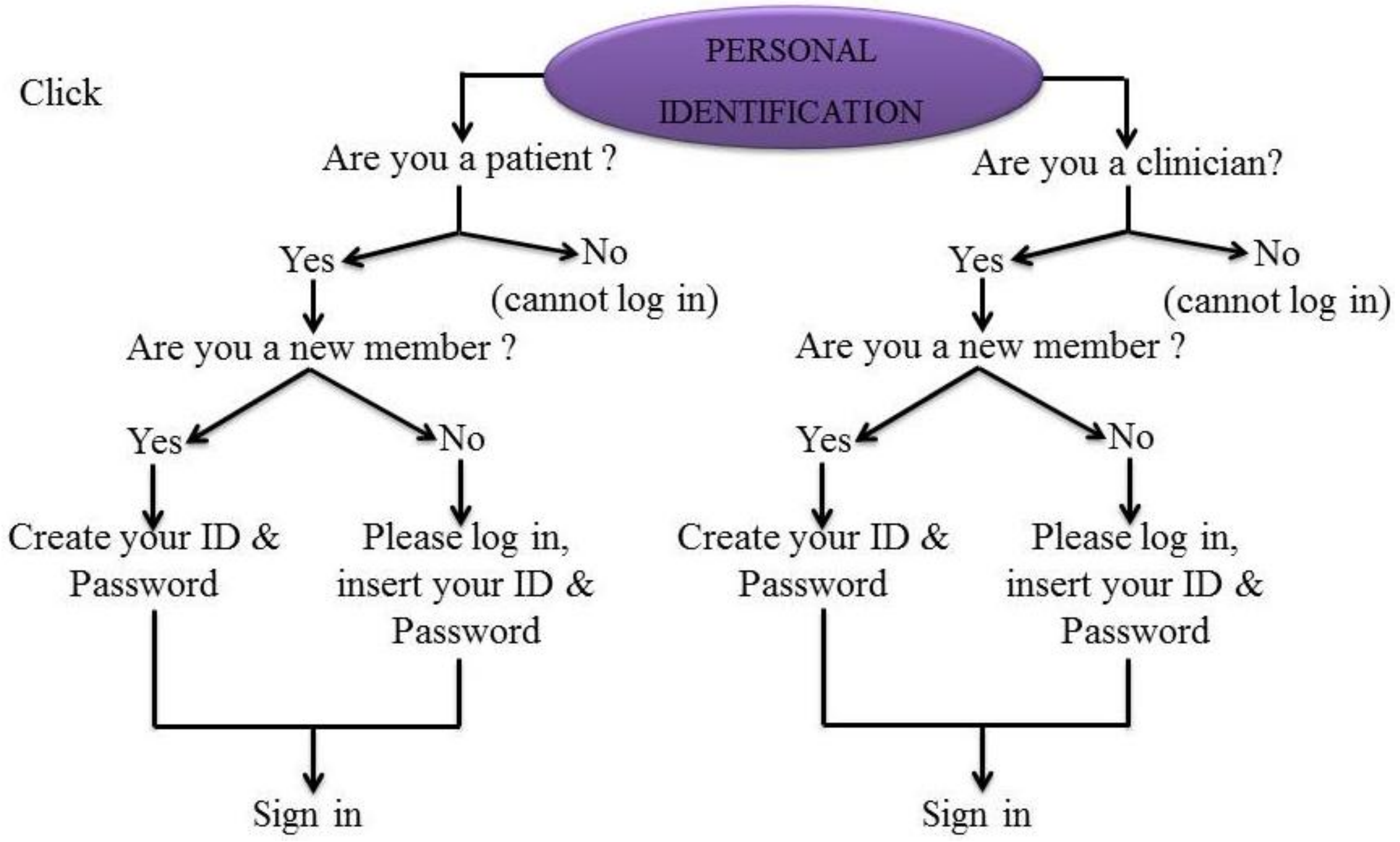
3. Forum ***-My peer support***	Children and adolescents can interact with each other through the bulletin board (discussion board). This bulletin board becomes a platform for social/peer support.	Children and adolescents are encouraged to chat with their diabetic peers at least once a week. Children and adolescents are able to communicate with each other and share problems and information by sending their messages on this bulletin board. Clinicians are able to monitor the forum.	The social support might increase children's and adolescents belief in their self-efficacy to manage their life circumstances and for personal success. It might promote children and adolescents to make behavioural changes by promoting health and effective self-care.	**Plan social support or social change** Prompting consideration of how others could change their behaviour to offer the person help or social support, including buddy system and/or providing social support.
-My Story	A few children and adolescents with good metabolic control will share their experience of how they control their diabetes, enjoy their life like other normal children and success in education and other activities.	Other children and adolescents can also share their experiences or story and get feedback from other peers. Children and adolescents can send their story to the administrator or moderator. After editing, this story will appear under the My Story component.	The social support might increase children's belief in their self-efficacy to manage their life circumstances and for personal success. It might promote children to make behavioural changes by promoting health and effective self-care.	**Plan social support or social change** Prompting consideration of how others could change their behaviour to offer the person help or social support, including buddy system and/or providing social support. **Prompt identification as a role model** Indicating how the person may be an example to others and influence their behaviour or provide an opportunity for the person to set a good example

4. E-Consultation ***-Feedback***	This component is a platform for interaction between children, adolescents and HCP (Doctor, dietician and clinical nurse). Children and adolescents are able to seek advice and get feedback from HCP.	If they need help, children and adolescents can send their question to the HCP by using the send button. HCP receives notification from alert button and replies to the question. Children receive notification that feedback is available for them to read.	It will enhance communication between children, adolescents and their HCP. It might improve self-efficacy and self-management skills.	**Provide feedback on performance** Providing data about recorded behaviour or evaluating performance in relation to a set standard or others performance, i.e. the person received feedback on their behaviour.
-Question and answer (Q&A)	This component contains questions and answers related to diabetes and can be viewed by all the children and clinician. Future plan	The administrator/moderator will edit the question and answer from feedback component and display them under Question and answer (Q&A) component without mention the children's name.		

4.3.2 Establishing the web components

“My Diabetes” was designed and programmed by a web design company ‘Ready Salted’ who are experienced in creating user-friendly interfaces for adults and children, with the original concepts, ideas and assistance from the researcher (RI). The website has a slick user interface which is fast loading and works on PC, Mac, IPad, IPhone and any other mobile devices. It successfully runs on internet explorer 7 or 8; FireFox 1.5, 2.0 or 3.6; Chrome 5; and Safari 4. It requires internet access and Adobe Flash player. The researcher (RI) designed a basic structure for the users (children, adolescents and the clinicians) to log in to the programme first, followed by the *Diabetes Diary*, *E-Consultation*, the *Forum* and finally the *E-Learning* component then worked with the web design company to realise the design. Figure 9 shows a map structure for the users. Figure 10 shows a screenshot homepage.

Figure 9: Map structure for users to log in into the programme



WELCOME TO MY DIABETES

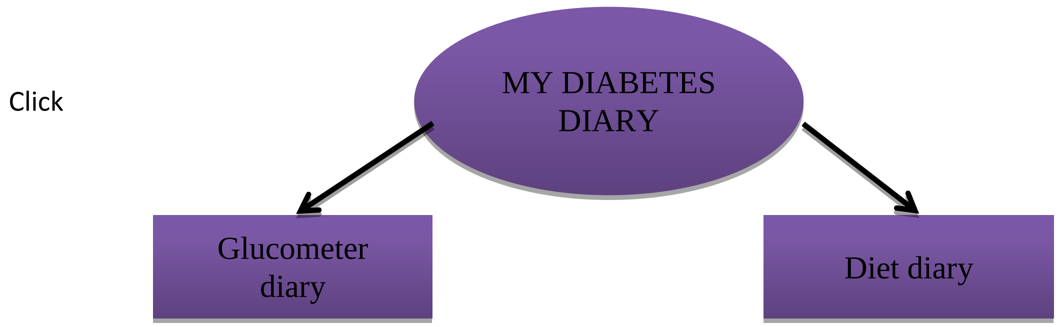
My diabetes is a web based program dedicated for children with type 1 diabetes in University Malaya Medical Centre (UMMC). It contains a lot of information on diet management with more than 300 photos of food and drink available in Malaysia together with energy, carbohydrate and sugar content. All the diet information can be used not only for children but also their whole family.

My diabetes is also a support program which enable children to share their problem and experience with other diabetic children. Children and parents also can seek help and get advice from their diabetes team if they got any problem.

Figure 10: Screenshot of the homepage

Diabetes Diary

The diabetes diary is an online personal diary whereby children and adolescents are able to record their blood glucose results and dietary intake. They are encouraged to record their results every time they check their blood glucose into the glucometer diary. In addition to that, they are asked to record their dietary intake three times a week at baseline, three months and six months during the intervention (into the diet diary). Figure 11 shows the map structure of the online diabetes diary. Figure 12 is a screenshot of the online glucometer diary. Table 12 shows map structure of the online diet diary. Figure 13 shows a screenshot of the diet diary.



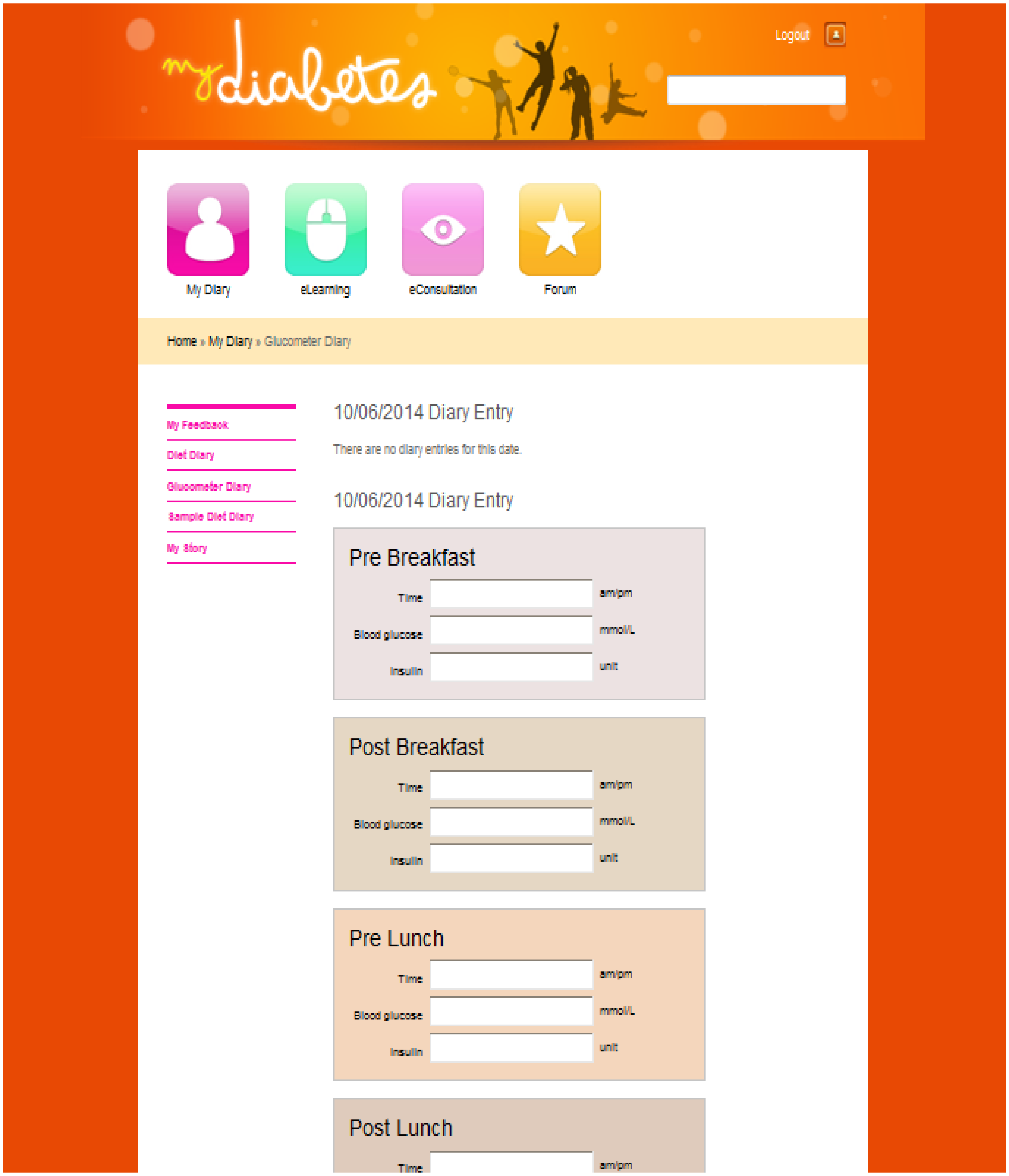
My glucometer

Date		Pre Breakfast	Post Breakfast	Pre Lunch	Post Lunch	Pre Dinner	Post Dinner	Notes/ Remarks
	Blood Glucose (mmol/L)							
	Insulin Dose (unit)							

Patient:

- Please enter your insulin and blood glucose value into this table.
- Do you need any help regarding your blood glucose reading? Yes ____ No ____
  If yes, please click on help button, clinician will give you some advice.

Figure 11: Map structure the online diabetes diary



10/06/2014 Diary Entry

There are no diary entries for this date.

10/06/2014 Diary Entry

Pre Breakfast

Time am/pm
Blood glucose mmol/L
Insulin unit

Post Breakfast

Time am/pm
Blood glucose mmol/L
Insulin unit

Pre Lunch

Time am/pm
Blood glucose mmol/L
Insulin unit

Post Lunch

Time am/pm

Figure 12: Screenshot of the online glucometer diary

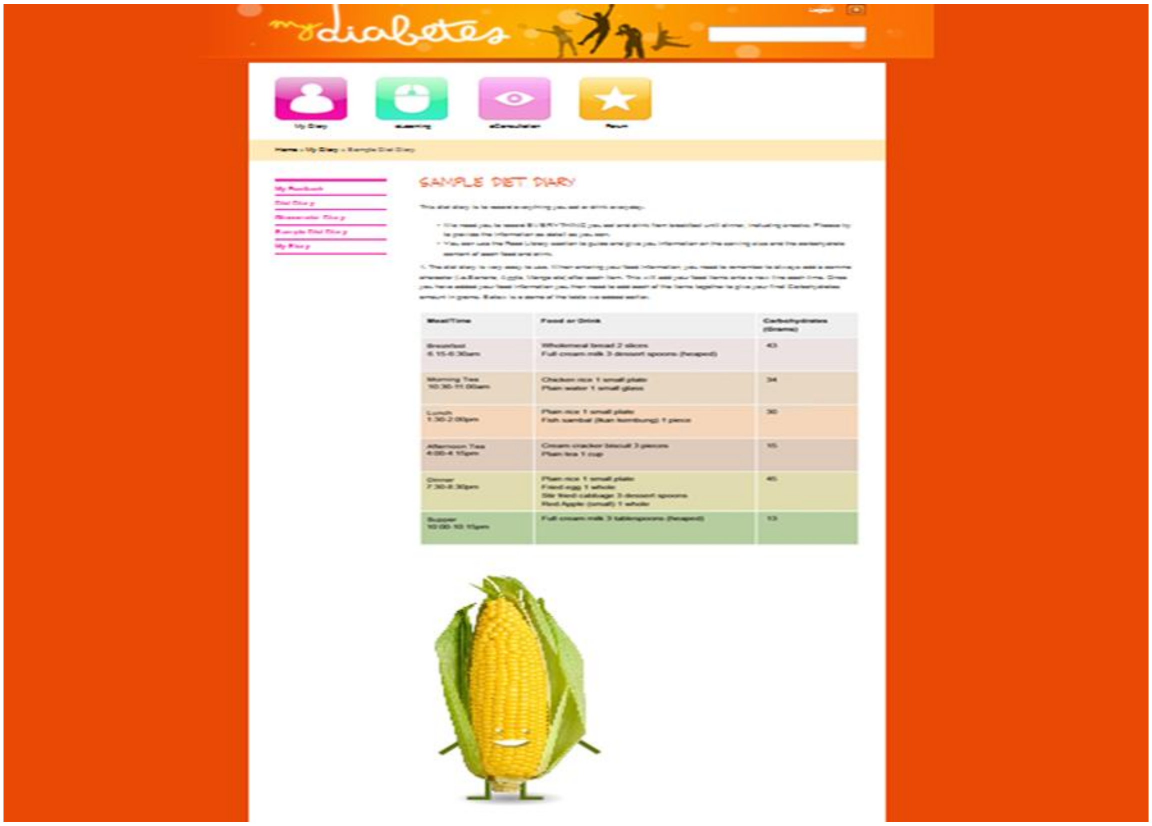
Table 12: Map structure of the online diet diary

My Diet

Date	Meals & Time	Types of food	Carbohydrate (exchanges/gram)
	Breakfast (time)		
	Morning tea (time)		
	Lunch (time)		
	Afternoon tea (time)		
	Dinner (time)		
	Supper (time)		

Patient:

- Please enter your diet intake into this table
- Do you need any help regarding your diet? Yes ____ No ___.
  If yes please click on help button, Dietician will give you some advice.



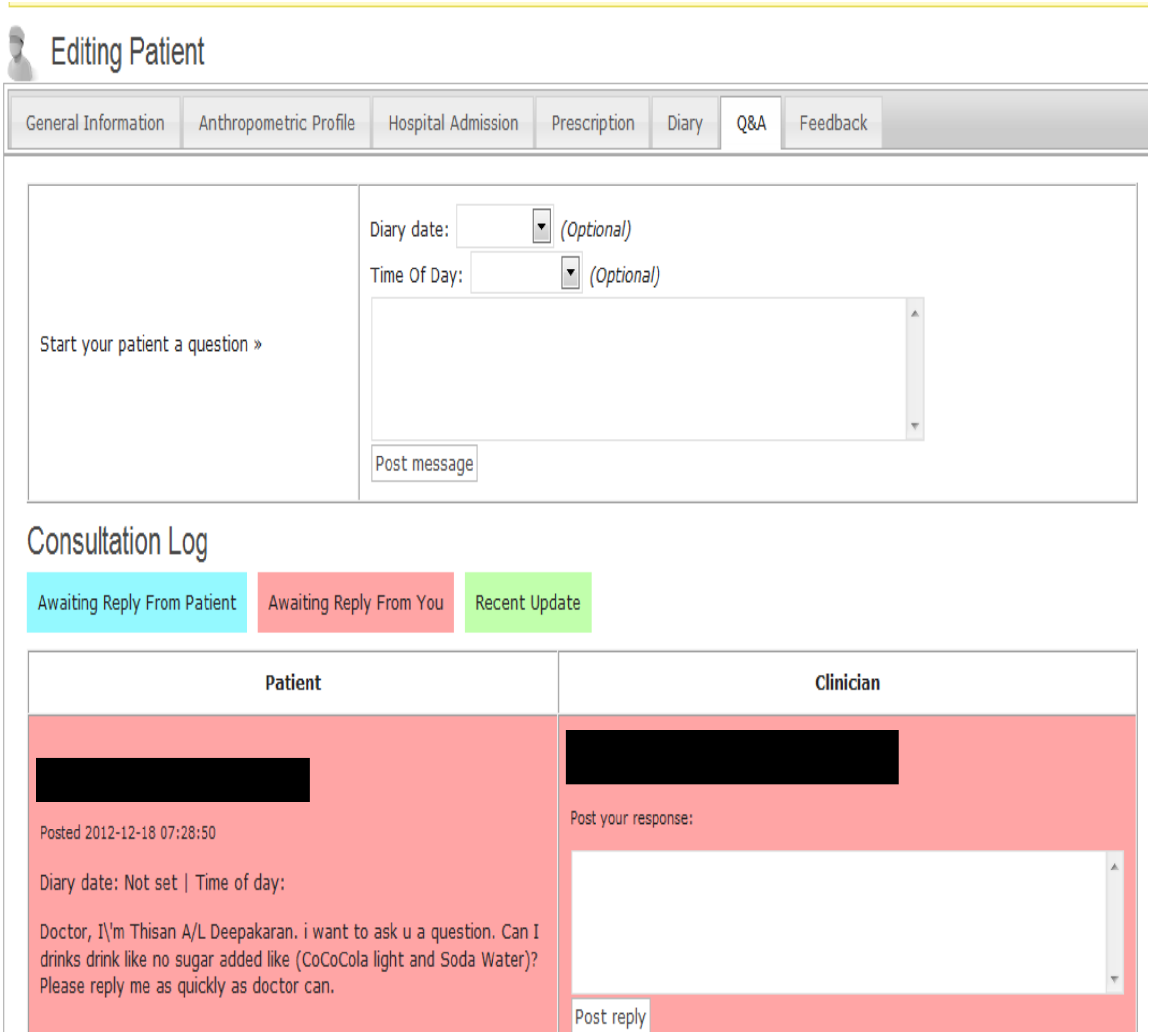
SAMPLE DIET DIARY

Meal/Time	Food or Drink	Carbohydrates (Grams)
Breakfast 6.15-6.30am	Wholemeal bread 2 slices Full cream milk 3 dessert spoons (heaped)	43
Morning Tea 10:30-11.00am	Chicken rice 1 small plate Plain water 1 small glass	34
Lunch 1:30-2:00pm	Plain rice 1 small plate Fish sambal (Ikan kembung) 1 piece	30
Afternoon Tea 4:00-4:15pm	Cream cracker biscuit 3 pieces Plain tea 1 cup	15
Dinner 7:30-8:30pm	Plain rice 1 small plate Fried egg 1 whole Stir fried cabbage 3 dessert spoons Red Apple (small) 1 whole	45
Supper 10:00-10:15pm	Full cream milk 3 tablespoons (heaped)	13

Figure 13: Screenshot of the diet diary

E-Consultation

The E-Consultation component is a platform for interaction between children, adolescents and healthcare professionals (doctor, dietician and clinical nurse). Children and adolescents are able to seek advice and get feedback from health care professionals (HCP). Figure 14 is a screenshot of the E-Consultation page as it appears on the web screen.



Diary date: (Optional)

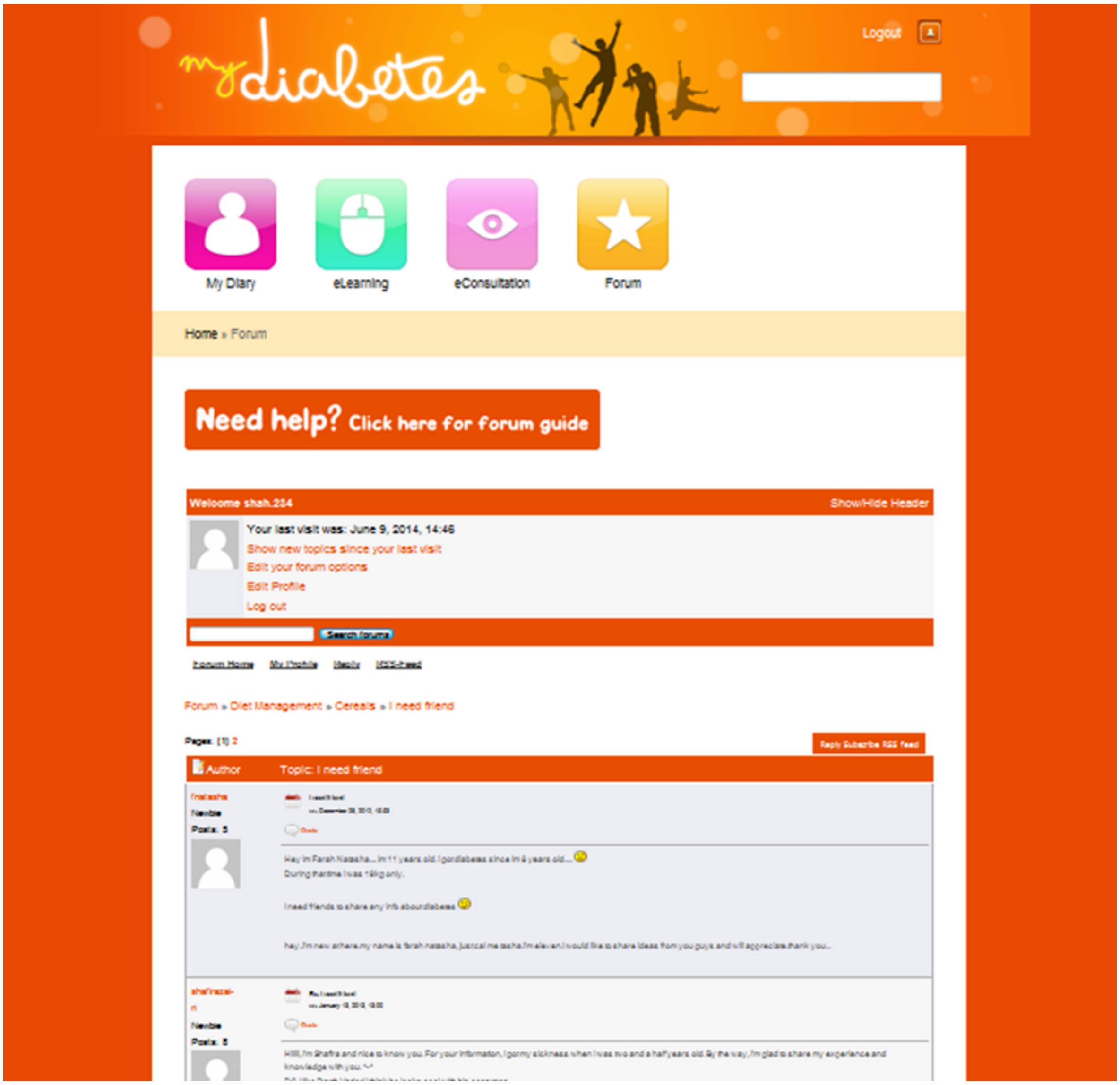
Time Of Day: (Optional)

Patient	Clinician
[redacted] Posted 2012-12-18 07:28:50 Diary date: Not set | Time of day: Doctor, I\'m Thisan A/L Deepakaran. i want to ask u a question. Can I drinks drink like no sugar added like (CoCoCola light and Soda Water)? Please reply me as quickly as doctor can.	[redacted] Post your response:

Figure 14: Screenshot of the E-Consultation

The Forum

The Forum or discussion board is a platform for social/peer support. The Forum is hierarchical or tree-like in structure: a Forum can contain a number of sub forums, each of which may have several topics. Within a forum's topic, each new discussion started is called a thread, and can be replied to by as many people as so wish. Figure 15 is a screenshot of the forum as it appears on the web screen.



Your last visit was: June 9, 2014, 14:46

Figure 15: Screenshot of the Forum

My Story

My story is a platform for children and adolescents share their success stories on living with and managing their diabetes. Children and adolescents are able to get information on how their diabetic peers are able to control their diabetes and success in their life whether in education, career or others. Figure 16 is a screenshot of My Story as it appears on the website.

Do you have a diabetes story you would like to share? sharing helps others with diabetes learn! If we put your story online it won't show your name, so what are you waiting for?

Your story will be held in a queue until it has been approved by a moderator.

Figure 16: Screenshot of My Story

4.4 Part One C: Establishing the education component

The aim of part one C of the intervention was to deliver high quality and up-to-date education, relevant to the user's needs. The content of the educational component was based upon the most recent consensus guidelines from the International Society of Paediatric and Adolescents Society (ISPAD) (*Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence*, 2011) and structured into various topics. In order to verify that the information contained within the educational component was adequate, up-to-date and reliable, and the structure of the component sensible, expert opinions were obtained from the Paediatric Endocrinologist from UMMC and Paediatric diabetes dietician from Royal Victoria Infirmary (RVI), Newcastle. Information on what topics and types of foods needed to be included in the E-learning component was based on guidelines from ISPAD (*Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence*, 2011), and further supported by the findings from part one A (refer to chapter two).

Dietary management is one of the important elements in the management of T1D in children and adolescents. When used in combination with other components of diabetes care, dietary management can further improve clinical and metabolic outcomes (Smart *et al.*, 2009a). Although diet is integral to successful diabetes care, the question as to what dietary education methods to use remains controversial and poorly evaluated (Waldron, 2005). There is no strong evidence to demonstrate that one particular educational tool or method is superior to another (Smart *et al.*, 2009c). To date, most dietary education tools have focused primarily on glycaemic control, and rarely on reducing cardiovascular disease (CVD) risk. The 2009 International Society for Paediatric and Adolescent Diabetes (ISPAD) Consensus Guidelines recommend that nutritional strategies should place equal importance upon glycaemic control and reduction of CVD risk (Waldron, 2005).

Similarly, the 2011 Global International Diabetes Federation (IDF) /ISPAD guidelines advise that dietary recommendations for children with diabetes should be based on healthy eating principles suitable for all children and families with the aim of improving general health, diabetes outcomes and reducing vascular risks (*Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence*, 2011). Different countries and regions have varying cultures and socio-economic characteristics that influence and dominate dietary habits. Consequently, nutrition education must take into consideration the role of cultural, ethnic and familial factors in shaping eating behaviour and food choices (*Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence*, 2011). The education component in *"My Diabetes"* not only focused on carbohydrate intake, but also included material on principals of healthy eating including a discussion of protein requirements for healthy growth, the need for reducing fat intake to reduce CVD risk, and the importance of fibre rich foods in relation to improving blood glucose control. Overall, the food listed in the Food library component of *"My Diabetes"* takes into consideration foods and beverages consumed among all races in Malaysia including Malay, Chinese and Indian along with the findings from part One A (see website http://mydiabetes.readysalteddev.co.uk, username: admin, password: 1234).

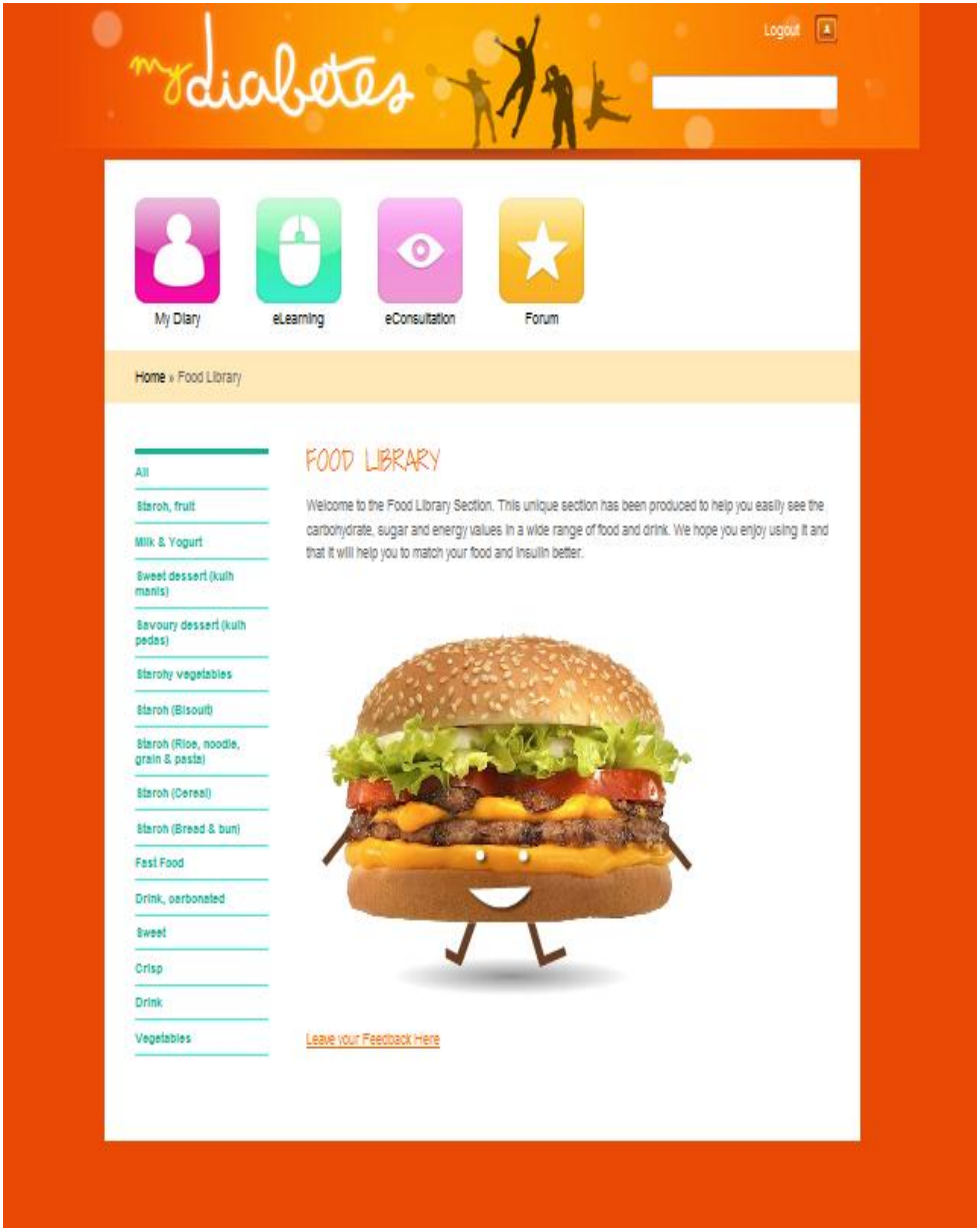
Figure 17 shows information on *"What is type one diabetes"* one of the topics in the E-learning component as it appears on the website. Figure 18 shows the Food library interface. Once the database, system and all the components were designed, developed and ready to use, the first version of *"My Diabetes"* was used in phase two of the study. Figure 19 is a screenshot of the E-Learning homepage.

WHAT IS TYPE ONE DIABETES

Diabetes is a long life disease. In people with diabetes, their pancreas (a large gland behind the stomach), stops making or producing insulin.

Diabetes is a long life disease. In people with diabetes, their pancreas (a large gland behind the stomach), stop making or produce insulin.

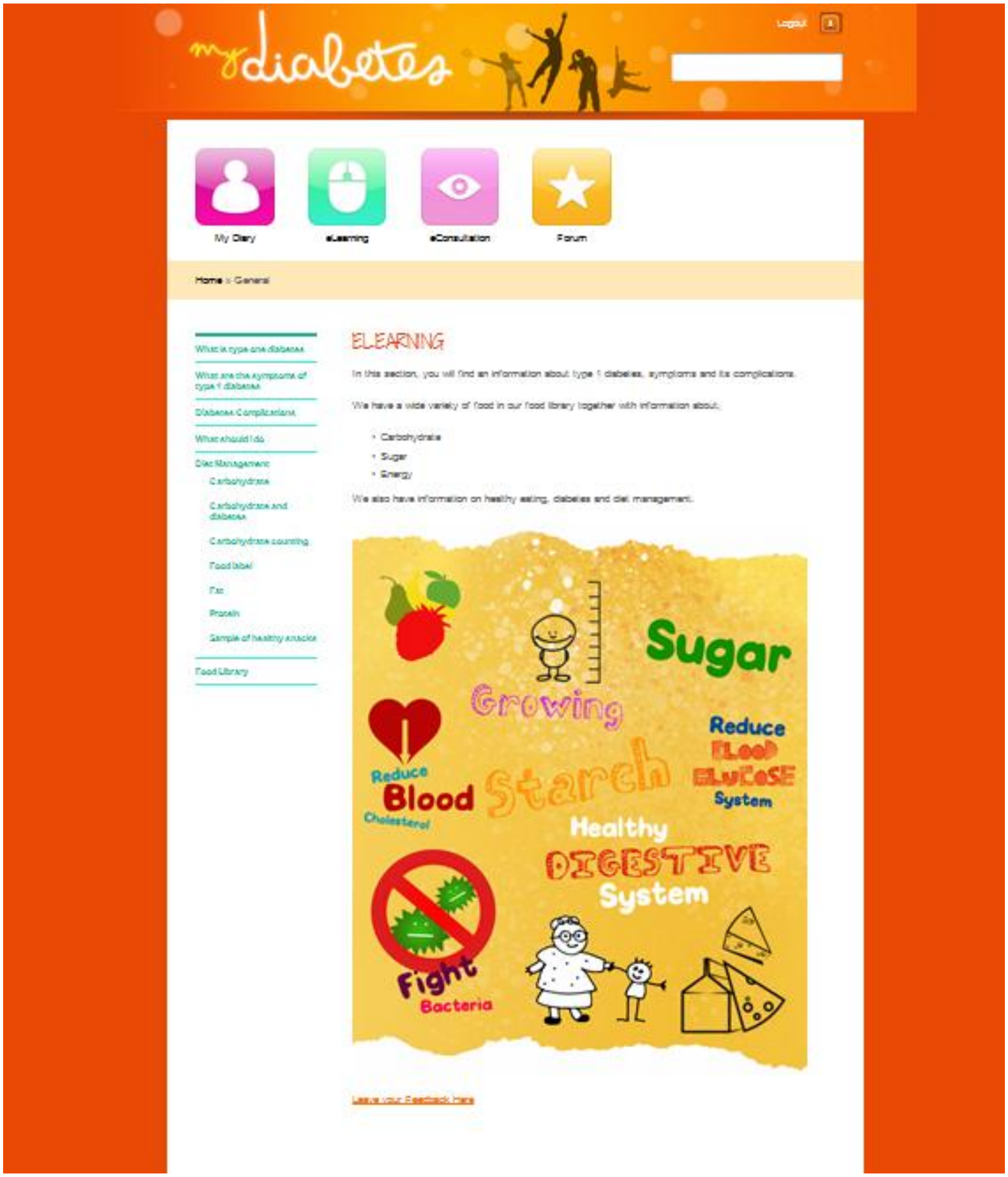
Figure 17: Screenshot one of the content in E-Learning



FOOD LIBRARY

Welcome to the Food Library Section. This unique section has been produced to help you easily see the carbohydrate, sugar and energy values in a wide range of food and drink. We hope you enjoy using it and that it will help you to match your food and insulin better.

Figure 18: Screenshot of the Food library interface



ELEARNING

In this section, you will find an information about type 1 diabetes, symptoms and its complications.

We have a wide variety of food in our food library together with information about.

- Carbohydrate
- Sugar
- Energy

We also have information on healthy eating, diabetes and diet management.

Figure 19: Screenshot of the E-Learning interface

Chapter 5 Feasibility study in Newcastle (Phase two)

5.1 Introduction

This chapter describes Phase two of the research study which was undertaken after designing the web-based education programme in order to test usability and participants' acceptability with this programme and to assess the feasibility of the research process. The chapter includes the aim and objective of Phase two, the methodology, a discussion of the findings and the limitations of the research study. The results from this Phase were used to refine the programme and the refined version of the web-based programme was then used in Phase three of this study (chapter 6).

5.2 Objective

To undertake usability testing in order to test the general usability and acceptability of the system and gain feedback on the web-based diet and diabetes education programme with Malaysian children and adolescents living in Newcastle. It was intended that the programme would to be visually appealing, to be easy to navigate, and provide understandable and meaningful information. The children taking part in this Phase of the study were of similar age to the target population but did not have diabetes (T1D). Testing by children with a similar age to the target population (end users) was necessary to ensure that these aims are met.

Usability testing refers to evaluation through the analysis of typical users interacting with the programme, allowing for iterative modifications (Kushniruk, 2002). It can give valuable information on user experiences and help the developer and researcher determine if a programme will turn out to be effective and achieve its purpose (Currie *et al.*, 2010; Thompson *et al.*, 2012). The vast amount of usability problems and issues can be identified with only a small number of test subjects, as few as 8 to 10 participants (Kushniruk, 2002).

5.3 Methodology

5.3.1 Participants and recruitment

The recruitment of participants for Phase two of the study started in early November 2012 following approval from the Newcastle University Ethics Committee. Twelve children and adolescents were recruited from the Malaysian community living in Newcastle. Malaysian children without mental health problems, leaning difficulties or disability living in Newcastle were asked to take part. Only those between the ages of 10-14 years were asked to participate. The Newcastle Malaysian Society Committee agreed to assist with recruitment and identified eligible families from their records. The Newcastle Malaysian Society is a nonprofit and voluntary organization which is responsible for assisting and helping Malaysian students and their families in studying, working and living in Newcastle. Recruitment packs were given to the committee who sent these to eligible families on behalf of the researcher (RI). The packs included a study information sheet [Appendix 5] consent and assent form [Appendix 6] and a covering letter [Appendix 7] along with a pre-paid envelope to return the consent form. The covering letter asked families to contact the researcher (RI) directly [by telephone, email or letter] if interested in taking part. The researcher then contacted the families by phone to discuss the study, and answer any questions. A study information sheet was given to all parents and children explaining the study and its procedures (Appendix 5). The researcher's contact details were included so that they could get in contact for further information. The study was explained verbally to all parents and children and any questions were answered. The consent and assent forms were completed by participants and sent back to the researcher via post using the pre-paid envelope. If they agreed to participate, the researcher went to their home at a mutually convenient date and time.

All participants chose their home as a place for the meeting. The meeting was conducted with parents in a different room. At the meeting, participants were given a demonstration of the web programme and its services, along with a username and password which allowed them access onto the *"My diabetes*" system. They were encouraged to use the programme at home for two days; to explore and browse all components by themselves. While using the programme, they gave their comments and suggestions for improvement for each component in a feedback form located at the end of each component. After two days, the researcher called the participant to identify whether they were finished using the programme and to collect their feedback. At the same time, the researcher arranged to go to the participant's home to conduct an interview. Interviews were conducted with the participant only after the period of using the programme at home, where parental consent was given, to collect their feedback on the system including their views on, satisfaction with and acceptance of the system. Refer to Figure 20 for phase two study flow chart.

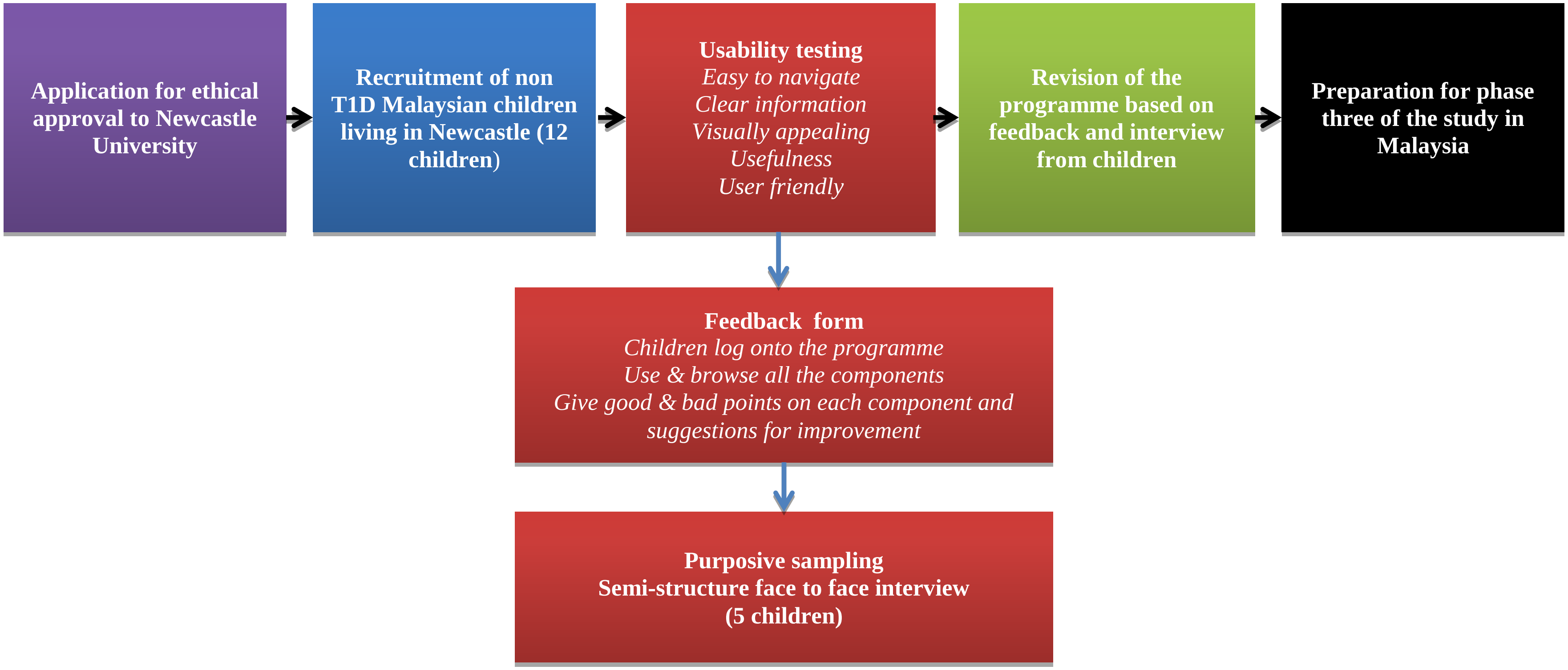


Figure 20: Phase two study flow chart

5.3.2 Research design

Qualitative methods were adopted for the usability testing with semi-structured interviews and open ended questions (feedback form) used to assess how the participants used and experienced the programme. Usability tests were carried out in two sequences, first by an open ended question (feedback form) used during the testing period and secondly by a semi-structured interview after two days of exploring and using the systems.

5.4 Data collection

All participants were asked to complete a self-report questionnaire that included basic demographic data. Participants used the feedback forms (open ended questions) to give their comments and suggestions about the programme. The interview was conducted to clarify their answers and to allow them to express their views and acceptance of the system.

5.4.1 Demographic data

Basic data consisting of age, gender and educational level were collected at baseline.

5.4.2 Feedback form (open-ended questions)

The feedback form was located at the end of each component in the web programme. This feedback form is a blank table for free text writing. This form used two open-ended questions first: “How would you improve this section”? and second: “Any other comments”? The feedback form was designed in such a way that children and adolescents had the freedom to express their views in response to the question asked without any influence or clues from the researcher. This feedback form could be used to gather facts about children and adolescents’ experiences and challenges in using the web-based education programme. The feedback regarding experiences using the web programme was gathered from Malaysian children and adolescents living in Newcastle.

In 2008, Ballou published a paper in which she described “The open ended-question does not provide answer categories” (Ballou, 2008). The respondent who is asked this type of question formulates the answer and gives the response in his or her own words (Ballou, 2008).

According to Bryman (2012), open-ended questions have certain advantages as described below (Bryman, 2012):

- Participants can answer in their own terms. They are not forced to answer in the same terms as those foisted on them by the response choices.
- They allow unusual responses to be derived.
- The questions do not suggest certain kinds of answer to respondents. Therefore, participant' levels of knowledge and understanding of issues can be tapped. The salience of issues for participants can also be explored.
- They are useful for exploring new areas or ones in which the researcher has limited knowledge.
- They are useful for generating fixed-choice format answers.

5.4.3 Semi-structured interviews

Bowling (2009) points out that an interview includes the collection of data through talking to respondents (interviewees) and recording their responses (Bowling, 2009). There are three types of interviews: structured, unstructured and semi-structured (Crabtree and Miller, 1999; Patton, 2002). Structured interviews are based on questions that are asked of each and every participant (Crabtree and Miller, 1999; Patton, 2002). There is no variation in the questions between participants. Whereas unstructured or informal conversation interviews have no predetermined set of questions (Crabtree and Miller, 1999; Patton, 2002). According to some authors, the interviewer starts the conversation with a broad/holistic question (e.g. Tell me about your life?). Semi-structured interviews strike a balance between a structured interview and unstructured interview (McCracken, 1988; Gubrium and Holstein, 2002). Additionally, in the semi-structured interviews the questions are open ended thus not limiting the of the respondents/interviewees choice of answers (McCracken, 1988; Gubrium and Holstein, 2002). The purpose of the open ended question is to provide a setting/atmosphere where the interviewer and interviewee can discuss the topic in detail (McCracken, 1988; Patton, 2002; Creswell, 2003). The interviewer therefore can make use of cues and prompts to help and direct the interviewee into the research topic area thus being able to gather more in depth or detailed data set (McCracken, 1988; Patton, 2002; Creswell, 2003).

In 1995, Morse et al. described, the semi-structured interview as being used when the researcher knows most of the questions to ask but is unable to predict the answers. It is useful because this technique ensures that the researcher will obtain all information required, at the same time it gives the participant freedom to respond and illustrate concepts. It is advisable to establish an informal tone during the interview, so that the participants are able to explain their situation in their own words. According to Bryman (2012), for the semi-structure interview, the researcher has a list of questions or fairly specific topics to be covered (referred to as an interview guide), but the interviewee has a great deal of leeway in how to reply.

The interview may be conducted face-to-face or by telephone (Bowling, 2009). Face-to-face semi-structured interviews were carried out among children and adolescents in Newcastle. The advantages of face-to-face interviews are: interviewers can probe fully for responses and clarify any ambiguities; more complicated and detailed questions can be asked; more information of greater depth can be obtained; inconsistencies and misinterpretations can be checked; there are no literacy requirements for respondents; questions in structured schedules can be asked in predetermined order; response rates are generally higher with friendly interviewers than for questionnaires which are sent through the post or telephone interviews (Bowling, 2009). The open-ended questions can be included in the questionnaire so that respondents will be able to provide their opinions in full on more complex topics (Bowling, 2009). They also provide rich and quotable material which enlivens research reports. Normally for topics which are largely unknown or complicated the open-ended questions will be used (Bowling, 2009).

A sub-sample of five participants agreed to participate in a semi-structured interview following the period of time exploring the programme at home. The interview took place in the participant’s home at a mutually convenient date and time. The researcher informed the participants of the aims of the interview and that their names would remain confidential, and collected only for research purposes. An interview topic guide along with their answers from the feed-back form were used as a guide [Appendix 8]. A general introductory question was asked, followed by broad questions and probes to encourage the participants to elaborate on their views and comments. In order to make sure participants felt comfortable and there was minimal distraction, all interviews were conducted in a room chosen by the participants with parents' absence. The interview lasted approximately 40 minutes and no more than an hour. After five interviews were completed, content saturation was achieved and no more interviews were scheduled. Interviews were digitally recorded and transcribed verbatim by the researcher.

5.5 Data analysis

Qualitative data from the interviews and feedback from participants were analysed using a system of coding and framework analysis facilitated by the use of NVivo software. Table 17 shows the thematic charting (coding framework) collected from the interview and feedback form.

5.6 Results

5.6.1 Demographic characteristics

The study sample's characteristics are presented in Table 13. A total of 12 children and adolescents (42% boys, 58% girls) participated in the study. The sample was of Malay ethnic background and ranged from 10 to 14 years old (mean = 12.58 ± 1.31).

Table 13: Participants characteristics (Phase two)

Number of participants	**N = 12**
Sex	
Boys	*5 (41.7%)*
Girls	*7 (58.3%)*
Age	
Mean (SD)	*12.58 (1.31)*
Ethnicity	
Malay	*12 (100%)*
Level of education	
Key stage 1	*0 (0%)*
Key stage 2 (10 years old)	*1 (8.3%)*
Key stage 3 (11-14 years old)	*11 (91.7%)*

5.6.2 Feedback form data

Table 14 shows the feedback and suggestions from the participants collected through the feedback form which was located at the end of each component in the programme.

Table 14: Feedback from children and adolescents

Component of My Diabetes	**Actual comments and feedback from participant (Direct quotes)**
Section: My Diary	**Participant 2 (Boy, 13y.o):** I think you should do more bright colours like bright red and other colours. That I don't understand it either. **Participant 4 (Girl, 14y.o):** This page was quite plain because only one picture was used and the font and colour did not stand out. The font should be eye catching and bolder because now it is very faded and not likely to be looked at. **Participant 5 (Boy, 13y.o):** Improve it to make more attractive and colourful for users because at the moment it is just plain. **Participant 6 (Boy, 12y.o):** It is easy to read but try to make the table in colour to make it more attractive for age 10-12 and when it says 'My Diary' on the top make it in another writing style which kids like. **Participant 7 (Girl, 13y.o):** Put something on. Maybe a bit more colourful. **Participant 9 (Boy, 13y.o)**: We do not know our weight and height on the information about us, so we can cannot know how much our weight before we follow this diet. We also will know that this program is success or not. It is also for us to make decision that this programme gives any good to us or not. **Participant 10 (Boy, 13y.o):** The timetable is helpful and friendly user. However it's depend whether he got time or not to do it. What is morning tea and afternoon tea? Colourful and entertaining. We could add pictures of foods on the background e.g. pictures of bread and milk on the breakfast section. **Participant 11 (Girl, 11y.o):** In this section I want you to put more nice picture so it will look more cool and children want to know more. **Participant 12 (Girl, 14y.o):** Not really understand for what purpose. Attractive. Simple and easy to understand. **<u>Summary</u>** **Most of the participants suggested adding more colours and adding some picture to the diary in order to make it more attractive.**
Section: E-Learning home page	**Participant 2 (Boy, 13y.o):** I think I really understand it and that I really like the picture and I understand it.

	Participant 3 (Boy, 13y.o): This section looks very good and to improve it you could maybe put more colour into it and animations. **Participant 4 (Girl, 14y.o):** This page is fine the way it is, especially by the use of creative fun pictures. **Participant 5 (Boy, 13y.o) :** The picture is great and suitable for kids. More information and facts about the page. **Participant 6 (Boy, 12y.o):** The picture of the information on healthy eating, diabetes and diet management is very colourful and very attractive for kids. Kids will understand what is the picture trying to explain as it is easy to understand and clear pictures and colourful words. **Participant 9 (Boy, 13y.o)**: This photo looks really good and colourful, even though it looks good, some of the word are quite difficult to understand especially for the young people like us. Some of them that speak another language also hard to find the meaning of the words. **Participant 10 (Boy, 13y.o):** You could improve it by adding more information into e-learning introduction such as, information about the population who has diabetes. Although it needs more information, e-learning introduction is very vibrant, attractive and eye-catching. Overall for e-learning you should change the size and style of the font due to children age 10 to 14. Add vibrant colours and moving pictures. **Summary** **Some of the participants commented that the photos and colours were attractive and suitable for the children and adolescents. A few of them were suggested adding additional information and changing some of the words so that it was easy for them to understand.**
2.1 Sub section: What is type 1 diabetes	**Participant 2 (Boy, 13y.o):** I would not improve anything on this section. I like how you gave a title and that how the font stands out that people can read it. It is very bold as well. I think you could give more writing on this section. I think I really like it. **Participant 3 (Boy, 13y.o)**: I really like the moving pictures and it's got good information inside it. The writing on the bottom is the colour grey maybe change the colour so you can see it better. **Participant 4 (Girl, 14y.o):** It should be more outstanding and eye catching, because once you catch their eyes, the attention will be on the description. **Participant 5 (Boy, 13y.o):** Nothing to change in this section because the animation is great. **Participant 6 (Boy, 12y.o):** The numbers shown on the pictures should be on the top not at the bottom because it is hard to notice the numbers. Secondly, make the words and the table more bigger to the kids can easily read it. Thirdly, when it shows on the first clip of the pictures it says that 'G – Glucose', the words fond is very small and very hard to notice it. Lastly, on the seventh clip of the pictures it

	says that 'the fat is broken down to this energy instead', I can't really understand that and also I can't understand what is the picture trying to say. **Participant 7 (Girl, 13y.o):** It would be much better if there's more writing and little bit more information in this section. **Participant 8 (Girl, 11y.o):** When going through the slideshow I thought It had a sound activated for it to explain more better. Also, you could add a slideshow showing where it ends. The font could be slightly enlarge it to make it easier to read. Below the slideshow there could be a bit more writing to explain the slideshow purpose. **Participant 10 (Boy, 13y.o):** You could improve the video by making it simpler due to students at the age of 10. Also, it might have been more entertaining by adding sound to it. Thanks for the video, I will keep it in mind until my biology test. Moreover, it helps people to understand why diabetes happens. **Participant 11 (Girl, 11y.o):** The information is too lengthy. The picture is nice and it give me more information about what is happening. **Participant 12 (Girl, 14y.o):** I can't understand on my own, I need my mom to explain. Too lengthy, difficult to understand. **<u>Summary</u>** **Some of the participants commented that the animation photos were attractive and the page contains good information and made suggestions for additional information. Conversely there were comments that information should be simplified and the font size made larger.**
2.2 Sub section: What are the symptoms of type 1 diabetes	**Participant 1 (Girl, 14y.o):** List the stuff out inside of putting them all in one bug picture because it is too scattered and children will get very confused. Pictures are very colourful and will attract then person's attraction. **Participant 3 (Boy, 13y.o)**: This section is nice, it's plain and it's easy. It's also better for the children to understand. **Participant 5 (Boy, 13y.o):** Need to put animation to make it looks good. **Participant 6 (Boy, 12y.o):** The picture is very good and very easy to understand. If the kids can't really understand they will still understand by looking at the pictures. **Participant 7 (Girl, 13y.o):** The picture is very useful but could be better if there's few writing. **Participant 8 (Girl, 11y.o):** I think the heading should be bold and bigger to show that it's a heading for that page. I thought there could be a small description before showing the poster. **Participant 9 (Boy, 13y.o)**: Put description below pictures under symptoms. **Participant 10 (Boy, 13y.o)** I cannot think of any simpler way to improve the page.

	JOB WELL DONE! The page helps us to learn new words by adding picture next to it such as lethargy as in sleeping. **Participant 11 (Girl, 11y.o):** I want you to put colour on the old woman and the little children because it look so boring without the colour. **<u>Summary</u>** **Some of the participants commented that the pictures were good, colourful, useful and attractive. A few of them also commented the information was easy to understand and they had learned new words. A few of them also suggested adding an explanation under the pictures.**
2.3 Sub section: Diabetes complications	**Participant 1 (Girl, 14y.o):** The pictures show a good example. **Participant 3 (Boy, 13y.o)**: By putting more information like how bad it effects your health in a different font. **Participant 5 (Boy, 13y.o):** Change the image because it can scared little kids. **Participant 6 (Boy, 12y.o):** Very clear pictures. **Participant 7 (Girl, 13y.o):** The information are very useful, but the pictures are quite shocking. Also, you might need to change the language, cos it’s quite hard for children to understand. **Participant 8 (Girl, 11y.o):** To start off, you could use underlining the heading. Then the pictures could be less shocking and maybe stick to 1 type of picture (model or photograph). I like how you list the damages **Participant 10 (Boy, 13y.o):** You could add more facts to it such as; gangrene can lead to …. and this meant that ….The picture really puts attention to people. It also makes them think about their healthy lifestyle. **Participant 11 (Girl, 11y.o):** The photo is scary because its about blood and bacteria and more other disgusting things, I think you should change it to a cartoon picture so it doesn’t look that disgusting and children would like to know more about it. **Participant 12 (Girl, 14y.o):** Too simple. Write instruction below photos. **<u>Summary</u>** **Some commented that the photos showed good example while there was some suggestions that some photos be replaced with different photos and that an explanation should be added under each images.**
2.4 Sub section: What should I do	**Participant 3 (Boy, 13y.o)**: It’s got good pictures and good advice and children will be able to understand it. **Participant 5 (Boy, 13y.o):** Put animation on and make the page look more colourful. **Participant 6 (Boy, 12y.o):** Very colourful pictures and healthy looking food.

	Participant 7 (Girl, 13y.o): Very very useful. **Participant 8 (Girl, 11y.o):** Very good however bigger writing. **Participant 10 (Boy, 13y.o):** You could improve it by adding extra information. One of the method; checking blood, might not be suitable for the age between 10 and 14 because its painful. **<u>Summary</u>** **Some of the participants commented that the information was easy to understand, useful and colourful pictures. A few of them made suggestion for extra information, bigger writing and extra animation pictures.**
2.5 Sub section: Diet management	**Participant 3 (Boy, 13y.o)**: There's some grammar mistakes and it doesn't really make sense but the information is good. **Participant 5 (Boy, 13y.o):** Animation because this section is the most important **Participant 8 (Girl, 11y.o):** You could explain why it's important to have it otherwise good. **Participant 10 (Boy, 13y.o):** Maybe the information to the section is too short for kids between the age of 10 and 14. Simple and yet completely vibrant and cartoony. **Participant 11 (Girl, 11y.o):** Put more about food that we should eat every day and the food that we shouldn't eat it every day. **<u>Summary</u>** **Some of the participants indicated that the information was simple and had good explanation. There were suggestions for extra information and adding more animation pictures.**
2.6 Sub section: Carbohydrate	**Participant 3 (Boy, 13y.o)**: This section is really good, the pictures are good especially for children. **Participant 5 (Boy, 13y.o):** More facts and information. **Participant 6 (Boy, 12y.o):** Very simple short information that children could understand and lots of pictures to look instead of words so it will not make it boring for children to look. **Participant 7 (Girl, 13y.o):** Probably the best pages among the others. **Participant 8 (Girl, 11y.o):** Try to use a same quality of pictures and add a brief information to explain why it helps. You could also tell the impact of getting carbohydrate. **Participant 10 (Boy, 13y.o):** The page contains lots of information. No needs to improve. I like the fact about the carbohydrate; the page entertains me.

	Summary **Some of the participants commented that this section was good, informative, was easy to understand and contain good pictures. There were some suggestion for extra information to be included.**
2.7 Sub section: Carbohydrate and diabetes	**Participant 1 (Girl, 14y.o):** Have it more colourful and not too plain. The text should be different fonts. There is lack of games. **Participant 3 (Boy, 13y.o)**: The picture is really good because it shows you need to plan your meal before you eat and the writing is good as well because it's in capital letters and it shows that you need to do it also the red writing. **Participant 6 (Boy, 12y.o):** Cut in paragraph so it makes it easy for children to read and the words are in colour to show that is important. **Participant 7 (Girl, 13y.o):** Very good. Lot's of information and simple **Participant 8 (Girl, 11y.o):** I think you could add the underline all the headings for the whole category and try to keep the distance between on line to another the same. **Participant 10 (Boy, 13y.o):** You could add more advice and link it to facts. Good advice. **Summary** **Some of the participants commented that the page contain a lot of information, simple and provide a good advice. A few of them suggested for more information and more colours be added.**
2.8 Sub section: Carbohydrate counting	**Participant 3 (Boy, 13y.o)**: The animation is good and there are lots of information which we need to know about what you have put in and that's really good. **Participant 5 (Boy, 13y.o):** More picture and information about the page **Participant 6 (Boy, 12y.o):** Very easy to understand and nice looking big moving picture. **Participant 8 (Girl, 11y.o):** You could add more pictures otherwise good. **Participant 10 (Boy, 13y.o):** You could improve on the text and add background picture. I prefer less writing for the sake of younger patients. **Participant 11 (Girl, 11y.o):** The picture is really good but can you put more picture on this page because it look a little bit boring but the good thing is that I understand about it. **Summary** **Some of the participants commented that the information was good and easy to understand and had nice pictures. A few of them suggested for extra pictures should be included.**
2.9 Sub section: Food label	**Participant 3 (Boy, 13y.o)**: This section is good the presentation is also good. I can understand it because it hasn't got any hard words inside it. So a child would be

	able to read it as well. **Participant 5 (Boy, 13y.o):** More facts and information for readers. **Participant 6 (Boy, 12y.o):** Very big clear picture and the words are very easy to read because of the highlight and clear information. **Participant 8 (Girl, 11y.o):** Good nothing to comment about. **Participant 9 (Boy, 13y.o)**: Good. **Participant 10 (Boy, 13y.o):** Maybe moving arrows to attract children and change the colour to make it more vibrant. The text might be complicated for children patient. **Participant 11 (Girl, 11y.o):** It’s interesting but I don’t understand what is happening and the information is too long. **<u>Summary</u>** **Most of the participants commented that the page was good and the information was easy to understand. A few of them suggested simplifying the information and adding extra colours.**
2.10 Sub section: Fat	**Participant 1 (Girl, 14y.o):** The font is quite small and there is no background to the section. The examples are really good because they have pictures and explain clearly what the person needs to do. **Participant 3 (Boy, 13y.o)**: There’s good pictures and good examples for what they are. **Participant 5 (Boy, 13y.o):** More information, **Participant 6 (Boy, 12y.o:** Very big clear pictures and kids will understand it very easily also will not make it boring for them. **Participant 7 (Girl, 13y.o):** Good good. **Participant 8 (Girl, 11y.o):** You could maybe tell some of the impacts of being fat and tell why we can’t be overweight. **Participant 9 (Boy, 13y.o)**: Interesting. **Participant 10 (Boy, 13y.o):** The first picture was dull therefore it needs improving. You also could add sounds to annotate the foods. **Participant 11 (Girl, 11y.o):** Can you put more picture on it but I think it really good I understand what happening in this page. But some of the page I don’t understand because the information is too long. **Participant 12 (Girl, 14y.o):** What is saturated fat? Cannot understand the explanation.

	Summary **Some of the participants commented that the page was interesting, easy to understand, contain good pictures and provide examples. A few of them requested more information and some changes some of the words to make text easier to understand.**
2.11 Sub section: Protein	**Participant 3 (Boy, 13y.o)**: There's good examples of different things inside and good information. **Participant 4 (Girl, 14y.o):** For the title on every page it should be a different colour other than black or purple. It should be a different font as well and not underlined, how it looks now makes it seem boring and unappealing. **Participant 5 (Boy, 13y.o):** More information in each picture. **Participant 6 (Boy, 12y.o):** Very clear and big picture. **Participant 7 (Girl, 13y.o):** Very colourful, would love some more writing. **Participant 8 (Girl, 11y.o):** You could tell how the food help and what you should eat more. You could tell what happen if you don't have enough protein. **Participant 10 (Boy, 13y.o):** The first page is attractive however the colour doesn't look like they are blending together. I like it when you label the picture but its better when you add extra stuff such as restaurant music. **Summary** **A few of the participants commented that the page contain good information and provide an examples and clear picture. A few of them suggested for more colours would be a good addition.**
2.12 Sub section: Sample of healthy snacks	**Participant 3 (Boy, 13y.o)**: The moving pictures are good and the information is very detailed. **Participant 5 (Boy, 13y.o):** Change the malay food name in English so other people could understand. **Participant 6 (Boy, 12y.o):** Clear and big pictures. **Participant 7 (Girl, 13y.o):** Very easy to understand and colourful, good. **Participant 8 (Girl, 11y.o):** You could use some food that are well known because if you show it to a European citizen they may not know what food it's. Overall, good! **Participant 10 (Boy, 13y.o):** Change all the sample snack pictures, instead you can use moving and cartoony to pictures to attract children. The number 3 sentence does not make any sense **Summary** **Participants commented that the page was good, informative, easy to understand, colourful and contain clear picture. A few of them suggested for**

	extra food information to be added.
2.13 Sub section: Food library	**Participant 1 (Girl, 14y.o):** The types of foods from each company should be sorted out so that it is easier, like McDonald's should have one group. Also, it should be colour coded. The bad ones which are good should be in red and the good ones should be in green. **Participant 3 (Boy, 13y.o)**: There's good examples of food and nutrition information. **Participant 6 (Boy, 12y.o):** Easy to understand. Very helpful to look the information of the food that you're going to eat. **Participant 7 (Girl, 13y.o):** The information is good, maybe few writing? Very helpful. **Participant 8 (Girl, 11y.o):** Really useful however you could organise in boxes instead than list to avoid getting a lot of pages. **Participant 10 (Boy, 13y.o):** The information is useful however its quite boring for children to read it. **Participant 11 (Girl, 11y.o):** This food library give information about food and it available in Malaysia. **Participant 12 (Girl, 14y.o):** Good. **<u>Summary</u>** **Some of them commented that the page was useful, informative and was easy to understand. There were some suggestion to organise the food in box and adding a colour coded.**
E-consultation/My story and others	**Participant 1 (Girl, 14y.o):** The icons 'My diary' 'E-learning' etc. don't have any movement and this could bore the person reading. The top of the page is very pattern? And attracts attentions. **Participant 4 (Girl, 14y.o):** For the title on every page it should be a different colour other than black or purple. It should be a different font as well and not underlined, how it looks now makes it seem boring and unappealing. The pictures used on every page is very attractive and fun. It was a good presentation and colourful as well. **Participant 5 (Boy, 13y.o):** Make it more attractive (my story). Make it look more attractive and picture. **Participant 6 (Boy, 12y.o):** Very simple to fill in (e-consultation). Very easy to fill in (my story). **Participant 10 (Boy, 13y.o):** You could have e-consultation access to any language in the world (e-consultation).

	Participant 11(Girl, 11y.o): Can we add photos when we are chatting with someone else in the forum??? **<u>Summary</u>** **A few of the participants suggested adding photos of the patients or participants in the Forum component and more colours on every pages.**

5.6.3 Interviews

Table 15 shows the interview topic guide for the phase two study and Table 16 shows one sample of the interview transcription.

Table 15: Interview topic guide (Phase two)

INTERVIEW SCHEDULE

Child’s ID: ______________________________________

Date:_________

Question

1. Tell me what you thought about using this web program?
2. Tell me what you thought about using this web program?
3. What parts, if any were easy?
4. What parts, if any were hard?
5. Is there any part you did not understand?
6. Did you enjoy using the programme?
7. Is there a section you like most than others? Why?
8. Is there anything you would change about this program? If yes – what?
9. What do you think about the overall look of the program? Colour? Font? Background? Photos?
10. Anything that you want to tell me about this program?

Table 16: Interview transcription

Interview transcription

I: Interviewer **IV: Interviewee**

I: Tell me what you thought about using this web program?

IV: Entertaining, vibrant, is really exciting and eye-catching as well.

I: Alright, aa, do you think that children like your age would like to use this program in the future?

IV: Yes, yes especially for test, like exam test.

I: Exam test? What do you mean? Because you can get information from there?

IV: Yeah

I: Alright, ok, what part if any were easy, easy to understand?

IV: Easy to understand? Maybe the type 1 diabetes or the, the

I: Is it the introduction?

IV: Introduction, yes easy to understand. Most of the e-learning easy to understand.

I: How about the English language? Is it hard to understand?

IV: No, easy to understand.

I: Is it any sentence or word I need to change?

IV: umm, that the, the insulin part, the, the, line, the sentence no 3, it does not make sense.

I: What part is any were hard?

IV: Any were hard? Mmm, maybe the part, the type 1 diabetes, were maybe like scientific.

I: Too scientific for you?

IV: Make it simpler

I: Is there any part you did not understand at all?

IV: No, no, I can understand

I: Ok, Did you enjoy using the program?

IV: Yes, I am enjoy using the program

I: Ok, Is there a section you like most than others?

IV: mmm, the diary, coz there are a lot of colours and the table like you can write stuff.

I: Is there anything you would like to change about this program?

IV: To change, umm, colours, maybe, like background music such as like jazzy music and moving picture and animation.

I: Do you think that you need background music for all the component or maybe…

IV: No, maybe some of them, maybe like one or two

I: For example…

IV: for example, maybe like a snack, snack part you can put background music

I: Background music, ok. What do you think about overall look of the program?

IV: Yes, vibrant, colourful and useful

I: Ok. How about the font?

IV: Maybe too small. Maybe need to change that.

I: To change to the large one. Ok. How about the style of the font?

IV: Maybe you can change it into like aaa, like a cartoony font

I: Ok. Some of your comment especially under fat component, your comment that, all the food pictures looks like 70's.

IV: Yeah, that's what my mom said.

I: Ok. How about you? Do you think…

IV: Look 20's, like 2000, maybe like modern pictures.

I: OK. But you like cartoon rather than real photos.

IV: Yeah

I: OK. But you like cartoon rather than real photos.
IV: Yeah

I: OK. For the food label, your comment, maybe moving arrow to attract children, and change the colour to make it more vibrant. That means arrow for the food label you need the moving one and the text might be complicated for children. You think that the text not easy to understand?
IV: Yeah, the food labelling, maybe too high for children.

I: Too high! What do you mean the language? or the instruction?
IV: Like, like, the percentage, number percentage in the food label things they might not understand.

I: Ok. Umm, for the food diary, your comment, you could add pictures of the food on the background. For example picture of bread and milk for the breakfast section.
IV: Yeah, on the table things.

I: Ok. And then for the carbohydrate and diabetes, your comment, you could add more advise and link to fact. What do you mean by that?
IV: By, like to eat advise, like back up information, to make it like people think about it. You really think about it.

I: I can’t understand.
IV: For example, like you advise to eat healthy, and you say why you eat healthy because etc etc

I: Ok, you need explanation
IV: Yeah, explanation, more explanation

I: Ok. For the healthy snack, you want the photos of the sample of healthy snack to be change. You like more on moving, animation, cartoony rather than just the normal food.
IV: Yeah, yeah.

I: Ok. For the e-learning, you want to add more information. Do you think that one is not enough for children?
IV: Well, I think, it is enough for like children aged like 10 and 11 and 12, but maybe for like key

stage 3 people a bit more information. You can like separate them into like for example, 10, 11, 12 like section for them, like 13 and 14 section for them.

I: To add another extra explanation
IV: Yeah

I: You also like us to add information like the population of people who has diabetes
IV: Yeah

I: Do you think that one is important to know?
IV: Yeah, yeah, sure

I: Ok. Is there any other comments or suggestion you want to make for this program?
IV: Yeah, maybe, for the e-consultation things, the ask question things, you might like can access to any language for people

I: What do you mean by that?
IV: Like instead of write English, maybe like, people doesn't understand English can write in other language.

I: Ok
IV: Translate it, people can translate

I: Translate it? Ok. Any other comments?
IV: No

I: Ok, I would like to ask regarding the forum. You know about the forum right? That one you can chat with other friends. Do you think, you will use that forum to chat with your other friends?
IV: Yeah

I: Because this is not really your friend but, maybe…
IV: Random people?

I: Not random people because this is for children with diabetes. Ok. Maybe they don't know about this children. For example, like you. If you don’t know about other children, do you think that you are interested to chat with them?

IV: Yeah, I like to chat with other people

I: When you don’t know them?

IV: Yes

I: Alright, Ok. Thank you very much.

IV: Thank you

5.6.4 Feedback data and interviews

Based on the qualitative interviews conducted among the sub-sample of five participants and from the feedback form completed by all 12 participants, four major themes were identified through analysis of the data, each with several subthemes. The emergent themes were classified as: Theme 1: Layout; Theme 2: Colour scheme; Theme 3: Content arrangement; and Theme 4: Benefit of the web based programme. Table 17 shows the coding framework (thematic chart) for the feedback data and interviews.

Theme 1: Layout

Font

The majority commented that the font size was too small and they suggested using a bigger font size

Too small, need to change to large. Change to cartoony font (P5, Boy, 13y.o).

The text should be different fonts. Bigger font size and keep font style (P1, Girl, 14y.o).

I think the heading should be bold and bigger to show that it's a heading for that page. I thought there could be a small description before showing the poster (P8, Girl, 11y.o).

Photo

The majority of participants commented that the photos used in the programme were interesting, attractive and acceptable for children and adolescents of the same age.

The picture of the information on healthy eating, diabetes and diet management is very colourful and very attractive for kids. Kids will understand what are the picture trying to explain as it is easy to understand and clear pictures and colourful words. The picture is very good and very easy to understand. If the kids can't really understand they will still understand by looking at the pictures. Very simple short information that children could understand and lots of pictures to look instead of words so it will not make it boring for children to look (P6, Boy, 12y.o).

The picture is really good because it shows you need to plan your meal before you eat and the writing is good as well because it's in capital letters and it shows that you need to do it also the red writing. The moving pictures are good and the information is very detailed. All the icons are good, got different section, so we know where to go. The colours are good. Keep the photos. The moving pictures are good and the information is very detailed. I really like the moving pictures and it's got good information inside it (P3, Girl, 10y.o).

However, a small number of participants suggested more animation photos and one participant suggested adding music to the photos.

The overall look is very good. The picture and the section were equally segregate out except the font and the background. More colour, more picture, more animation (P1, Girl, 14y.o).

You could add more pictures otherwise good (P8, Girl, 11y.o).

The first picture was dull therefore it needs improving. You also could add sounds to annotate the foods. Need modern picture looks 20's Change all the sample snack pictures, instead you can use moving and cartoony to pictures to attract children. Maybe moving arrows to attract children and change the colour to make it more vibrant (P10, Boy, 13y.o).

Theme 2: Colour scheme

There were mixed responses to the colour scheme. Some of the participants indicated the programme was colourful. However, some of them indicated the colour needed to change or suggested adding more colours.

It is easy to read but try to make the table in colour to make it more attractive for age 10-12 and when it says 'My Diary' on the top make it in another writing style which kids like. Make it in table form and more colourful (P6, Boy, 12y.o).

It was a good presentation and colourful as well. For the title on every page it should be a different colour other than black or purple. It should be a different font as well and not underlined, how it looks now makes it seem boring and unappealing (P4, Girl, 14y.o).

Pictures are very colourful and will attract then person's attraction (P1, Girl, 14y.o).

Vibrant, colourful and useful (P5, Boy, 13y.o).

Theme 3: Content arrangement

Half of those interviewed indicated that the language and information in the programme were easy to understand and very informative.

The information is simple, not too scientific, able to understand (P1, Girl, 14y.o).

Very good. A lot of information and simple (P7, Girl, 13y.o).

Very simple short information that children could understand and lots of pictures to look instead of words so it will not make it boring for children to look. Very helpful to look the information of the food that you're going to eat (P6, Boy, 12y.o).

However, another half of participants suggested simplifying or changing some of the words or information.

Easy except saturated fat, unsaturated need to change. Introduction (What is type 1 diabetes), information too long, need short information. Diabetes complication need explanation under the photo (P2, Boy, 13y.o).

Can understand except the instruction for food labelling need to simplify. More information and explanation for carbohydrate and diabetes and e-learning. Add information the population of people who has diabetes and more information in each picture (P5, Boy, 13y.o).

Easy. No need to change or simplify except lethargy and frequent urination. There are good examples of different things inside and good information. This section is nice, it's plain and it's easy. It's also better for the children to understand. It's got good pictures and good advice and children will be able to understand it (P3, Girl, 10y.o).

Theme 4: Benefit of the web based programme

All of the participants commented that the programme was useful, contained a lot of information on diabetes, healthy eating and was appropriate not only for children and adolescents with diabetes but also for non-diabetic children as well.

Entertaining, vibrant, is really exciting and eye-catching as well. Children can use this program to get information for the exam. The pages contain lots of information. No needs to improve. I like the fact about the carbohydrate; the page entertains me. Thanks for the video, I will keep it in mind until my biology test. Moreover, it helps people to understand why diabetes happens (P10, Boy, 13y.o).

Very helpful and a guide for diabetes people, like if they don't know what to eat they can go to the web. The web is very helpful coz tells you how to keep your food, healthy eating balance (P6, Boy, 12y.o).

Quite useful, a lot of pictures, very detail, suitable for children, easy to use, got label on everything (P1, Girls, 14y.o).

Gain a lot of information about diabetes. Using as a reference for science subject. Is good. Can share what we eat. We able to know nutrient in the food (P9, Boy, 13y.o).

Some of them also reported that the programme could be used as a tool for communication and sharing information among diabetic children and among non-diabetic children.

The program is good. We can learn something that we do not know. We can share the information to other people, so other people can visit this website, so they know and share the ideas to other people. Other people can prevent this diabetes from them, so cannot *make the disease increase and make population of people with diabetes in this world decrease. Yes, is good. Can learn something, use the information and apply the knowledge (P3, Girl, 10y.o).*

Can relate to other people which also had DM and communicate with other diabetes children. Enjoy. Quiet good. Learn a lot of things about diabetes. It was really good (P1, Girl, 14y.o).

Very helpful and a guide for diabetes people, like if they don't know what to eat they can go to the web. Very useful because you can talk to each other, like if you don't know something or you can't understand you can ask your friends to explain (P4, Girl, 14y.o).

The revision of the web-based programmed based on comments from the feed-back form and interviewed session was presented in Table 18. This table also outlined strengths and which areas need to be improved. The researcher revised the programmed with assistance from the Ready Salted Company and it was used for Phase three study.

Table 17: Coding framework (thematic chart) from feedback data and interviews

Theme 1: Layout
1.1 Font size & Style ***Acceptable*** ***Bigger font*** ***Cartoon style*** The text should be different fonts. Bigger font size and keep font style (P1, girl, 14y.o). The font is quite small and there is no background to the section (P1, girl, 14y.o). Is ok, but some need to make it bigger. For the style make it childish (P1, girl, 14y.o). This page was quite plain because only one picture was used and the font and colour did not stand out. The font should be eye catching and bolder because now it is very faded and not likely to be looked at (P1, girl, 14y.o). Too small, need to change to large. Change to cartoony font (P5, boy, 13y.o). Font size is acceptable, easy to write (P9, boy, 13y.o). Font is acceptable. Background is fine. Enjoy to use (P2, boy, 13y.o). I think the heading should be bold and bigger to show that it's a heading for that page. I thought there could be a small description before showing the poster (P8, girl, 11y.o). Very good however bigger writing (P8, girl, 11y.o). It should be a different font as well and not underlined, how it looks now makes it seem boring and unappealing (P1, girl, 14y.o). I would not improve anything on this section. I like how you gave a title and that how the font stands out that people can read it. It is very bold as well. I think you could give more writing on this section. I think I really like it (P2, boy, 13y.o).
1.2 Image ***Good photos*** ***Animation*** ***Cartoon*** ***More photos*** ***Some need changes***

The picture is really good because it shows you need to plan your meal before you eat and the writing is good as well because it’s in capital letters and it shows that you need to do it also the red writing (P3, girl, 10y.o).

There are good pictures and good examples for what they are (P3, girl, 10y.o).

More moving picture (P1, girl, 14y.o).

In this section I want you to put more nice picture so it will look more cool and children want to know more (P11, girl,11y.o).

Very big clear pictures and kids will understand it very easily also will not make it boring for them. Able to understand. The photo is ok (P6, boy, 12y.o).

Interesting. The photo is good (P9, boy, 13y.o)

The first picture was dull therefore it needs improving. You also could add sounds to annotate the foods. Need modern picture looks 20’s (P10, boy, 13y.o)

All the icons are good, got different section, so we know where to go. The colours are good. Keep the photos (P3, girl, 10y.o).

The overall look is very good. The picture and the section were equally segregate out except the font and the background. More colour, more picture, more animation (P1, girl, 14y.o).

Actual or real photo were acceptable (P1, girl, 14y.o).

The moving pictures are good and the information is very detailed (P3, girl, 10y.o).

Clear and big pictures (P6, boy, 12y.o).

Very easy to understand and colourful, good (P7, girl, 13y.o).

Change all the sample snack pictures, instead you can use moving and cartoony to pictures to attract children (P10, boy, 13y.o).

I really like the moving pictures and it’s got good information inside it (P3, girl, 10y.o).

Nothing to change in this section because the animation is great (P5, boy, 13y.o).

Quite easy, a lot of photos. Colourful, animated, can add music but too lengthy (P9, boy, 13y.o)

The picture is nice and it give me more information about what is happening (P11, girl, 11y.o).

Is good. We can know what the protein is. The photo looks interesting (P10, boy, 13y.o).

This section is really good, the pictures are good especially for children (P3, girl, 10y.o).

Very simple short information that children could understand and lots of pictures to look instead of words so it will not make it boring for children to look (P6, boy, 12y.o).

Like animation photo (P12, girl, 14y.o)

Maybe moving arrows to attract children and change the colour to make it more vibrant (P10, boy, 3y.o)

This section looks very good and to improve it you could maybe put more colours into it and animations (P3, girl, 10y.o).

This page is fine the way it is, especially by the use of creative fun pictures (P4, girl, 14y.o).

The picture is great and suitable for kids. More information and facts about the page (P5, boy, 13y.o).

The picture of the information on healthy eating, diabetes and diet management is very colourful and very attractive for kids. Kids will understand what are the picture trying to explain as it is easy to understand and clear pictures and colourful words (P6, boy, 12y.o).

This photo looks really good and colourful, even though it looks good, some of the word are quite difficult to understand especially for the young people like us (P9, boy, 13y.o)

Need to put animation to make it looks good (P5, boy, 13y.o).

The picture is very good and very easy to understand. If the kids can’t really understand they will still understand by looking at the pictures (P6, boy, 12y.o).

It’s got good pictures and good advice and children will be able to understand it (P3, girl, 10y.o).

Put animation on and make the page look more colourful (P5, boy, 13y.o).

The picture used on every page is very attractive and fun. It was a good presentation and colourful as well. For the title on every page it should be a different colour other than black or purple. It should be a different font as well and not underlined, how it looks now makes it seem boring and unappealing (P4, girl, 14y.o).

The animation is good and there are lots of information which we need to know about what you have put in and that’s really good (P3, girl, 10y.o).

Very easy to understand and nice looking big moving picture (P6, boy, 12y.o).

You could add more pictures otherwise good (P8, girl, 11y.o).

The picture is really good but can you put more picture on this page because it look a little bit boring but the good thing is that I understand about it (P11, girl, 11y.o).

We could add pictures of foods on the background e.g. pictures of bread and milk on the breakfast section (P10, boy, 13y.o).

Theme 2: Colour scheme

Attractive
Colourful
Interesting photos
Useful
Some need changes
Add more colours

It was a good presentation and colourful as well. For the title on every page it should be a different colour other than black or purple. It should be a different font as well and not underlined, how it looks now makes it seem boring and unappealing (P4, girl, 14y.o).

Quiet plain. More picture. More colours. The whole background was orange. Need different colour (P1, girl, 14y.o).

Good. Colourful (P3, girl, 10y.o).

Colour is fine. Font is acceptable. Background is fine. Enjoy to use (P2, boy, 13y.o).

Vibrant, colourful and useful (P5, boy, 13y.o).

The writing on the bottom is the colour grey maybe change the colour so you can see it better (P3, girl, 10y.o).

Colourful (P2, boy, 13y.o).

The colour is ok (P3, girl, 10y.o).

Pictures are very colourful and will attract then person’s attraction (P1, girl, 14y.o).

I want you to put colour on the old woman and the little children because it loo so boring without the colour (P11, girl, 11y.o).

Put animation on and make the page look more colourful (P5, boy, 13y.o).

Very colourful pictures and healthy looking food (P6, boy, 12y.o).

Improve it to make more attractive and colourful for users because at the moment it is just plain (P5, boy, 13y.o).

It is easy to read but try to make the table in colour to make it more attractive for age 10-12 and when it says ‘My Diary’ on the top make it in another writing style which kids like. Make it in table form and more colourful (P6, boy, 12y.o).

Put something on. Maybe a bit more colourful (Girl, 13y.o)

Background is fine. Colour is nice (P2, boy, 13y.o).

I really like the moving pictures and it’s got good information inside it. The writing on the bottom is the colour grey maybe change the colour so you can see it better (P3, girl, 10y.o).

Very big clear pictures and kids will understand it very easily also will not make it boring for them. Able to understand. The photo is ok (P6, boy, 12y.o).

Is good. We can know what the protein is. The photo looks interesting (P10, boy, 13y.o).

The picture of the information on healthy eating, diabetes and diet management is very colourful and very attractive for kids. Kids will understand what are the picture trying to explain as it is easy to understand and clear pictures and colourful words (P6, boy, 12y.o).

This photo looks really good and colourful (P9, boy, 13y.o).

Overall for e-learning you should change the size and style of the font due to children age 10 to 14. Add vibrant colours and moving pictures (P10, boy, 13y.o).

The picture is very good and very easy to understand. If the kids can’t really understand they will still understand by looking at the pictures (P6, boy, 12y.o).

The picture is very useful but could be better if there’s few writing (P7, girl, 13y.o).

It’s got good pictures and good advice and children will be able to understand it (P3, girl, 10y.o).

Theme 3: Content arrangement

3.1 Information
Easy to understand
Good information
Useful
Too lengthy
Simple text
Need to add some information

Overall were simple and easy to understand except the My diary no definition or instruction (P1, girl, 14y.o).

Easy except saturated fat, unsaturated need to change (P2, boy, 13y.o).

Easy. No need to change or simplify except lethargy, frequent urination (P3, girl, 10y.o).

Easy to understand. Able to understand except for the introduction need to simplify (P4, girl, 14y.o).

Can understand except the instruction for food labelling need to simplify. More information and explanation for carbohydrate and diabetes and e-learning. Add information the population of people who has diabetes (P5, boy, 13y.o).

Introduction (What is type 1 diabetes). Information too long. Need short information (P2, boy, 13y.o).

Diabetes complication, need explanation under the photo (P2, boy, 13y.o).

Introduction: What is type 1 diabetes. Is scientific need to simplify (P5, boy, 13y.o).

Very good. A lot of information and simple (P7, girl, 13y.o).

You could add more advice and more information and link it to facts. Good advice (P10, boy, 13y.o). .

Easy to understand. Very helpful to look the information of the food that you’re going to eat (P6, boy, 12y.o).

The information are good, maybe few writing? Very helpful (P7, girl, 13y.o).

Is good. Can share what we eat. Attractive colours. Font size is acceptable, easy to write. We able to know nutrient in the food. It is useful to give information (P9, boy, 13y.o).

This food library gives information about food and it available in Malaysia (P11, girl, 11y.o).

Good. Acceptable & useful (P12, girl, 14y.o).

3.2 Language
Easy to understand
Need to change

You could maybe tell some of the impacts of being fat and tell why we can’t be overweight (p8, girl, 11y.o).

Interesting. The photo is good. The sentence is good and easy. We know what happened when eat too much fat. Able to understand the explanation (P9, boy, 13y.o).

Can you put more picture on it. But I think it really good I understand what happening in this page. But some of the page I don’t understand because the information is too long (P11, girl, 11y.o).

Instruction is able to understand except the term saturated fat and unsaturated fat. Font size is acceptable. Easy to read (P12, girl, 14y.o).

The information is simple, not too scientific. Able to understand (P1, girl, 14y.o).

It would be much better if there’s more writing and little bit more information in this section (P7, girl, 13y.o).

Able to understand the information. Quite easy, a lot of photos (P9, boy, 13y.o).

You could improve the video by making it simpler due to students at the age of 10. Also, it might have been more entertaining by adding sound to it. Thanks for the video, I will keep it in mind until my biology test. Moreover, it helps people to understand why diabetes happens (P10, boy, 13y.o).

The information is too lengthy. The picture is nice and it give me more information about what is happening (P11, girl, 11y.o).

I can't understand on my own, I need my mom to explain. Too lengthy, difficult to understand (P12, girl, 14y.o).

There are good examples of different things inside and good information (P3, girl, 10y.o).

More information in each picture (P5, boy, 13y.o).

Is good. We can know what the protein is. The photo looks interesting (P10, boy, 13y.o).

Able to understand the language (P12, girl, 14y.o).

More facts and information (P5, boy, 13y.o).

Very simple short information that children could understand and lots of pictures to look instead of words so it will not make it boring for children to look (P6, boy, 12y.o).

The pages contain lots of information. No needs to improve. I like the fact about the carbohydrate; the page entertains me (P10, boy, 13y.o).

There are some grammar mistakes and it doesn't really make sense but the information is good (P3, girl, 10y.o).

You could explain why it's important to have it otherwise good (p8, girl, 11y.o).

Simple and yet completely vibrant and cartoony. Maybe the information to the section is too short for kids between the age of 10 and 14 (P10, boy, 13y.o).

More facts and information for readers (P5, boy, 13y.o).

Very big clear picture and the words are very easy to read because of the highlight and clear information (P6, boy, 12y.o).

Good nothing to comment about (P8, girl, 11y.o).

Good. We can know what it is, what we eat, what to eat and also the nutrient inside the foods. Able to understand the instruction given (P9, boy, 13y.o).

The text might be complicated for children patient (P10, boy, 13y.o).

It's interesting but I don't understand what is happening and the information is too long (P11, girl, 11y.o).

Easy to understand (P12, girl, 14y.o).

I think I really understand it and that I really like the picture and I understand it (P2, boy, 13y.o).

The picture of the information on healthy eating, diabetes and diet management is very colourful and very attractive for kids. Kids will understand what are the picture trying to explain as it is easy to understand and clear pictures and colourful words (P6, boy, 12y.o).

This photo looks really good and colourful, even though it looks good, some of the word are quite difficult to understand especially for the young people like us. Some of them that speak another language also hard to find the meaning of the words (P9, boy, 13y.o).

You could improve it by adding more information into e-learning introduction such as, information about the population who has diabetes. Although it needs more information, e-learning introduction is very vibrant, attractive and eye-catching (P10, boy, 13y.o).

This section is nice, it’s plain and it’s easy. It’s also better for the children to understand (P3, girl, 10y.o).

The picture is very good and very easy to understand. If the kids can’t really understand they will still understand by looking at the pictures (P6, boy, 12y.o).

The picture is very useful but could be better if there’s few writing (P7, girl, 13y.o).

I thought there could be a small description before showing the poster (P8, girl, 11y.o).

Put description below pictures under symptoms. Is ok but some words needs to change like lethargy, frequent urination. The photos are ok (P9, boy, 13y.o).

I cannot think of any simpler way to improve the page. JOB WELL DONE! The page helps us to learn new words by adding picture next to it such as lethargy as in sleeping (P10, boy, 13y.o). .

It’s got good pictures and good advice and children will be able to understand it (P3, girl, 10y.o).

Very useful (P7, girl, 13y.o).

Very good however bigger writing (P8, girl, 11y.o).

Able to understand the instruction (P9, boy, 13y.o).

You could improve it by adding extra information (P10, boy, 13y.o).

The program is good. We can learn something that we do not know. We can share the information to other people, so other people can visit this website, so they know and share the ideas to other people. Other people can prevent this diabetes from them, so cannot make the disease increase and make population of people with diabetes in this world decrease. Is good (P3, girl, 10y.o).

Very helpful and a guide for diabetes people, like if they don’t know what to eat they can go to the web (P4, girl, 14y.o).

The animation is good and there are lots of information which we need to know about what you have put in and that’s really good (P3, girl, 10y.o).

More picture and information about the page (P5, boy, 13y.o). Very easy to understand and nice looking big moving picture (P6, boy, 12y.o). You could add more pictures otherwise good (P8, girl, 11y.o). You could improve on the text and add background picture. I prefer less writing for the sake of younger patients (P10, boy, 13y.o). The picture is really good but can you put more picture on this page because it look a little bit boring but the good thing is that I understand about it (P11, girl, 11y.o).
Theme 4: Benefit of the web based programme
Education component ***General guide to diabetes*** ***Healthy eating*** ***Informative*** ***Communication*** ***Sharing information*** Quite useful, a lot of pictures, very detail, suitable for children, easy to use, got label on everything (P1, girl, 14y.o). Very helpful and a guide for diabetes people, like if they don't know what to eat they can go to the web (P6, boy, 12y.o). Gain a lot of information about diabetes. Using as a reference for science subject (P9, boy, 13y.o). Entertaining, vibrant, is really exciting and eye-catching as well. Children can use this program to get information for the exam (P10, boy, 13y.o). Very useful. Learn and get information about eating (P12, girl, 14y.o). Enjoy. Quiet good. Learn a lot of things about diabetes. It was really good (P1, girl, 14y.o). Enjoy. Learn about healthy food (P2, boy, 13y.o). Yes, I am enjoy using the programme (P5, boy, 13y.o). Yes. Is good. Can learn something, use the information and apply the knowledge. Enough information (P3, girl, 10y.o). Can relate to other people which also had DM and communicate with other diabetes children (P1, girl, 14y.o). Can communicate and know other people (P2, boy, 13y.o).

Is good. We can make friend, share our ideas about diabetes (P3, girl, 10y.o).

Very useful because you can talk to each other, like if you don't know something or you can't understand you can ask your friends to explain (P4, girl, 14y.o).

I like to chat with other people (P5, boy, 13y.o).

Very good. A lot of information and simple (P7, girl, 13y.o).

You could add more advice and more information and link it to facts. Good advice (P10, boy, 13y.o).

There are good examples of food and nutrition information (P3, girl, 10y.o).

Is good. Can share what we eat. Attractive colours. Font size is acceptable, easy to write. We able to know nutrient in the food. It is useful to give information (P9, boy, 13y.o).

The information are good, maybe few writing? Very helpful (P7, girl, 13y.o).

This food library gives information about food and it available in Malaysia (P11, girl, 11y.o).

This website is interesting and attractive. The program is good. We can learn something that we do not know. We can share the information to other people (P3, girl, 10y.o).

I really like the moving pictures and it's got good information inside it. The writing on the bottom is the colour grey maybe change the colour so you can see it better (P3, girl, 10y.o).

The program is good. We can learn something that we do not know. We can share the information to other people, so other people can visit this website, so they know and share the ideas to other people. Other people can prevent this diabetes from them, so cannot make the disease increase and make population of people with diabetes in this world decrease. Is good (P3, girl, 10y.o).

Very helpful and a guide for diabetes people, like if they don't know what to eat they can go to the web. (P4, girl, 14y.o).

The web is very helpful coz tells you how to keep your food, healthy eating balance (P6, boy, 12y.o).

Really useful, however you could organise in boxes instead than list to avoid getting a lot of pages (P8, girl, 11y.o).

Table 18: Areas that need improvement

Items	***Amendment and improvement***
Content arrangement Language/information/explanation	*The introduction topic has been simplified.* *The explanation was written under the "diabetes complication" photos.* *Will add information about insulin management and blood glucose monitoring and exercise in future works.* *The terms of saturated and unsaturated fat have been changed to good and bad fat.* *Changed word of "lethargy" to "tired" and "frequent urination" to "always go to toilet".* *Checked the grammar and did some corrections.* *Moving icon in future works.*
Layout Font size & style Images	*Changed some of the photos to animation photos.* *Added more animation photos* *Some photos have been changed to more attractive photos.* *Changed font size from size 14 to size 16*
Colour scheme	*Add more colours and attractive photos*
Food diary	*Organized food diary into table form and added information about "what is the food diary" and "how to enter the data of food intake into the food diary". There was also an example of completed food diary.* *Improved the background by adding the animation photo and more bright colours to make it attractive.*
E-learning	*Changed font size from 14 to 16.* *Added more colours and animation photos. Some difficult words were changed to simple words.* *Will add information about insulin management and blood glucose monitoring and exercise in future works.*
Introduction- What is type 1 diabetes	*Simplified words and information, and changed the font to bigger font so easy to read.* *Added the word "start" to the first slide and word "the end" to the last slide* *Plan to add music background in the future.*

What are the symptoms of type 1 diabetes	*Add some animation photos.* *Put description or explanation under "symptoms".* *Changed words of "lethargy" and "frequent urination*
Diabetes complications	*Added information under each photos.* *Kept the photos and need more comments from participants in stage 3.*
Diet management	*Checked the grammar and did some corrections.* *Added more food photos.* *Added information under each photo*
Food label	*Added the moving arrow and more colourful.* *Simplified the text making it easier to understand.*
Healthy snacks	*Added English and Malay names.*
Food library	*Rearranged some of the food photos.* *Arranged fast food items in same group.*

5.7 Discussion

This Phase of the study provided valuable feedback from children and adolescents' which proved useful in revising the programme. The feedback from participants was mainly positive and highlighted some points that required improvement. The results indicated that a web-based diet and diabetes education programme was viewed by a small sample of non-type 1 diabetes children and adolescents as potentially accessible, convenient and an acceptable way to provide education on diet and diabetes management to children and adolescents with type 1 diabetes. The participants commented that in their view, as children without diabetes, the programme was useful and contained a lot of information on diabetes, healthy eating and was appropriate not only for children and adolescents with diabetes but for non-diabetic children as well. Half of those who were interviewed indicated that the language and information in the programme were easy to understand. Some provided useful suggestions of how to simplify and change the wording so that it would be easier for children to understand. The majority of participants commented that the photos used in the programme were interesting, attractive and acceptable for children and adolescents of their age. However, a small number of participants suggested including more animation and one of them suggested adding music to the photo.

There was mixed feedback on the overall look of the programme. Some participants indicated the programme was colourful. However, some of them indicated the colour needed to be changed or suggested adding more colours. The majority commented that the font size was too small and they suggested using a bigger font size. As a result of these comments, more animation was added to the programme and the new programme looks more colourful and bright. Some of the information was changed to make it more simple and so easy to understand. The programme was refined to use a combination of cartoon-like and normal font to attract children and adolescents so they would read the information. Participants highlighted that the forum component could be used as a communication tool between people with or without diabetes. Feedback from the participants indicated that all the components (*My diary*, *E-Learning*, *E-Consultation* and the *Forum*) in the programme were useful and should be maintained. The web-based diet and diabetes education programme proved to be appropriate for Malaysian children and adolescents without diabetes. After revision of the programme, the new version was used in Phase three of the study with diabetic children and adolescents in Malaysia.

There were some aspects of the feedback for which it was not possible to make in the current revision, including adding music to the photos, due to time and budget constraints. Only one participant suggested adding music. A few of the participants also suggested changing the photos of the diabetes complications to different photos. The decision of adding music and changing the photos needs to be included in the future plan if confirmed in the results of the Phase three study among children and adolescents with T1D in Malaysia.

5.8 Strengths and limitations

5.8.1 Strengths

The strength of using an open-ended feedback form is that the participants have the freedom to explain or write whatever they wish in their own words. They are not forced to answer in the same terms. At the same time interviews were conducted so that they could elaborate on the answer they wrote in the feedback form, and to elicit further information. The children and adolescents who participated in the interview were talkative and provided useful information and suggestions. When probed during the interview, participants were able to talk and give their views and experiences of using the system. This provides rich, valuable and interesting information. The participants provided the same information in interview and written feedback. Most of them explained in more detailed and provided more comprehensive answers during the interview. The interview served the intended purpose; to add depth to the written feedback.

In the current study, parents were not present during the interview, so as to provide comfort and freedom to the children and adolescents so they would speak freely, without any interference from parents. The views and opinions expressed were genuinely from the children and adolescents, not from their parents. Parental presence was felt to be comforting to participants, but it may also affect the child’s ability to speak freely without parental influence. In this study the researcher chose home as a location for the interview based on participants preferences, therefore they felt comfortable during the interview session.

5.8.2 Limitations

Open-ended questions required greater effort from the participants. They did not have a clue or guide for what to write in the form. The participants had to be literate and comfortable expressing their views in writing. They must have had an idea and the ability to write. In view of that, some of the participants did not give comments in some of the components. The timing of testing and duration of using the programme was for only two days, and may have contributed to some of the results. Some of the participants did not give their comments on some of the components because they did not have sufficient time. Participants had a busy schedule at school and could only use the programme at night or during weekends. In the next Phase of the study, consideration was given to conducting the interview among all of the participants.

This Phase of the study should be conducted among children and adolescents with T1D. The children and adolescents with T1D may provide different ideas and views. However, costs and time constraints limited the ability to extend subject recruitment to children and adolescents with T1D in Malaysia. The researcher already conducted the Phase one study in Malaysia, and the next Phase (Phase three) study was also conducted in Malaysia, among children and adolescents with T1D. For the above reason, the Phase two of the study was only conducted in Newcastle among Malaysian children and adolescent without T1D.

Chapter 6 Evaluation of web based programme in Malaysia (Phase three)

6.1 Introduction

This chapter describes the methodology, data collection and analysis process and then presents the results followed by discussion and summary of Phase three of the research study. The aim of Phase 3 was to evaluate the feasibility of delivery of the web-based programme to children and adolescents with T1D attending the UMMC, Malaysia. The primary objective was to evaluate the impact of this programme on children's and adolescent's nutrition knowledge, dietary management and self-efficacy and to determine whether this programme could become an effective dietary management and support programme for these children.

6.2 Specific objectives

1. To conduct a cross-sectional study to evaluate the impact of this programme in improving dietary management, nutrition knowledge and self-efficacy of children and adolescents with T1D in UMMC, Malaysia.
2. To evaluate the acceptability and usability of the programme among HCP to teach and support their children and adolescents with T1D in UMMC

Phase two of the study was conducted with 12 non-diabetic Malaysian children and adolescents living in Newcastle during November 2012. This web-based diet and diabetes education programme named *"My Diabetes"* was revised based on their comments and feedback and the revised version *"My Diabetes"* was used for this Phase three study (Figure 21:).

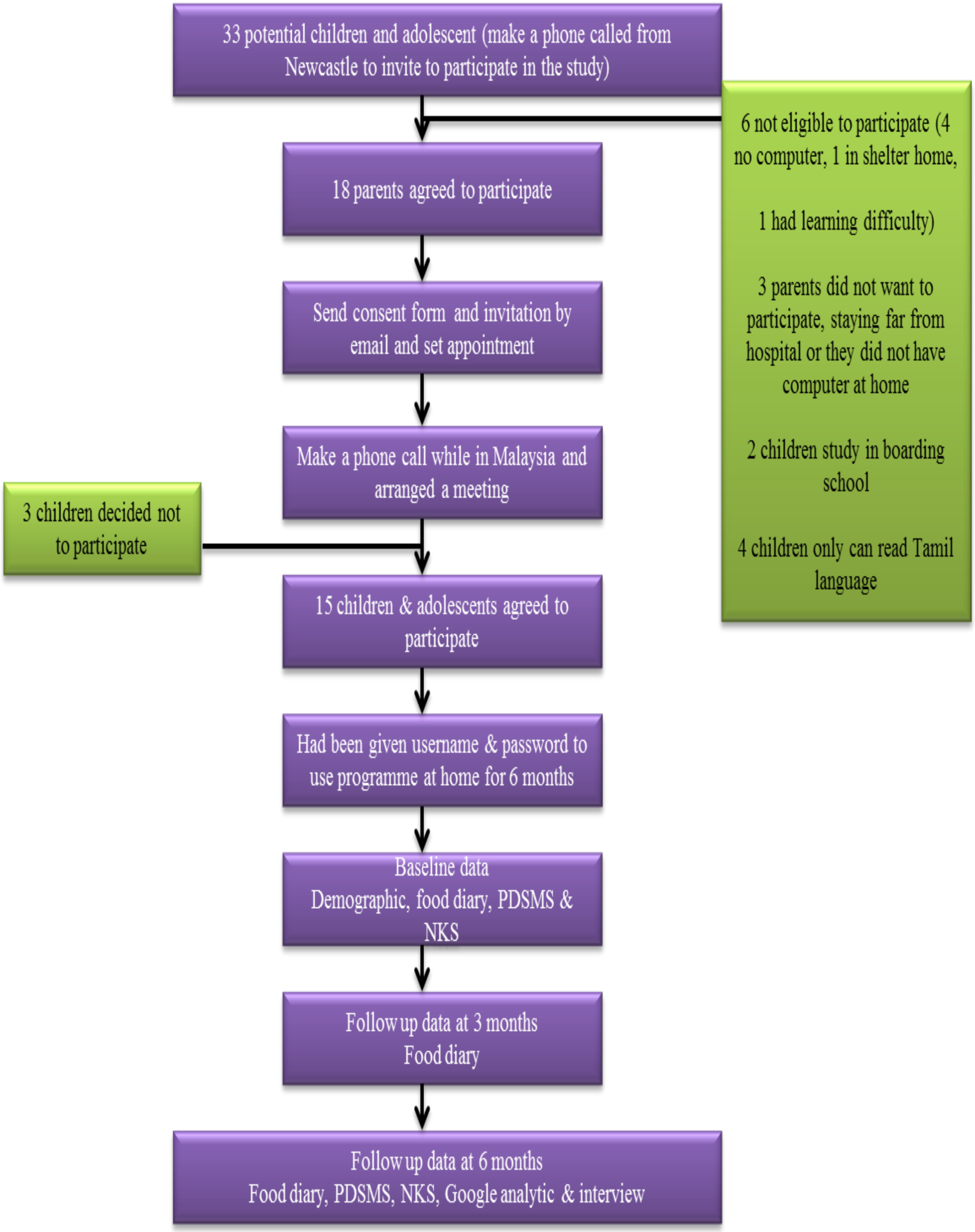


Figure 21: Phase three study flow chart

6.3 Methodology

6.3.1 Sample selection and recruitment

This study was conducted in UMMC, Malaysia with children and adolescents with T1D. During a one month recruitment period, a sample of 12 children with T1D, ages 10 to 14 years old, were recruited to participate in this study. Below are inclusion and exclusion criteria of study children:

Inclusion criteria

- Children aged 10 to 14 years old with T1D
- On insulin treatment
- Diagnosed with T1D for minimum 1 year
- Has internet access

Exclusion criteria

- Children with T2D
- Children with T1D but with mental health problems and/or other chronic illness.
- Children aged less than 10 years and more than 14 years

Ethical approval was obtained from UMMC Ethical Committee. The recruitment of participants for Phase three started at the end of October 2012. A list of all patients with T1D was received from the Diabetes Division, Paediatric Department of University of Malaya. From this list there were 200 children and adolescents with T1D registered in UMMC but only 33 were children and adolescents aged 10-14 years old, and thus eligible for participation in the study. Information sheets and a letter of invitation were sent to all eligible participants (Appendix 8 & 9). The researcher telephoned all the parents, and from 33 families 18 parents agreed to participate (55% response rate). From those 18 families, 15 children agreed to participate, three children were not interested in taking part, as they had already participated in Phase one of the study. The researcher arranged an appointment for the families to go to the UMMC paediatric clinic at a date and time which was convenient for them. Participants completed and returned the consent and assent forms to the researcher when they came to the UMMC paediatric clinic during an appointment date (See Appendix 9 & 10) for letter of invitation and consent form).

At the clinic, participants were given a demonstration of the web programme and its services, along with a username and password which allowed them access onto '*My Diabetes'* where they explored and browsed all components by themselves. After this introduction, participants were encouraged to use the programme at home for the duration of six months. They were encouraged to use the '*Diabetes Diary'* to record their dietary intake and blood glucose results and participants were told if they had any questions they could send their question directly to their diabetes team using the '*E-Consultation'* component. They were encouraged to share their stories and experiences with their diabetic peers using the '*Forum'* component. The researcher contacted participants again at three and six months for collection of follow-up data.

In order to obtain the HCP acceptance of *'My Diabetes'*, they were invited to participate in this study. There were five HCP in the diabetes paediatric team in UMMC: one professor (head of department), one paediatric endocrinologist (senior lecturer), two clinical diabetes nurses and one dietician. The researcher telephoned four of the HCP, except the head of department, and all agreed to participate except one clinical diabetes nurse. She was not able to participate because she was not always in the paediatric diabetes clinic as her job included working in the adult diabetes clinic and ward. The researcher arranged an appointment to meet with them at the UMMC paediatric clinic at a date and time which was convenient for them. The HCP completed and returned the consent forms to the researcher during an appointment date at the clinic.

All HCP (n=3) were given a demonstration of the web programme and its services and shown how to create their own username and password to access *'My Diabetes'*. The HCP could view the information on each child and adolescent participant, including the blood glucose and dietary intake data that were provided by the children and adolescents via the '*Diabetes Diary'* component. The HCP were able to monitor children's and adolescents' blood glucose and also their dietary intake. Any questions or queries sent by children and adolescents via the '*E-Consultation'* component were reviewed and answered by the related HCP. The HCP used this programme for the duration of six months at the clinic visits as an educational tool to review and discuss blood glucose control, dietary intake, insulin management and other problems with the participants and their parents, for both newly diagnosed patients and for existing patients. After six months, interviews were conducted with the three HCP to determine their views, experiences, utility and acceptance of the system.

6.4 Data collection

All participants were asked to complete a self-reported questionnaire that included basic demographic data, self-efficacy measured by the Perceived Diabetes, self-management Scale (PDSMS), and nutrition knowledge measured by the T1D Nutrition Knowledge Survey (NKS). Outcomes were evaluated at three months and six months of access to '*My Diabetes'* using 3-day food diaries, PDSMS (appendix 11) and NKS (appendix 12). Google analytic was used to identify the frequency with which the website was visited, the visit duration, which component of the web was visited most and time spent on each component. A face to face interview was conducted after children and adolescents had six months of access to the web-based programme in order to gain insight to their views, experiences, satisfaction with and acceptance of the system and also their experience of managing their diabetes.

A face to face interview was also conducted with the parents of participants in order to gain insight to their experience of management of children with T1D and their views of the system. The telephone interview was carried out among HCP in UMMC, Malaysia. Face-to-face interviews were not possible with the HCP in Malaysia due to the majority of HCP being busy with their clinic and one HCP attending a conference abroad. Therefore, telephone interview was conducted when the researcher was back in Newcastle.

6.4.1 Demographic data

Basic demographic data including age, gender, educational level and duration of T1D were collected at baseline by questionnaire.

6.4.2 The Perceived Diabetes Self-management Scale (PDSMS)

The Perceived Diabetes Self-Management Scale (PDSMS) developed by Wallston et al (Wallston *et al.*, 2007) was administered with permission from Dr Kenneth A. Wallston (via the email). The PDSMS (appendix 11) consisted of eight items to measure how confident the patient was in managing their glycaemic control well, also known as self-efficacy. The total scores ranged from 8 to 40 with higher scores indicating a greater level of confidence in self-managing diabetes. All participants were asked to complete the PDSMS at baseline and at six months. Participants were asked to rate how confident they were in managing their diabetes. Data were collected pre and post intervention to measure any changes in self-efficacy after using the web-based programme.

6.4.3 Type 1 Diabetes Nutrition Knowledge Survey (NKS)

The T1D Nutrition Knowledge Survey (NKS) was developed by Rovner et al (Rovner *et al.*, 2012). The NKS (appendix 12) is an American validated tool consisting of 23 items. It was specially developed for youth with T1D to assess both general nutrition (for example healthful choices and label reading) and diabetes specific nutrition knowledge (example carbohydrate counting and glycaemic response to foods). Data were collected at baseline and at six months post intervention to measure change in nutrition knowledge after using the web-based programme.

6.4.4 Dietary Intake

Dietary intake was collected in the form of 3-day food diaries. Participants were asked to record all items of food and drinks (with amount and preparation) eaten at each meal or snack. A food diary component was included in the web programme along with instructions and an example of how to complete the diary. The 3-day food diary method allowed for both assessment of individual diets and identification of commonly consumed carbohydrate foods. Children and adolescents were asked to record all food and drinks consumed over a three day period, of which one day should be a weekend day, on three occasions. Where possible, they were also required to record food weights or household measures, cooking methods and brand names. Dietary intake was obtained at baseline, three months and six months post recruitment. The exact dates were given to the participants for them to record their dietary intake at three and six months. The researcher (RI) contacted them one week before the due date each time to remind them about the food diary record. Nutrient Composition of Malaysian Foods Database Programme (Siong *et al.*, 1997) was used to calculate total energy and macronutrient composition of total diet (3 day mean) and of each meal and snack and to determine variability between time points for each participant.

6.4.5 Google Analytic

For each participant, individual use of the web-based programme '*My Diabetes'* was recorded for six months using Google analytic. It was used to identify the frequency of visits to the website, visit duration, which component of the site was visited most and time spent on each component.

6.4.6 Interviews

For the qualitative part of the study, data were gathered using face-to-face semi-structured interviews. An open-ended interview guideline was developed by the researcher to answer the research questions. See Table 19, Table 20, Table 21 for the interview topic guide for children, parents and HCP. A general introductory question was asked, followed by broad questions and probes to encourage the children and adolescents to elaborate on their experiences. Questions were compiled from the literature and the clinical experience of the researcher. The objective of the interview was to elicit the participant's story. The researcher asked the participants and their mothers to explain or give details of their experience with T1D. "The researcher asked probing questions to encourage the participants to elaborate on the details to achieve clarity and to stay close to the live experience (Starks and Brown Trinidad, 2007)".

The researcher (RI) conducted an interview with participants and their mothers at the participant's home during June 2013. The interview was conducted after six months of using the web-based programme in order to clarify and allow participants to express their views, experiences, satisfaction with and acceptance of the system and also their experiences of diabetes. All twelve participants and their mothers agreed to participate in the interview. Each interview lasted approximately 45 minutes to one hour. In order to make sure participants felt comfortable and there was minimal distraction, all interviews were conducted in a room chosen by the participants. After interviews were completed, nine interviews with children and nine with mothers, content saturation was achieved. However, the researcher still conducted another six interviews (three with children and three with mothers) in order to identify any other different themes or issues raised. No additional themes were extracted from these interviews. No more interviews were scheduled or needed. Interviews were also conducted with the three clinicians by telephone at the clinic. Each interview lasted approximately 45 minutes to one hour. All interviews were digitally recorded and transcribed verbatim.

Table 19: Interview topic guide for participants (children)

INTERVIEW SCHEDULE

Child ID: ____ Date:____________

General Questions

1. Can you tell me how long you have diabetes and how do you fell about it?
2. What do you find to be the biggest challenges of living with diabetes?
3. Can you tell me how diabetes effect the other aspect of your life such as diet, family routines, and physical activity.

Self-efficacy questions

1. What do you think is important to know about your diabetes in order to feel comfortable to managing it on your own?
2. How and where do you learned about your diabetes and how to manage it?
3. Are you able to cope or manage your diabetes?
4. How do you feel about your diabetes?
   Probe: when do you feel your diabetes is under control?
   When do you feel your diabetes is not under control?
5. Do you mind if your diabetes is not under control?
   Probe: why do/don’t you mind?
6. How do you feel about your diabetes treatment?
   Probe: Diet
   Glucose monitoring
   Insulin
   Exercise
7. What is easy about controlling your diabetes? What is difficult?
8. Do you do any changes about your diabetes management for the past six months?
9. If you had to tell someone about how to manage or cope with their diabetes what would you tell them?
10. Is there anything else you would like to tell us about what you think is important to know, so that you can learn to manage or take care of your diabetes on your own?

Diet & knowledge questions

1. Could you please tell me what do you know about food or diet for diabetes? Or what to eat in order to control your diabetes?
2. Where did you get information about food or diet for diabetes? Probe: Hospital, home, newspaper, internet, friend etc?
3. Who give to you information about diet for diabetes? Probe: Doctor, Parents, Friends, etc…
4. Who help you to choose your food or take your food? Probe: How? Cooking Together? Shopping together etc…
5. Did you change your diet for the past six months?
6. Did you eat diabetes diet for the past six months? Probe: How many times per week/month
   Tell me the example of diabetes diet

Support questions

1. Have you received any support about your diabetes?
2. Who give you support to manage your diabetes? Probe: Parents, Family, Clinician, Teacher, Friends, Diabetes peers
3. Did you get enough support to manage your diabetes?
4. Did you always contact your clinician to seek advice about your diabetes?
   How about your other friend who had diabetes?

Web questions

1. How frequently do you log in onto the website?
2. Which parts of the website do you use most?
3. Which parts of the website do you use least?
4. What did you like most useful about the website?
5. What do you think overall look of the website?
6. In general, was the website has easy to use?
7. What part or information you find difficult to understand?
8. Was the language used in the website easy or difficult to understand?
9. What difficulties did you have to log in onto the web site?
10. What benefit did you get from using the website?
11. Overall, how useful the website did you find in helping you to manage your diabetes?
12. How enjoyable did you find using the website?
13. What challenges did you have in using the website?
14. What would have liked to be included to improve the website?

Table 20: Interview topic guide for parents

INTERVIEW SCHEDULE

Parents ID: ________________________________ Date:____________

General question

1. Can you tell me how long your child had diabetes and how do you feel about it?
2. What do you find to be the biggest challenges of living with children with diabetes?
3. Can you tell me how diabetes effect the other aspect of your life such as diet, family routines, and physical activity.

Self-efficacy question

1. What do you think is important to know about diabetes in order to feel comfortable to managing your children with diabetes?
2. How and where do you learned about diabetes and how to manage it?
3. Are you able to cope or manage your children with diabetes?
4. When do you feel that your children diabetes is under control? Or not control
5. Do you mind if your children diabetes is not under control?
   Probe: why do/don’t you mind?
6. How do you feel about diabetes treatment?
   Probe: Diet
   Glucose monitoring
   Insulin
   Exercise
7. What is easy about controlling your children diabetes? What is difficult?
8. Do you do any changes about your children diabetes management for the past six months?
9. If you had to tell someone about how to manage or cope with their diabetes what would you tell them?
10. Is there anything else you would like to tell us about what you think is important to know so that you can learn to manage or take care of your children diabetes on your own?

Diet & knowledge questions

1. Could you please tell me what do you know about diet for diabetes?
2. Where did you get information about diet or food for diabetes?
   Probe: Hospital, home, newspaper, internet, friend etc?
3. Who give to you information about diet for diabetes?
   Probe: Doctor, Parents, Friends, etc…
4. Do you help your children to choose their foods?
   Probe: How? Cooking Together? Shopping together etc…
5. Did you change your children diet for the past six months?
6. Did you cook or buy diabetes diet for the past six months?
   Probe: How many times per week/month
   Tell me the example of diabetes diet

Support question

1. Have you received any supports to manage your children with diabetes?
2. Who give you support to manage your children with diabetes?
   Probe: Family
   Clinician
   Teaches
   Friends
   Diabetes peers
3. Did you get enough support to manage your children with diabetes?
4. Did you always contact your clinician to seek advice about your children with diabetes?
   How about your other friend who also had children with diabetes?

Web questions

1. What did you find most useful about the website?
2. What did you like least about the website?
3. What are the advantages in using the website?
4. What are the disadvantages in using the website?
5. What do you think overall look of the website?
6. In general, was the website has easy to use?
7. What part or information you find difficult to understand?
8. Was the language used in the website easy or difficult to understand?
9. What difficulties did you have to log in onto the web site?
10. What benefit did you get from using the website?
11. Overall, how useful the website did you find in helping you to manage your children with diabetes?
12. How enjoyable did you find using the website?
13. What challenges did you have in using the website?
14. What would have liked to be included to improve the website?

Table 21: Interview topic guide for HCP

INTERVIEW SCHEDULE

Clinician ID: ____

Date: ___________

Questions

1. How would the website be useful for you to support parents and children with diabetes?
2. In general, was the web site easy to use?
3. Overall how would the website useful in helping you to manage your children with diabetes?
4. Is the website useful for you to support parents and children with T1D?
5. How would the website useful for your current practice?
6. How do you think the website is useful for the children with type 1 diabetes?
7. Would you recommend your children and their parents to use the website?
8. Would you use the website in your clinic or during treatment?
9. Did you find any difficulties to log in into the web site?
10. What did you find most useful about the website?
11. What did you like least about the website?
12. What if any advantages are there in using the website?
13. What if any, disadvantages are there in using the website?
14. What do you think about the overall look of the program? Probe: background?
15. How about the photo and colours?
16. What do you think about each components of the website? How about my diary?
17. How about the e-learning component? Is it enough information for them?
18. How about the food library?
19. How about the e-consultation? Do you think it is good for them and also the parents?
20. As the clinician do you think the e-consultation component might give burden to you?
21. How about the forum? The discussion board for the children? Because at the moment the children do not use frequently?
22. At the moment do you use this programme at your clinic? And how often?
23. If you can use this programme, would you like to use this programme to teach your children or parents?
24. At the moment this website is for the children aged 10-14 years old. Do you think that this website is suitable for younger age and also older age?
25. Do you think that this website is just useful for newly diagnosed patient with T1D or for everyone?
26. Do you think this website is useful for other patients in other hospital?
27. What else would you liked to be included to improve the website?

6.5 Data analysis

The quantitative data from the questionnaires were coded, scored, and entered into a Statistical Package for the Social Sciences (SPSS) database. Paired t-tests were performed to assess change pre and post intervention. Statistical significance was set at $p < 0.05$. Interview transcriptions were analysed using a system of coding and framework analysis facilitated by the use of NVivo software. The steps of the framework analysis are described fully in chapter 3 (page 51).

6.6 Results

6.6.1 Demographic characteristics

The study sample's characteristics are presented in Table 22. A total of 15 children and adolescents participated in the study at baseline. Participants were predominantly female (75%) with an age range of 10 to 14 years (mean = 12.07 ± 1.39 years). All participants had been diagnosed with T1D for at least one year prior to the study and were receiving outpatient diabetes care at a paediatric clinic in UMMC, Malaysia. Sixty-per cent of the participants were in primary school and the remaining 40 per cent in secondary school. All lived in an urban area. Most parent respondents (mothers) were married and one was widowed. The majority of parents 12, (80%) were employed full-time, one had stopped working after her daughter was diagnosed with diabetes, one was full time housewife and another one was self-employed.

Table 22: Participants characteristics from Phase three (baseline data)

Characteristics	N=15	%
Gender of child		
Male	*4*	*26*
Female	*11*	*74*
Age of child		
10	*2*	*13*
11	*4*	*27*
12	*3*	*20*
13	*3*	*20*
14	*3*	*20*
Mean, standard deviation 12.07 ± 1.39		
Years with diabetes		
1	*3*	*20*
2-5	*3*	*20*
5+	*9*	*60*
School level		
Primary	*9*	*60*
Secondary	*6*	*40*
Language at home		
Malay	*6*	*40*
Chinese	*1*	*7*
Tamil	*1*	*7*
English	*7*	*46*
Parent marital status		
Married	*14*	*93*
Widow	*1*	*7*
Parent occupation		
Full-time employed	*12*	*80*
Self-employed	*1*	*7*
House wife	*2*	*13*

6.6.2 Google analytics: Number of logons

All fifteen participants viewed themselves to be proficient in computer and internet use. After three and six months, twelve (80 percent) of the participants were still actively using the web programme. Three (20 percent) of the participants withdrew from the study after one month of the intervention. One of the participants (14 year old boy), discontinued using the programme giving the reason “he was too lazy to continue the study”. Another two, who were siblings, were discouraged from using the internet by their mother for the rest of the six months as she felt they needed to concentrate on their studies prior to a forthcoming national exam.

Twenty five percent (three) of participants accessed or logged on to the system every day or seven times per week, 8 percent (one) participant logged on four times per week, 42 percent (five) logged on two times per week, 17 percent (two) logged on once per week and another 8 percent (one) logged on only once a month. Figure 22 shows the usage of the web programme and how this changed over time. In the first month, 1427 page views were recorded, reducing to 483 in the second month. However, usage then increased gradually to 731 page views in the final month. The most commonly accessed component was the *‘Food Library’* and *‘Diabetes Diary’*. Table 23 shows the number of page views every month for each component in the web programme. Participants used the *‘Food Library’* to obtain information about carbohydrate content of foods and drinks to help them to adjust their insulin dose and used the *‘Diabetes Diary’* to record their blood glucose value and also diet intake.

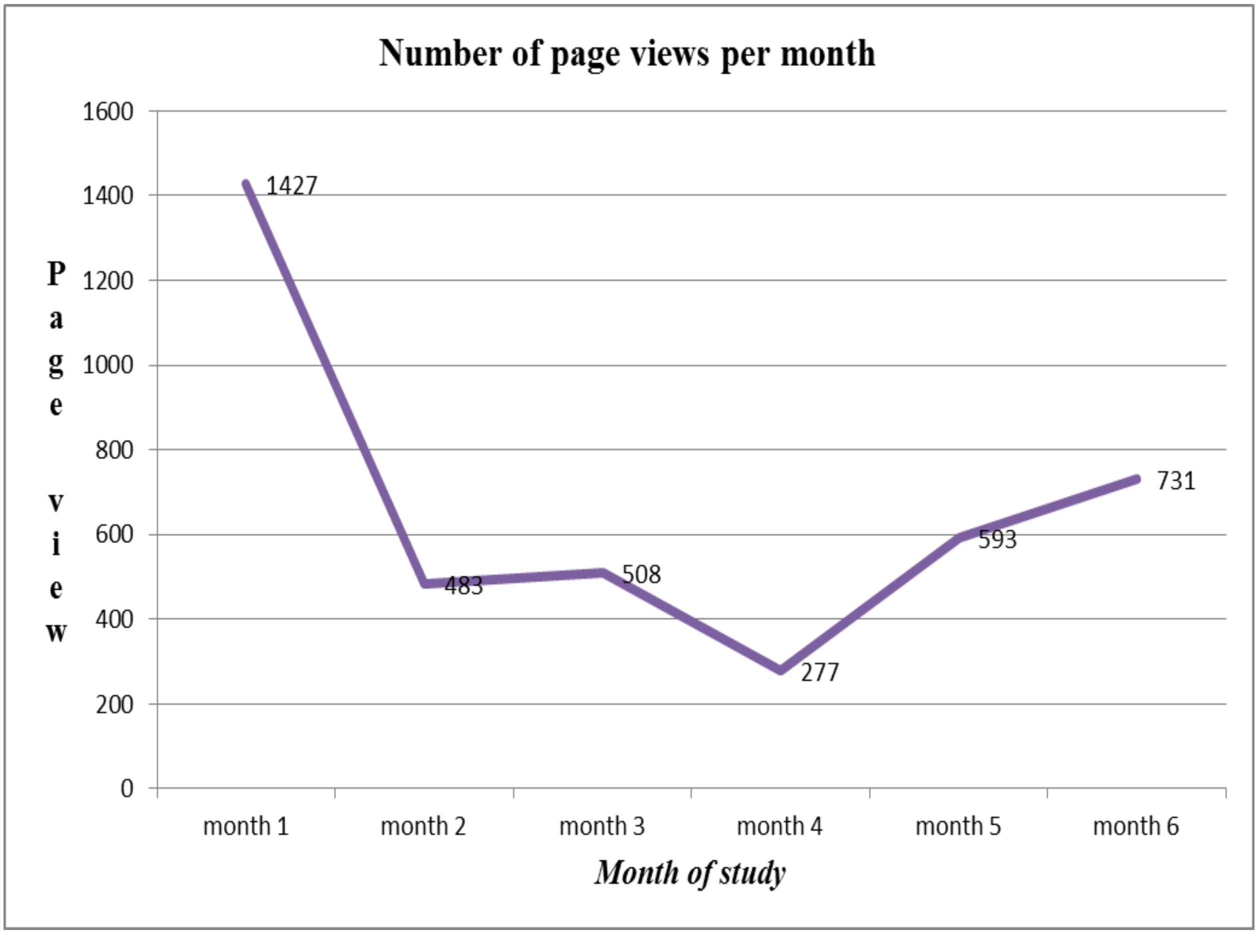


Figure 22: Number of page views per month by participants

Table 23: Number of page views per month by participants for every component in the web

Web component	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6
Diabetes diary	*687*	*291*	*235*	*141*	*329*	*350*
E-learning	*63*	*21*	*20*	*1*	*23*	*53*
Food library	*487*	*129*	*140*	*90*	*196*	*245*
E-consultation	*33*	*2*	*13*	*0*	*10*	*20*
Forum	*157*	*40*	*100*	*45*	*35*	*63*
Total views	***1427***	***483***	***508***	***277***	***593***	***731***

6.6.3 Self-efficacy

Twelve participants completed the Perceived Diabetes Self-Management Scale (PDSMS) pre and post intervention. Three participants only completed the PDSMS questionnaire at baseline and withdrew from the study after one month. The average PDSMS scores at baseline and at six months were 25.83 ± 3.74 and 28.25 ± 4.11 respectively. There was a significant difference between pre and post test score for the PDSMS using paired sample t-test (*p* = 0.001). High scores indicate higher self-efficacy indicating that in this study self-efficacy was increased after the intervention. Only two participants showed no difference in the score pre and post- test, the other ten participants' scores were increased following the intervention. The results obtained from pre and post intervention for the PDSMS can be compared in Table 24.

Table 24: Participant characteristics and PDSMS score

Participant ID (N=12)	Gender	Age	PDSMS scores at baseline	at six month	Percentage of improvement
P1	*Female*	*14*	*29*	*30*	*2.5*
P2	*Female*	*13*	*26*	*32*	*15.0*
P3	*Female*	*10*	*22*	*25*	*7.5*
P4	*Female*	*12*	*30*	*30*	*0.0*
P5	*Female*	*11*	*25*	*25*	*0.0*
P6	*Female*	*13*	*26*	*28*	*5.0*
P7	*Female*	*12*	*28*	*32*	*10.0*
P8	*Female*	*13*	*32*	*36*	*10.0*
P9	*Male*	*12*	*28*	*30*	*5.0*
P13	*Male*	*11*	*22*	*24*	*5.0*
P14	*Female*	*10*	*20*	*22*	*5.0*
P15	*Female*	*11*	*22*	*25*	*7.5*
Mean score			***25.83 ± 3.74***	***28.25 ± 4.11***	***(p=0.001)***

6.6.4 Nutrition knowledge

Twelve participants completed the T1D Nutrition Knowledge Survey (NKS) pre and post intervention. Pre and post NKS scores were 7.67 ± 2.39 and 10.50 ± 2.24 respectively. The difference between pre and post scores and percentage of improvement are highlighted in Table 25. The table shows that nutrition knowledge was increased from baseline in all but three participants for whom there was no change. There was a significant difference between pre and post test score for the NKS using paired sample t-test (*p* = 0.012).

Table 25: Participant characteristics and NKS score

Participant ID (N=12)	Gender	Age	NKS scores at baseline	at six month	Percentage of improvement
P1	*Female*	*14*	*8*	*9*	*4.3*
P2	*Female*	*13*	*11*	*12*	*4.4*
P3	*Female*	*10*	*3*	*14*	*47.9*
P4	*Female*	*12*	*9*	*9*	*0.0*
P5	*Female*	*11*	*11*	*11*	*0.0*
P6	*Female*	*13*	*8*	*8*	*0.0*
P7	*Female*	*12*	*5*	*10*	*21.8*
P8	*Female*	*13*	*9*	*14*	*21.8*
P9	*Male*	*12*	*8*	*9*	*4.3*
P13	*Male*	*11*	*8*	*13*	*21.8*
P14	*Female*	*10*	*5*	*8*	*13.0*
P15	*Female*	*11*	*7*	*9*	*8.7*
Mean score			***7.67 ± 2.39***	***10.50 ± 2.24***	***(p=0.012)***

6.6.5 Dietary intake

The macronutrient profile of the participants was compared against the ISPAD (International Society of Paediatric & Adolescence Diabetes) recommendation (Smart *et al.*, 2009b), which is also the Malaysian national recommendation. The result is shown in Table 26.

Table 26: Mean (SD) macronutrient intakes (as a percentage of contribution to overall energy intake) and fibre, fruits and vegetables intake compared to ISPAD and Malaysian guidelines

Nutrient	**ISPAD/Malaysia recommendation**	**Month (N=12)**		
		Baseline	*At three month*	*At six month*
% of energy from Carbohydrate	*50-55*	*52.8 (3.8)*	*52.8 (3.7)*	*55.4 (3.5)*
% of energy from Protein	*10-15*	*15.3 (1.4)*	*16.4 (2.2)*	*15.7 (1.6)*
% of energy from Fat	*30-35*	*31.9 (3.2)*	*30.7 (2.2)*	*28.9 (3.1)*
Fibre (gram)	*20-25*	*6.9 (3.0)*	*9.8 (3.4)*	*11.8 (4.3)*
Fruits	*2 servings*	*1.3 (0.9)*	*1.6 (0.7)*	*1.6 (0.7)*
Vegetables	*3 servings*	*1.6 (0.5)*	*0.9 (0.9)*	*1.3 (0.8)*

Results showed that the percentage of energy from carbohydrate and fat met the current nutrient recommendations pre and post intervention, for protein the intake was slightly higher than the recommendation. The fibre, fruits and vegetables intake were lower than the recommendation.

6.6.6 Interview (children and parents experiences and perceptions)

Based on qualitative interviews conducted after the intervention, both participants and their mothers described the web-based programme as useful, accessible and beneficial to them in managing their diabetes. During the analysis, the researcher listened to the tapes and transcribed the interviews, and the themes were developed after that. The themes or codes were identified from the literature reviews and from the analysis of the interviews. One of the supervisors rechecked the interview transcriptions and the themes were discussed. Finally several major themes were identified each with several subthemes and agreed between researcher and the supervisor. The themes were classified as: Barriers to web use; Perceived benefit of the web; Suggestions for improvement to web programme; Experiences of diabetes; Communication and support; Regimen adherence; and Dietary adherence.

Theme one: Barriers to web use

<u>Subtheme: Usability and acceptability</u>

Most of participants and some mothers mentioned that the web programme was easy to use, no problem was identified during the log on and entering of the data and they enjoyed using the programme. One participant reported:

"Nothing challenge at all. It is not stressful" (P6, female, 13y.o)

Another participant had a similar answer:

"All okay. Yes, easy to use. I enjoyed used the website" (P7, female, 12y.o)

One mother reported:

"She is enjoyed using the website. Easy to use but the problem is she very busy, so she cannot use the web daily" (M7).

However, one participant and one mother reported that they had some problems when they used the programme:

"The rest is okay except the forum, I got stuck on how to start the Forum" (P5, female, 11y.o).

Her mother also reported the same thing:

"From my child feedback sometimes she gets stuck halfway" (M5).

A few of the mothers also had a problem with the web (*'My Diabetes'*), they reported:

"I mean of course the human problem not the technical. To understand and to get used to it was a bit tough. Well there was a problem in sending and we facing a bit of difficulty" (M6).

"Is not easy to use, not to say not benefit, you need to learn" (M1).

The majority of the participants and mothers also agreed that the language and information in the web programme were easy to understand.

"The language and information were easy to understand" (P1, female, 14y.o).

"Language very simple. Suitable for her age" (M3).

Only a small number of participants (one participant and one mother) reported that the information in the food label section was difficult to understand.

"I think it is the one with the food label. I just don't understand the percentage of the food" (P8, female,13y.o).

"Easy to understand except the way to calculate"(M7)

Subtheme: Lack of time

Insufficient time affected the use of the web programme. Twenty five per cent (three) of participants had accessed or logged on to the system every day or seven times per week, 8 per cent (one) logged on four times per week, 42 per cent (five) logged on two times a week, 17 per cent (two) logged on once per week and another 8 per cent (one) logged on only once a month.

"Every day I log on to the system. The information was easy to understand" (P3, female, 10y.o).

"Not to say every day, but I will use it. If I open internet means I will use the web. At least 15 to 20 minutes I will use that. Information was easy to understand" (P4, female, 12y.o).

Initially, participants logged on to the programme in order to obtain information about the diet for diabetes from the E-learning component. For the rest of the intervention study, they used the web to record their blood glucose and diet intake into the diabetes diary and they used the food library component in order to obtain information about the carbohydrate content of food and drink, so that they could adjust the dose of insulin based on the amount of food and drink consumed on that particular day. In response to the question, "which component they like most and which component they used frequently", most of those interviewed indicated that the food library and the diabetes diary were the two components most visited and which they liked most.

"Maybe in one month, three or four times log in. Component used most was food library and diabetes diary, and less used was forum" (P8, female, 13y.o).

"One week, two times three times to learn about the food, the carbohydrate. The language and information were easy to understand. Component used most was food library and less used was nothing" (P9, male, 12y.o).

Busy schedule, school homework and lack of time were the reasons participants reported for not logging on to the website every day.

"I think the program is good. Like what you advise, everything is there. But you need to find time to really sit. Not for one hour, maybe more than one hour you really can go through on the program look through. Not just go one hour and half an hour. You sit and you study the things then only you can. It's really useful actually. The program is useful but you need time actually to sit properly. Manage your time then only you can get the more information from that"(M5).

"She is enjoyed using the website. Easy to use but the problem is she is very busy, so she cannot use the web daily" (M7).

"Because during Monday to Thursday she has tuition, so she goes to bed straight away. Maybe on Friday, Saturday onwards two days only she wants to go in, she can go in. If not she was too tired to stay up late" (M5).

One mother indicated that for her the web programme was good unfortunately her daughter is too lazy to log on every day:

"The web is good but she is lazy to do it. If she can do it every day is good for us and also for doctors. But she is lazy" (M2).

Subtheme: Content arrangement

When asked if the components in the web programme were beneficial to them, the overall response to this question was very positive. The response from the participants on each components of the web programme was described as below:

Diabetes Diary

"For me diabetes diary is good because sometimes when you wrote it down on the paper, you don't know where you put it. In the web you can log in and check it is safe" (P8, female, 13y.o).

"That is ok. That is good. It seems that you can be wise, look back if you want to do correction if you want to go and see what is wrong with the sugar level even if I control, I take the same food the same amount but the blood sugar is increased so you know what is happening around that day with the diary. If you take the same food the same amount suddenly the sugar is high up you can trace back prior to that maybe intense activity or less activity you will revise and then from there you can do correction" (M8).

E-Consultation

"I think it is ok. If you have a problem just sent question to them rather than calling them" (P8, female, 13y.o).

"Yes, that is very good. You can look every day or twice a day. It will be wonderful rather than disturbing the doctor with a phone call. I feel so reluctant to call and then just to leave a message I feel bad unless emergency" (M8).

E-Learning

"I think is useful" (P5, female, 11y.o).

"I think for now the information is enough for me" (P4, female, 12y.o).

Food Library

"We can know more about the food for those having diabetic" (P4, female, 12y.o).

"Yes, If I do not know about food, I will go to food library" (P5, female, 11y.o).

"Food library? Especially when you travel then you know. When you travel abroad then you know how much food intake necessary"(M8).

Forum

“I can share with my friends, I can share my problems” (P9, male, 12y.o).

“It’s good. She can expand her horizon, her friendship, her way of thinking. Children now days get attached to technology very fast. So they know how to manoeuvre in between. They know how to create discussion group, socially, it is good. It is good with limitation” (M8).

Theme 2: Perceived benefits of the web

Subtheme: The use of the web as a diabetes management system

All of the participants and mothers found that the web programme assisted them in managing their T1D. Mothers identified substantial benefits from the web programme, including monitoring of participant’s blood glucose and diet intake by the HCP and parent. They also could obtain diet information from the website, so thought it might help them to improve their children’s diet intake. For them this programme also helped their child’s HCP to manage their diabetic patients.

“I think definitely it will help because if they implement this website seriously and correctly. Doctors will find it more easier because children are giving their information before appointment so they can do correction before. I think is very useful if government can implement this and give access to this for those who don’t have” (M6).

“For me the system is good. We can get more information, asked the doctor, and chat with diabetic friends. If she did not know about the diet, she can refer to the web” (M7).

“I don’t use. She is the one who is using it. So the benefit would be for her. For me I benefit to monitor her, to be aware of her diet since she is putting it in the web and it will be looking by the doctors so indirectly it will lessen my burden of having to monitor her alone” (M8)

For participants, the programme assisted them in monitoring their blood glucose and helped them to obtain more information about the diet for diabetes.

"I think it can affect the way I control my diabetes because all of those information inside the website. Like food library if I don't really know for the calculations for the carbohydrate exchange, but when I log in and I read through those now I know"(P8, female, 13y.o).

"I think it helps me for all aspects of my diabetes" (P3, female, 11y.o)

"It's good. It is easy also to know so that I don't have to take my book and see" (P6, female, 13y.o).

Subtheme: Opinion of the web programme

Participants and mothers shared the same opinion about the web programme. All five components in the web programme were beneficial to them even though they did not access all of the components regularly. For mothers, their child could use the programme to get more information about the diet from the *'Food Library'* and *'E-learning'*, to monitor their blood glucose and diet control from the *'Diabetes Diary'*, to share information and stories with their diabetic friends by using the *'Forum'* and if they had any problems they could send their question to their HCP immediately through *'E-Consultation'*.

"Very helpful. Good. You can update you information every day. So you can see whether you control or diet is good or not. Lots of information. You can chatting with your friends. You can ask your doctor. It is a lot. Very good. It's help my daughter to monitor her control. So she knows how much to eat. She also can share information with her friends" (M3).

"A lot of information she can share with her friends. She can know better. A lot of things she doesn't know she can learn from the web. A lot of information, sometimes like bread, we do not know how many calories there. Everything got inside. Useful for her"(M4).

"Well from what I know a little, sharing, they can share and then they can know more things from others. For more information and more friends from them. For her I can see the information and the details of sharing with others and you are giving your details and like doctors can come in and say no you should you know. Do the corrections. I know is very good. It is a useful tool"(M6).

"What I know is, usually you give a book to the children they will never study. So once you put in the computer all day they can use it. They can communicate with their doctors. They know how much to eat. I feel it is good for me. He is learning there a lot. The website I never go to use it. Only my son. But he will tell me he will send a message to the doctor and the doctor will send a message back. Then he say he can learn something about the food, the food calculation. Usually I have got no time. Then he will go to diabetics and food this one, he will tell me. Diabetics can eat this. He will inform me then he will come and say this one, this alright, after that yes, finished" (M9).

One mother raised her concern that when the internet server went down, internet and computer access in rural areas is not always affordable. She described during an interview:

"Well again she become herself disciplined, she knows what she is supposed to do. The web is like an alert button. The web is for her. The disadvantage when the computer is not working. Yeah when the internet is not functioning well. It is very good for children. This one is made for children so they can get used to the tools, they know how to manage and then they become more disciplined in controlling their diet. This is fortunate for me because I am staying in urban area but if you go to other hospital which is not in urban area I don't think so they have access to the computer unless they are equipped with the computers from the hospital and if they've got a notebook then that would be beneficial but that would be interesting. I am not sure the percentage of diabetes among children outside of but it will be nice if benefiting to other states. Because what I am saying is one friend of my daughter she met at camp, she doesn't change the needle for the past how many months? That is very bad. She doesn't really change whereby those who stay in urban region they have access to go to diabetes centre to buy needles with small margin of money but if in the other states the travelling and the amount that you should pay and how

frequent you are going to use them, you change every day or every injection or once a day or once a week that is very much the frequency" (M8).

Most of participants found the web programme was beneficial for them to get more information about diet and diabetes and sharing information with other diabetic peers.

"One of them is I can understand more about diabetes and it makes me, when I opened the introduction they have some slight, the movement and the sound, it makes it more interesting and it makes me want to read it more. Including my brothers they like to"(P8, female, 13y.o).

"You know the level of the food. The information on food, the food information, the grams, how much the carbohydrate level. That's all" (P9, male, 12y.o).

"Is actually you can know more about diabetic. You can get more information from others about diabetes. Useful for those who having diabetes" (P4, female, 12y.o).

However, one participant felt that she was expected to do extra work in the diabetes diary:

"Okay but it just very confusing. For example like if you wanted put the gram and insulin like every detail inside" (P1, female, 14y.o).

Theme 3: Suggestion for improvement to web programme

Participants and their mothers provided several recommendations for improvement to the web programme. Two participants and two mothers recommended more colour, pictures, sound, music and graphics and the ability to enter previous data into the *Diabetes Diary*.

"To make it attractive adding more pictures. That's all. Can able to change the date if you wanted to put our food" (P1, female, 14y.o).

"Need to be a more bit creative and exciting. It's a bit dull with just only a plain colour. There is no excitement. You know for children you need more creativity. But I think there should be a bit of music or like a bit of moving things. There is now but not much it is not so creative. I think I more pretty, more music, definitely to attract children" (M6).

"More colourful, fun with music. Yes. For something requiring interaction. Ok. Graphics especially when you do interaction you check there is a bubble coming out. And then posting somebody else birthday and it pops up a balloon or something. Then something more colourful to your life rather than when you open. It's like commentary welcome to halaman music which is not suitable sometime with the echo, the tempo. Not more on conventional type of, more informative and not looking at, lots of things to read, children more or less interested to see lots of images, colours, music, sounds, graphic interaction as compared to text"(M8).

One participant and one mother suggested the use of instant messaging such as Facebook or twitter in order to allow real-time peer dialogue and also listing the names of all diabetes patients on the *Forum.*

"Make it more attractive, colourful and you can do like tweeter or something like that would be very fun, you can put pictures, everything" (P6, female, 13y.o).

"What I would like to see. Everybody have face book. How nice in that Web site that you can advise all the diabetic patients have face book for them. They can check as like, usually all patients go to camp. Not everybody go to Camps because they are what they say they are friends. They are friends. Today I eat this much, I am healthy, they have got their story to tell. How many of them are listed in the website. Their name will be there so they can chit chat. Easy for them to communicate. I said today I am going for yoga. Exercise maybe. We can do in our house. Maybe we can do in your house. Good things. So something like that" (M9).

One participant recommended that the forum and information for adults especially adults with diabetes were separated so that they can share the information.

"I think, this web only for children right? Why not children one side, adult one side. And the problem of diabetic some patients having.....normally adults having a lot of problem" (P4, female, 12y.o).

Theme 4: Experiences of diabetes

Subtheme: Challenge of living with T1D

Participants and their mothers identified a number of factors perceived to be associated with their experiences of T1D and the challenge of living with T1D. The majority of them identified diet management as the biggest challenge of living with T1D. Other challenges included controlling blood glucose levels, insulin injections and checking blood glucose. For participants it was difficult to control their diet, especially to control and reduce the intake of sweet foods.

"I think controlling it. Because you know sometimes you feel that you want to eat sugary things but if you don't know the right amount of sugar inside that. So that is the biggest challenge for me" (P8, female, 13.y.o).

"I don't think that's not like one thing that is important is food. You cannot give them sweets. Only other children can eat sweets. He cannot eat. Like my son is ok he don't cry he is a very nice guy he can take care of himself. He knows, he understands. But it is things I don't feel different. I feel normal. I don't think I've got a son a sick patient. Only thing is food" (M9).

"First of all we are consistent, we must be disciplined that is where our first problem was sometimes and you know Malaysia better sometimes it makes you lazy, the hot season and all this thing sometimes make them to feel more eat or drink sweet drinks and this is where I have to come in and say no you can't take all this. Especially the biggest challenge is in the food and keeping up with them with the consistent of time of intake of the food." (M6).

One patient and her mother stated diabetes had changed their life and they are more disciplined in terms of diet.

“Diet. Since that I have scheduled on my diet. Eat healthy food” (P3, female, 10y.o).

“Good effect now we are discipline in terms of food. We eat vegetables, all follow the healthy food chart. No more sweet things” (M3).

One mother reported that the biggest challenge for her was when her daughter was still young and being away from the family for a while, like going to camp or co-curriculum because she needed to take care of herself.

“The biggest challenges? Ok. Being away from us for a while and then not being able to cope with, being away indirectly it is like she is being for camp or extra- curriculum activities. That’s the biggest challenge so far but that was a few years back now I don’t consider it as a challenge since she is able to cope with it very well and she is able to cope with it beyond expectation” (M8).

Subtheme: Effects of T1D in life

The majority of the participants and mothers stated in the interview that T1D had had an impact on their daily life including changes to diet, family routine and physical activities, to become more active and follow a healthy diet. Two mothers encouraged the whole family to follow the same diet as their daughters with T1D.

“Aaaa, physical activity not much effect because we just leave it as normal but sometimes on maybe other members, the early stage maybe they think they have to control themselves also but when we start to think about her and other children. For adult for me and my husband no problem but for others especially the eldest one. It effect a bit, They feel because of her, sometimes they got the feeling in early stage they have to follow the same thing but as Dr Yazid encouraged. The early stage I cooked separate dishes just for her but then Dr Yazid told me not necessary actually you just control sweet things, so we manage, so I just cooked the normal Malay food. Like sweet thing maybe once a while, before that

also we don't always buy sweet things and junk food for my children maybe once a while I bought for them" (M5).

"Since that I have schedule on my diet. I eat healthy food. I become more active after I got diabetes. I need to be active" (P3, female, 10y.o).

"It affects the whole family because of her diabetes, the whole family cannot eat the sweet stuff. Everybody needs to sacrifice" (M7).

At the time of first diagnosis, participants described initially feeling very upset and having difficulty adjusting to their diagnosis. However they generally found it more manageable over time with support from their HCP and family members.

"For first time I did not know what happened to me. So, I was confused. And then after that knowing about diabetes. Is kind of fun to know what is diabetes is. And I don't think that having a diabetes is a bad thing" (P1, female, 14y.o).

"I feel sad but after sometimes I can accept when got information from the hospital, from Dietician. Really helpful and now I can handle it" (M3).

One mother indicated that when her daughter was first diagnosed with T1D she would go to her bedroom every night to check whether she was hypoglycaemic. Her daughter had not been allowed to eat sweet food since being diagnosed with T1D.

"Since she got diabetes, I did not allow her to take sugar. Others all the same. But in early stage, every night 1 will go to her bedroom to check she was ok or not"(M2).

One patient mentioned that since being diagnosed with T1D, she needs to check her blood sugar before exercising in order keep her blood sugar under control.

"*I think, for the diet I think it doesn't really affect but I control it but I control by means that I have to control my insulin and I have to control the sugar. I can't really eat it every* *day and for the physical activities for like the sports day and all, my mum ensures that I have to inject glucose, if it is high I have to control it and if a hypo then I need to eat candy muller" (P8, female, 13y.o).*

Theme 5: Communication and support

When asked about where they obtained their support related to diabetes, the majority of participants indicated that they received support from family members and the diabetes team in the hospital and a few reported getting supports from friends in school. Support from the hospital related to information and education for diabetes and also provision of free blood glucose strips for monitoring of blood glucose.

"We have received support from the doctors in the hospital. They also provided free strips to us to check blood sugar two times a day. The strips are very expensive without support we can't afford to buy" (M2).

"Most for me the support is doctors. Ok because his insulin is free. They are giving me stick free. The doctors are giving me stick free. The doctors they are the one. The doctors do everything for me, the insulin, plus stick, injections they give me" (M9).

Support from family members was reported to be really important so that they are not facing the problem alone. Participants indicated that they got support from parents and also from other siblings. They also received support from grandparents and other relatives as well. Two mothers shared the same opinion:

"A lot, from family, doctors, dietician" (M3).

'My family give all the support to her, as well as her friends, her teacher and also my relative" (M7).

One mother expressed the belief that, besides support from people around you, the support must come from yourself as a patient.

"Support is when, you say support, I don't really believe that it will come continuously so the most important thing is the support comes from inside of you, so really go and experienced it, of course we need support but that is secondary if they give, I mean those from hospital, dietician, they give support but we meet them officially. The support that comes from inside of you and those around you is important" (M8).

When asked about support from other families who have children with T1D, most of the participants and mothers mentioned that they only shared experiences or discussed diabetes with other patients and their families when they meet each other in the clinic on their appointment day. They had not had any contact with each other outside of clinic. The reason given for this was that everybody is busy with own their routine.

"Diabetes children, when I meet them. So far in my school no one has diabetes. So I see them in clinic only but I share with them" (P6, female, 13y.o).

"Family with diabetes children? Like I told you I got some of the parent phone number. Maybe time, sometimes we don't have much time. We are not from the same area. Everybody have their routine"(M5).

One of the mothers mentioned that some parents are reluctant to share or discuss their children as they felt each parent had their own way or style of raising their children.

"Family with diabetes children, not really. I am working so I don't really have much time to interact. Second I try to interact with other patients but it seems that some of them do not really give good feedback. We have one person, I met twice but it seems that there is no continuation about I do not know if they are become more personal or they have their own way of raising up their kids without having any interaction. I am not that sure" (M8).

One of the mothers described her unwillingness to share her problems with other people or her son's teacher because they might look down on her son's ability.

"I don't want to share. I don't want to tell everybody I have a diabetic son. Everyone they come they say oh different. So I don't share. I share about medicine which can help him to cure his diabetic. The type of person if I have seen it like traditional Indian medicine which can cure him, yoga. This time only thing. I don't go round telling even he don't go round telling his friends cos they will separate him from everybody even the teacher if they know, they don't want to take him because so I don't want the same issue. Once I gave the name of I know he can take care. The last minute the teachers saw him the class teacher saw him, he said why are you not going because you are diabetic. Then your mother will blame me. Then he come back home, he cries. He says he gave my name already. They don't want to take me so I don't want the same issue happening. He says he can take care like running. The teachers this time I don't share with anybody, I don't tell anybody. I know my son and my family know my son. It is enough. So when we go out four people around, and then one person know this. Then this is your son that's all. The other four people no. I feel that. It hurts me" (M9).

One mother reported it was difficult to control her children's diet at school due to peer group influence saying that she will buy anything her friend buys and eats at school even if the food is unhealthy.

"If her friend buy sweet food, she also tend to buy the same thing. Sometimes her friend will buy for her" (M5).

Subtheme: Diabetes education

The majority of the participants and mothers indicated that they obtained education and related information on T1D from the doctors and the diabetes team in the hospital.

"I learn through the hospital and dietician, through the doctors and every one" (P6, female, 13y.o).

"First thing when I discovered that she is having this sickness, doctor is the first, and nurses and dieticians are the one behind the screen that really help us to plan intake of insulin, to control her diet and then to go to plan everyday life theoretically but when she comes back practically I am the one who will be doing that with the rest of the others in the family" (M8).

Other sources of information included the diabetes camp and due to this study the web-based programme '*My Diabetes'.*

"First of all I learned from the website. I really like the inter-relation. I really loved that. And then the useful information about the food. The food library. It's very useful. The other thing, the second one is from diabetes camp. From the hospital? Yes, sometimes they give out pamphlets so I can read it" (P8, female, 13y.o).

"Doctor, from the doctor, from the web program" (P9, male, 12y.o).

The diabetes camp was also reported to be a good place for the participants to obtain information on T1D. They valued the information they received from the health care team and also sharing their experiences with their T1D peers.

"From the hospital and when we went to the Camp and also from others who got children with diabetes and also some from the internet. It's different when you search from the internet and when you mix with people who have the same diabetic child. It different from their experience. Camp is really much helpful" (M5).

Theme 6: Regimen adherence

Subtheme: Coping with disease and regimen adherence

When the patients were asked whether they could cope with the disease and control their diabetes, over half of the patients (55%) said that they could cope with their T1D.

"I can cope with diabetes, I can control my diet. Glucose monitoring and insulin are okay for me."(P3, female, 10y.o).

"Yes, I can cope with my diabetes. Diet yes, easy. Insulin it's normal. Glucose monitoring, it is all under control now. I have got 5 sometimes increase above 10 or 15. Exercise, I normally play at school with my friends when we are running" (P9, male, 12y.o).

"Actually diabetes is nothing for me. Yeah, I can cope. Glucose monitoring, sometimes I am feel sad. Sometimes if my sugar is high means, I feel so sad. Even if I control my food, sometimes my sugar is high do not know why. Sometimes my sugar is like 6, 7 I will be happy because I know I am control my food. Insulin injection actually normal for me." (P4, female, 12y.o).

However, a few of the participants had difficulties managing their diet, insulin, monitoring blood glucose and doing exercise.

"For me checking blood glucose is easy. The difficulty is to inject insulin. I think I can. If I don't know anything I will ask my mom. But sometimes I feel slightly difficult especially when need to count insulin aspart. I felt slightly difficult. But I think I am able to cope with that with the help from my mom" (P5, female, 11y.o).

Two participants felt sad because they have no freedom to eat like other normal children.

"Diet not good. Difficult to control" (P2, female, 13y.o).

"Quite sometimes I take too much food. That is a problem. Glucose monitoring is good. Insulin its good" (P6, female, 13y.o).

One participant felt annoyed she was required to inject insulin every day and another participant had pain when injecting the insulin in the stomach. One of the participants claimed there was lack of time to do exercise.

"I feel diet and glucose monitoring is okay but insulin injection, sometimes I feel boring because need to inject everyday" (P5, female, 11y.o).

"Sometimes control, sometimes not. Easy to control diet and blood sugar. The difficult part is to do exercise. No time to do. Yes, I can manage my diabetes" (P7, female, 12y.o).

Some of the participants commented that they can cope with the disease, but that they sometimes felt low on self-confidence especially when their blood glucose was not well controlled.

"Sometimes, I feel confident to manage my diabetes. Sometimes I feel not confident. Sometimes, I might get hypo" (P1, female, 14y.o).

"Sometimes yes, I can cope. Sometimes I feel like giving up. Sometimes I take too much food. That is a problem. Glucose monitoring, it's so for good. Whenever I am having sugar or anything, it will shoot up high. Insulin, it's quite good. It's just under control. Exercise Yes I do. Sometimes I just forget to do that but I do it every day" (P6, female, 13y.o).

Sometimes I can cope. Rarely my blood 20 and I did my correction .but for the following two hours it won't come down instead it increases sometimes. Glucose monitoring, I think it is ok for me. Insulin about that the stomach, that's where I inject. So sometimes it' a bit painful because I think I inject at the same place" (P8, female, 13y.o).

Only one participant stated that she was not sure whether she could cope with the disease. Injecting insulin was not a problem for her but she found glucose monitoring difficult.

"Not sure whether can cope. Diet not good, difficult to control. Insulin, easy to control. Glucose monitoring, not easy" (P2, female, 13.y.o).

All participants reported their self-confidence was increased after the intervention. Results from the questionnaire also showed that their self-efficacy was increased after six months in all but two participants. When the mothers were asked the same question, whether they can cope with their child's disease, the majority reported that they can cope and manage their child's diabetes.

"I think I can, take times, but after sometimes, I feel I can handle it" (M3).

"There's one day almost I give up, I don't know what to do but of course again I will see the doctors. I am still learning and I am still going on, and of course on and off I have the fears and scared also, but I can manage it. Type 1 is unpredictable so I still have fears not rest then"(M6).

All of the participants injected insulin themselves and monitored their blood glucose with their parent's supervision.

"She does check every day especially in the morning and on and off like the doctor said she can have checking for the pre-lunch, for dinner like alternating, one day afternoon the other day dinner. I think checking is going on. It must otherwise you cannot really manage your level. Insulin injection is as per doctor's advice. She is following that. Unless there is any party or anything the doctor say she can have extra and she can take that snack. Exercise, she is doing? I will check on her also. Whenever she has the time she will have a walk or just do in-house exercising, a lighter one" (M6).

"When she was in primary school yes I am the one and the rest of us in the family that will help her to monitor everything make sure that that she be testing of the blood and make sure her insulin intake is correct but now, she can handle it at this moment in secondary school. Most of the time she will be doing that. We have installed confidence in her to manage herself all by herself" (M8).

"Monitor glucose she will do herself. Insulin injection she also do herself" (M4).

For some, diabetes changed the dietary pattern of the whole family, now they all followed a healthy diet regimen.

"For me is easy because of diabetes we are more discipline about our food. Glucose monitoring, now, we inject insulin according to food intake. Insulin, about the same" (M3).

"Diet very good. I am not a diabetic, I love to follow the diabetic nutrition. It is very healthy (M6).

In contrast, some of the mothers commented that they encounter difficulties in T1D management.

"Diet is very difficult to control. If I say you must eat like this only but she never understood and that. If she wants to eat means she wants to eat. Monitor glucose she will do herself. Insulin injection she also do herself" (M4).

"I am worried cannot get the insulin. Sometimes I don't know what happened to my child. Suddenly the sugar is high and low. I am worried about her diet as well. I am not so confident. Glucose monitoring and insulin I am also not confident" (M1).

One mother interviewed believed that she would be more confident if she were able to manage the adolescent's emotional needs and hormonal changes. She hoped she could share this problem with other mothers and learn how to handle these matters.

"I have a problem with character hormone change and herself to grow. I don't know about other parents, for me maybe because need to handle others siblings grow up as well, so challenging for me, sometimes we cannot manage. Yes we have, I got those information during the camp those like they share their problem but I think that one depends on the family. Yes, you know we try to start face book right but among the family, but no response. After the camp at Janda baik, we try to start. There is one parent with small child she started. It could help, like which ever parent who have more experience to handle their children maybe they can share with us. We try that day but no response" (M5).

Subtheme: Acquiring knowledge and skills to manage the disease

The majority of participants and mothers explained that acquiring the knowledge and skills to manage dietary intake and insulin injections were critical aspects in learning to self-manage their disease or manage their children's disease. Overall, they understood and recognised the importance of developing knowledge about their disease to become more independent and become more confident.

"I think by learning how to inject and the eating. We learn it from the eldest, from the parents, now since I am growing so I really need to do it. I have discipline. When I am old enough to have a family, I think it is better if I can start doing it alone, slowly. I think the most important thing is your confidence. If you don't have that confidence you don't really, stand by the goal you want, so in order to stand by the goal you want you have to have confidence" (P8, female, 13y.o).

"What I need to know is manage blood sugar and my diet and exercise" (P6, female, 13y.o).

"For me, it is important for diet, food wise. Only food wise because of the food the sugar is getting higher, so food wise" (M9).

Theme 7: Dietary adherence

Subtheme: Dietary changes

In response to the question asking whether they had changed their diet during the past six months, most of the mothers indicated that they had made changes in meal preparation, food choices and also the quantity of food.

"When she goes to school it depends on her. For morning I choose milk for her and fruit, she likes apple. Afternoon and night, I asked my maid to cook brown rice" (M1).

"For the past six months, I stopped preparing the cake for them"(M5).

A few of the mothers commented that they knew how to make healthy food choices but their children were reluctant to follow the healthy food choices. Another mother reported not having made any changes.

"Oat is good, I ask her to eat, but she did not like it. Do not eat too much of carbohydrate foods such as bread. But the thing is she likes to eat bread, so it is difficult to control. I do not allow her to take sweet drinks so she must bring plain water to school" (M2).

One of the participants mentioned that currently she was eating more cereal food including high fibre cereal and another stated that now she was not afraid to eat sweet stuff because she had learned how to match the insulin and food intake and at the same time control her blood glucose.

"Before that I was afraid to eat sugar but since I know about how to control the insulin. I am not that afraid anymore because I know how to inject" (P8, female, 13y.o).

"Yes, I changed a lot. I take cereal. Last time, I don't used to. I take cereals, I take oats and different biscuits, juice, everything like that" (P6, female, 13y.o).

<u>Subtheme: Food choices</u>

The majority of those mothers who were interviewed indicated that they allowed their children to choose their own food. They were confident that their children had knowledge about good nutrition practices and that they would share their knowledge with each other.

"Initially yes, but now she is smart enough already. When we do marketing I will ask her what she wants to eat and then I will just buy and cook. If I am not around in case I have any emergency meetings, she will cook" (M6).

"Yes, I leave it to him. He knows what to eat, what not to eat. Sometimes we cook together. Then, when we go out and buy things he will tell me what to buy, what not to buy" (M9).

However, one mother commented that even though her children knew about good nutrition, sometimes her daughter was reluctant to follow these good habits.

"I know what to give to her, but it always difficult especially when eating out or at school. I told tell her not to eat sweet food, but at school I cannot control her. She tends to eat a lot of carbohydrate food. But we seldom take sweet foods except when she got hypo, then we will give her sweet drinks. I am always showed her and told her about the good diet but she did not want to follow" (M2).

Another mother reported that, even though her children had knowledge about good nutrition she would still tell her child what to choose.

"While we went for shopping, if she wants a cake, I will tell her, cake is sweet thing, but if you still want to eat you can take half of it. But if you still want to eat one piece of cake, we need to inject extra insulin. During cooking, I will tell her to eat vegetables and more protein but less rice" (M4).

Subtheme: Diet information (Source of information)

When participants and their mothers were asked where they obtained information about diet for diabetes, most of them mentioned that they received information from the hospital, and some of them reported that they had also obtained information from the web programme.

"First of all, there is book, this green book about food exchange. I learned it from there and also from the website and from diabetes camp" (P8, female, 13y.o).

"From the dietician and from the web" (P9, male, 12y.o).

"From the hospital and dietician and from the web" (M3).

Subtheme: Nutrition knowledge

All the participants knew about good nutrition for a patient with T1D. When asked about what was a diabetic diet, they were able to explain and provide detailed information. They also believed their nutrition knowledge increased after the intervention. The NKS questionnaire supported this finding as nutrition knowledge was improved after the intervention.

"Diet for diabetes eat healthy food, control the amount of food so can get good glucose number" (P1, female, 14y.o).

"We must control our food intake. For example, eat a lot of vegetables and reduced the amount of rice. But the amount of rice cannot too low as well. Must balance it" (P7, female, 12y.o).

The majority of mothers also had knowledge about nutrition for diabetic children.

"You must reduce sugar intake. Do not eat lots of carbohydrate. Drink low fat milk instead of whole milk. Do not inject too much of insulin, you might eat a lot because of that. And then you must be active" (M3).

"Less carbohydrate, more vegetables and fruits intake so that glucose is stable in the blood. For me, you can eat everything but you must control the amount of food" (M7).

6.6.7 Interviews (HCP views and expectations)

Qualitative interviews were conducted with three HCP after the intervention. They described the web-based programme as useful, accessible and beneficial to teach and support their children and adolescents with T1D. Five major themes were identified through analysis of the data, each with several subthemes. The themes were classified as: Barriers to web use; Benefit of the web; Layout and content arrangement; Feasibility of use of the programme in the clinic setting and Suggestions for improvement to the web programme.

Theme 1: Barriers to web use

Subtheme: Usability and acceptability

All of the HCP said that the web programme was easy to use and useful for them in their current practice to teach and manage children and adolescents with T1D.

"Definitely useful for me because at the moment we do not have kind of like….. You know…., when we spent time teach parents or the patient, we kind of like teach them only on the spot. And for them to go back to their home and to refer back or reflect back what we have teach them, those things are not readily available. So with this kind of website I think whenever they want to revisit or reflect on whatever they have learned in the clinic. They maybe more to do so. Or even at home just by going into the website" (Paediatric Endocrinologist, male).

"I think this website is very useful for patient and also clinician as well. For patient they can use this website at any-time and anywhere. For clinician and nurse educator, it is easy for us to review patient result and blood glucose result" (Clinical Nurse, female).

They did not have any difficulties logging on except when there was an internet problem.

"Not usually, occasionally when there is some problem with our internet access basically because sometimes I log in through from the hospital, sometimes from home. So occasionally when you have some internet access problem there is some issues. But not that many times"(Paediatric Endocrinologist, male).

"Easy to log in, no problem at all"(Dietician, male).

However, one HCP commented that some patients faced problems uploading previous data.

"For patients they had problem because they can't upload previous data must be up to date. Other than that, no problem at all" (Clinical Nurse, female).

Theme 2: Benefit of the web

<u>Subtheme: Education, diabetes management and support programme</u>

The HCP valued the programme as an educational tool for patients to obtain information and knowledge especially on diet. This programme can be used as a diabetes management tool to monitor their blood glucose and diet intake.

"I think the amount of knowledge in terms of the diet especially, that is available in the website. That will be my preference if you ask me what is the most useful thing. But I guess the whole things in the website are useful" (Paediatric Endocrinologist, male).

"As we know food is important, if patient can fully utilised this website as a reference to know carbohydrate content of food in order to match with their insulin, so it will really help the patient" Clinical Nurse, female).

One of the HCP stated that the programme could be a means for them to support their patients and their caregivers. However, patients and HCP would need to use the programme regularly in order to obtain the benefit.

"I think this website is useful for us to support our patients with diabetes, but they must use it, enter their data either blood glucose data or dietary data regularly. And as a clinician, our role is to support them and monitor them" (Dietician, male).

Another HCP indicated that the programme was useful as a communication tool between HCP and patients.

"Furthermore if patient got problem they can straight away ask clinician without need to wait until clinic time which within one or three month. And we know as a teenager they don't like to ask clinician face to face during clinic time, instead they would like to use the technology to help them to communicate with the clinician. So it is really helpful for the patient" (Clinical Nurse, female).

HCP also stated that the web programme was useful for patients with T1D and was not similar to any existing website on diabetes.

"Yes, yes definitely is useful for them and if they were to use the website. The more you use it the more you find is useful. If you don't use it you might think the website is some kind like other website. So depends on whether you use it regularly or not" (Paediatric Endocrinologist, male).

"I never found any website similar than this" (Dietician, male)

One of the HCP commented that the programme might improve their management of their T1D patients.

"As I told you before, if patients regularly upload their data and clinician also play their role, I think we can manage our patient more efficient. It is good for patients and clinician as well"(Dietician, male).

"As we know food is very important in order to control the blood sugar, through this website we can learn about food portion, so easy for patient to make insulin correction and match the insulin with CHO, which the information they can get from this website. And we also can see whether they get the correct information about food portion. This website contributes a lot" (Clinical Nurse, female).

One HCP also reported that the programme could reduce their burden in the clinic and also reduced the time spent with patients in the clinic.

"Now is the era of technology, so by using this website it might reduce our burden in the clinic, reduce time in the clinic, and we also can discuss with patient at any time outside than clinic time" (Clinical Nurse, female).

Subtheme: Advantages and disadvantages

HCP commented that one of the key advantages of the programme was that the information obtained by the patient was reliable information. The programme also made their job easy.

"I think the most important, most advantages is that you can get the knowledge with just clicking on certain icon. You do not need to go and find from a place you are not sure the integrity, you are not sure whether the information is correct or not. And the amount of knowledge you get from the website is actually a lot. I think that will be the most advantages" (Paediatric Endocrinologist, male).

"It makes my job easy and faster. No need to use paper so we don't waste papers" (Dietician, male).

The only disadvantage of the web programme identified was that it is reliant on access to the internet.

"When no internet access or server down or when the system lost their memory, it can be the disadvantages. It will be a problem" (Dietician, male).

"When no internet access" (Clinical Nurse, female).

Theme 3: Layout and content arrangement

The HCP reported that the colours and photos used in the programme were suitable for children and adolescents aged 10-14 years.

"To me looks good, aa is colourful, is for children. Photos and colour are good, aa, colourful as I said just know. So I think that's not an issue" (Paediatric Endocrinologist, male).

"Overall was good. Colour and photos are attractive for children, suitable for them. And also food photo in the food library also looks good. Easy for patient to look at the carbohydrate content" (Clinical Nurse, female).

They also commented that the text was easy to read, large enough and clear enough to hold the user's attention.

"Attractive. Colour are good, got contra colours. Photos used also attractive and acceptable. Font use also acceptable but it depends on individual actually. But if they want enlarge the size they can do it by themselves" (Dietician, male).

In addition, one HCP suggested having the programme available in another language for example Malay language as well as English so that it might improve usage among children and adolescents with T1D especially among the Malay community.

"I think if you can include another language especially Malay language it will improve usage among them especially among Malay children" (Clinical Nurse, female).

When the HCP were asked whether all of the components in the web programme were useful for patients and HCP, the overall response to this question was very positive. They reported all components were useful.

"I think the amount of knowledge, in terms of the diet especially that is available in the website. That will be my preference if you ask me what is the most useful things. But I guess the whole things in the website is useful"(Paediatric Endocrinologist, male).

"For me all important and need to be maintain" (Clinical Nurse, female).

All respondents indicated that the *Diabetes Diary* and *Food Library* were the most useful components in the programme.

<u>Diabetes Diary</u>

"For my diary I think is not too complex. It is ok for that age group. I think they can do that. So I don't find any issue on that actually" (Paediatric Endocrinologist, male).

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E-Learning

All of the HCP commented that information in the *E-learning* component was acceptable. However, one suggested including an interactive part to this component and emphasised the need to keep this information up to date.

"For e-learning component, the information is acceptable, is enough for that age group. But I think in terms of the amount of information, in terms of current information, I think we probably have to update all those information. Give thoughts or put on some questions based kind of like information. That will be probably also helpful for children. Because I think for children we kind of like put out some kind like very simple question and also try to answer in simple easy kind of way. So that will be helpful for them" (Paediatric Endocrinologist, male).

Food library

All of those who responded mentioned that the *Food Library* was one of the best components of the programme.

"That's good. That's the one thing I really like because you tried your best to try to put on the Malaysian kind of food, and also have other kind of food available in Malaysia. Which I think that is the beauty of the website because it kind of like resemble Malaysia basically. That kind of food" (Paediatric Endocrinologist, male).

"For me the food library because it contains information about food available in Malaysia" (Clinical Nurse, female)

E-Consultation

All of the HCP reported that this component was good for the children and parents. On the other hand, one HCP reported it has been underutilised by participants.

"Yes that part is very good but is underutilized I think. Because I am not sure whether the parents are also using it"(Paediatric Endocrinologist, male).

Furthermore, one of the HCP commented that this aspect allowed patients to discuss issues with them without the need for a face-to-face meeting, which was especially useful if they were not comfortable doing so.

"I think this is good especially for adolescents or teenagers. Because in the clinic they do not want to discuss with clinician maybe they were shamed or I don't know…..So by using this web no need for them to meet clinician face to face they can just use this web to ask about their problem" (Clinical Nurse, female).

In response to the question about whether the *E-Consultation* component might increase their work load, HCP commented that they could share the questions among themselves. It was not anticipated that this would not be an issue or problem.

"I think for that part, I mean occasionally I do get sms, I do get phone call asking me certain non-emergency question. And if this e-consultation is fully utilised it will be good. I do get this kind of question from parents especially from parents. These children do not call me directly. Most of the time the parents called and asked me thing. Asked me question so if this website is utilised and is monitored and checked regularly. I think that should be not a burden to the clinician because it can be shared among the clinician" (Paediatric Endocrinologist, male).

"It is not burden to the clinician. In order to improve I think the best if we can link e-consultation to clinician email so that clinician could answer the question immediately without needed to open the website" (Dietician, male).

One HCP indicated that this component might actually reduce their burden in the clinic and reduce the time spent in discussion with each patient, as it would enable them to review patients' data in advance of the clinic. It might also reduce the waiting time for other patients to be seen by the HCP in the clinic on the same day.

"No. I don't think so. It will reduce patients' burden. No need to wait until clinic appointment to discuss about patients problem. For clinician, it can reduce discussion time

with patient because they can review patients' data first before the clinic" (Clinical Nurse, female).

The Forum

All of the HCP felt that the *Forum* was useful for patients. When they were asked to suggest reasons for infrequent use of the *forum* or *discussion board* among the children and adolescents participating in the study, some commented that children did not know each other and perhaps may be uncomfortable communicating online. Another reason suggested was that children and adolescents might have thought they could only discuss issues related to T1D.

"The things with these children are that they do not talk to each other. Even when they come to clinic they are there with their parents and not like mingle with any other children who has similar problem like them. They only talk to each other when they go to camp and only in camp that they actually talk and even then is not like asking about how you would manage this and that related to that diabetes. You know that kind of things. So that's why I think the forum in this website is under-utilised because they do not know their friend. When they do not know their friend they don't talk about it. Because this is kind of type 1 diabetes website so for them when they chit chat they talk about T1D. Is not like a face book or twitter or whatsapp they can actually talk about anything. Because is general. They go into website T1D for them what they should be talking only about their problem so call diabetes. So I think that's a reason why it is under-utilised"(Paediatric Endocrinologist, male).

"I think we need to arrange them to meet each other first, and encourage them to discuss their problem with their peers using this website and inform them we as a clinician will help them as well" (Clinical Nurse, female).

Moreover, one of the HCP suggested expanding the use of the programme to all patients in the hospital in order to improve usage among them.

"I think first of all we need to expand the use of the programme to all the patients in the UMMC. So that they know, there is a programme which they can use to ask about their problem to the clinician and also they can communicate and share problem among their peers which have same problems" (Clinical Nurse, female).

Theme 4: Feasibility of use of the programme in the clinic setting

HCP were asked to indicate whether they used the programme in the clinic to teach children and adolescents with T1D. All of them indicated that they had used the programme among patients who participated in the study.

"Yes once they are recruited, once they are eligible so we definitely tell them, they need to go to website and learn and get some knowledge from that website and also if possible to also download and put up their blood glucose and keep asking question"(Paediatric Endocrinologist, male)

"Yes I do. I will inform any patients and also newly diagnosed patients and parents" (Dietician, male).

The HCP were enthusiastic about the system and reported that they would definitely use the system in the clinic regularly once it is available. One HCP suggested that the programme was also suitable for younger and older children.

"I do think this website can be used for everybody especially the younger once, yes. This website is kind like interactive but the parents are taught to use it with this children. I think this will be helpful. Because the amount of knowledge that is there is tremendous is a lot. So parents can also learn. As for those children above 14 years old, 15 years old. Some of the things especially those newly diagnosed they can use things that in the website. Yes maybe the older one probably does not really like it on certain grounds. But I think in terms of getting knowledge, in terms of having to be able to learn from a website that is already kind of like, you know that information that you get is correct. I think there is no reason for those even above of 14 years old to using this website" (Paediatric Endocrinologist, male.)

"If patient upload their blood sugar and food intake result to the web, we can review their food intake and blood sugar at any-time, so it will make our job more easier in the clinic. As we know patient do not like to enter blood sugar manually, maybe by using technology they will do it more frequently" (Clinical Nurse, female).

HCP indicated that they will recommend their children and parents use the programme once it is available in the hospital.

"Yes, I do. I will inform any patients and also newly diagnosed patients and parents" (Dietician, male).

"I like this website very much because this website can become a reference for food management. Definitely I would recommend to my patient and also their parents" (Clinical Nurse, female).

In response to the question about whether the programme is useful for newly diagnosed patients or anybody with T1D, one HCP suggested that the programme was useful not just for newly diagnosed patients but also for existing patients.

"I think everyone can use it. Because if we were to up-date our information, put in new things into the e-learning and all those things, I think even those who had been diagnosed after sometime can use this website. It is not just for the newly diagnosed. Because as we know diabetes is ongoing, there are new things coming in, we can also put in this website. Some of those new findings on T1D, where new paper or kind of like new things that they now find. Because some parents or some of this children even adolescents they are quiet smart they actually try to look for what is there, what they can learn about T1D. So I think is not just for T1D everybody can use it. Saying so, even in our clinic when we teach this patient on their food, we teach them on insulin, we are not telling them new things, is mainly strengthening. Whatever information that they already have or do kind of some minor correction on certain things that they probably have misunderstood. So I think this website is still important not for just newly diagnosed but for all of them all type 1 patient" (Paediatric Endocrinologist, male).

When the HCP were asked whether this programme is useful for patients with T1D in other hospitals, one commented that the programme could be used for patients with T1D in different hospitals in Malaysia.

"I think it is. Yes they can use, because I think most of our patient in Malaysia has similar a kind of like food intake or insulin injection. Similar kind of thought about food especially Malaysian food. I think this website can be used, can easily be used in any other Malaysian patients with diabetes whom currently been treated in other hospital. I think it can be easily adapt, they can easily adapt to it. So is not an issue" (Paediatric Endocrinologist, male).

Theme 5: Suggestions for improvement to web programme

The HCP provided several recommendations for improvement to the web programme.

Column for parents

One of the HCP suggested including another column for parents to discuss and communicate with each other and to share information.

"I think if we will to target not just for the children but also for the parents. Probably we can have somewhere some chatting for parents or something like that. I am not sure whether we have that at the moment. We do have some chat by the patient right? But we don't have chat part by parents, wants to share experience or something like that by parents themselves. So that maybe probably give you a little bit of, parents by parents or something like that" (Paediatric Endocrinologist, male).

E-Consultation

One HCP also suggested the parents be given their own password so that they could access the website and use the E-Consultation independently.

"Yes that part is very good but is under-utilized I think. Because I am not sure whether the parents are also using it. Because when this patient came to the clinic most the question

does not come from the patients. Most of the question that post to us come from the parents. If like say the patient do have question and they eagerly want to know about it then they will post the question for the e-consultation. Most of the time even the teenagers, the parents are the one that post the question to us in the clinic. So I think is also probably in future part of this website we probably can put in parents kind of, you know, parents can go into that, but probably they have different password. I don't know. Probably the children do not want the parents to know. Not sure. But we have to think about that"(Paediatric Endocrinologist, male.)

Another HCP suggested creating a link between the programme and the HCP's personal email.

"In order to improve I think the best if we can link e-consultation to clinician email so that clinician can answer the question immediately without needed to open the website" (Dietician, male).

<u>The Forum</u>

One of the HCP suggested encouraging use of the forum or discussion board among children and adolescents with T1D, by getting them to know each other through a clinic or through the diabetes camp.

"And how can we improve that, mmm that's a tough one. Because if they do not know their friend I don't think they will chit chat. So we have to make sure we actually get them to know each other either through camp or in the clinic. And by knowing their friends have that you know block or ice between the two broken, then I think they will talk to each other, start writing and start chit chatting"(Paediatric Endocrinologist, male.)

And another HCP suggested creating a link between the programme and social network to improve the usage among children and adolescents with T1D.

"We can include topic to the section so that they can discuss each other. To encourage children to use more often, I think the best if we can link this forum to patients and clinician social network like face book and so on"(Dietician, male).

Another suggestion was to expand the use of the *Forum* to all T1D patients in the hospital

I think first of all we need to expand the use of the programme to all the patients in the UMMC. So that they know, there is a programme which they can use to ask about their problem to the clinician and also they can communicate and share problem among their peers which have same problems (Clinical Nurse, female).

Diabetes Diary

In order to encourage all children and adolescents to upload their blood glucose data into the Diabetes Diary component regularly, one HCP suggested building a system to enable patients to connect their blood glucose meter to the programme so that blood glucose data appears immediately on the screen in the programme. This would reduce the burden of uploading blood glucose levels manually every day.

"I think if I were the patient, put in the blood glucose the one thing I probably bit difficult to do. So like I say just now, if we can upload the blood glucose by just click on the button. Basically they have their gadget and their tools, for them to just connect to somewhere and then up load all the blood glucose. I think they will be more helpful. And I think something like a care link for the blood glucose number where they can go in and put up their password and their username and all that and click on one button and everything is upload. I think if that can be done I think probably most of them or is not all will up load their blood glucose and start asking question what need to be done. Because that what they are when they come to see us. Those who really want to change they will try to upload their blood glucose numbers and start to ask question to us what to be done to improve their blood glucose number" (Paediatric Endocrinologist, male).

One HCP suggested enlarging the column component

"I hope you can improve my diary by enlarge the column. For me the column in my diary is small so not easy for me to look at the data especially if patients enter a lot of information about diet. I need to scroll to the right in order to look the whole data. This is for diet diary, for blood glucose diary is not an issue. But for blood glucose diary, is good if you can put also the type of insulin so that patients can just tick the column"(Dietician, male).

Another HCP suggested implementing the programme so that it could be used by all patients with T1D and expanding it to include other information for example information on insulin management.

"*I think we need to implement this website in the hospital because UMMC is one of the reference hospitals for patient with type 1 diabetes, so it will help us to manage our patient efficiently. And you also need to include information about insulin management because insulin also important for patient with diabetes" (Clinical Nurse, female).*

6.7 Strengths and limitations

6.7.1 Limitations

Several limitations to this pilot study need to be acknowledged. The sample size was restricted by inclusion and exclusion criteria and a few patients who refused participation and these findings are limited by the use of a cross sectional design. The cross sectional design might be not enable identification of the actual impact of this programme on improving knowledge, diet intake and self-efficacy among children and adolescents with T1D. A control trial design with a control group would be required to identify the real impact. The sample was representative only of children and adolescents living in urban areas and did not address children and adolescents living in rural areas. Children and adolescents in rural areas might have less access to technology or the internet and English proficiency may be limited. This study was not able to detect the impact of this programme on glycaemic control.

By using a food diary, participants are able to record their intake at the time of consumption so there is no need for them to remember all of the food and drinks consumed as all eating occasions are recorded in real time. They were provided with a detailed description of foods which enhance the accuracy of diet coding. This method is suitable for the assessment of foods eaten regularly. Unfortunately, it is time consuming as the participant needs to record their food and drink intake for three days including a week end day, this requires the children to be motivated to do this. Children may alter their diet to make it easier to record, or to cover up poor eating habits particularly when parents are not around. Many investigators have found that the most frequently under-estimated food items are ‘unhealthy’ ones such as sweets, desserts and snacks (Svendsen and Tonstad, 2006). The small sample size in this study may not represent a true picture of the usual dietary intake of children with T1D in Malaysia.

6.7.2 Strengths

The strengths of the current study were as follows: (1) the novelty of the study, which had not been conducted previously with children and adolescents in Malaysia, (2) the specific age category (children and adolescents) who were more susceptible to adverse changes in diet composition, knowledge and self-confidence, and (3) the potential clinical implications of the results, suggesting an important role of nutritional education in improving knowledge, dietary intake and self-efficacy. Data obtained from the interviews (qualitative) tended to support data from the quantitative method, including data from the food diary and questionnaires. The inclusion of parents, patients and HCP garnered diverse views that may be applicable to other hospitals and other districts in Malaysia. The study had a 6 months follow-up period which allowed the researcher to detect any changes in diet and diabetes management of children with T1D. Participants in the current study consisted of children and adolescents from different ethnic groups including Malay, Chinese and Indian. Those groups are the three largest ethnic groups in Malaysia. Therefore the system represents the different dietary patterns, cultures and lifestyle of the Malaysian population and should be suitable for use by all ethnic groups in Malaysia.

6.8 Discussion

6.8.1 Web-based programme as an education, diet and diabetes management and support programme

The present study was designed to determine the impact of a web-based education programme on self-efficacy, nutrition knowledge and diet intake. The results of this evaluation study demonstrated feasibility of this web-based education programme for children and adolescents with T1D in the UMMC, Malaysia. Participants and their mothers described the web-based programme as useful, accessible, beneficial to them managing their T1D and useful as a support programme. These findings are in agreement with Gerber et al (2007) and Nicholas et al (2012) who showed benefits of online education and support programmes for adolescents with T1D (Gerber *et al.*, 2007; Nicholas *et al.*, 2012). The web-based programme *('My Diabetes'*) assisted them in monitoring their blood glucose and dietary intake, contained information on diet and diabetes to improve T1D knowledge and also provided immediate support from HCP for any T1D related problems.

In the present study, the *Food Library* and *Diabetes Diary* were the two components used most by the participants. Most of the participants used the *Food Library* to obtain information about the carbohydrate content of the food and drink that they consumed. As far as the researcher is aware, in Malaysia currently there is only one book the *'Atlas of* *food exchanges and portion sizes'*, (Suzana *et al.*, 2009b) that contains information about carbohydrate and energy content of certain available foods. However, the information in this book is based on portion sizes for adults. In addition, the book does not provide information about some biscuits, bread, snacks and also packaged foods and drinks which are commonly consumed by children and adolescents in Malaysia. Parents are required to buy the book themselves and so most of them do not have this book. Without the book, parents depend on the food information provided by the Dietician in the hospital using a pamphlet which contains insufficient food information. It is important for the children and their parents to have complete information about carbohydrates for the food and drinks they consume in order to be able to adjust the dose of insulin given based on the intake of carbohydrate.

It is somewhat surprising that online interactivity with peers was not popular among participants in this study. This result differs from some published reports suggesting that adolescents with T1D access both information and support through online sources (Ravert *et al.*, 2004) with peer support being a stronger draw than the possibility of informational gain (Gerber *et al.*, 2007) and benefits of online peer support for patients with T1D (Nicholas *et al.*, 2012). The participants commented on the benefit of the online peer support and discussion board, however, the discussion board was used primarily by only four users. There are several possible explanations for this result, lack of time and being busy with school homework or preferring instant messaging like Face book and twitter or participants may have felt uncomfortable posting information to the online discussion board. A more focused online discussion, for example, with a specific topic assigned each week, might engage a larger fraction of adolescents with T1D.

While most of the participants were actively engaged in the programme throughout the duration of the study, the greatest intensity of web programme use occurred during the first month with a subsequent gradual decline. The findings of the current study are consistent with those of Gerber et al (2007) and Nicholas et al (2012) who found that the participants use of online services decreased overtime (Gerber *et al.*, 2007; Nicholas *et al.*, 2012). However, in this study the participant engagement was increased back at month sixth. The results from the qualitative study indicated that the main reason for less active participation and engagement was insufficient time. Only a few participants logged on to the system every day, the remaining logged on twice per week, once per week or once a month. This result may be explained by the fact that children in Malaysia have a lot of homework to do after school. Most of the participants arrived at home very late after school due to heavy traffic jams and taking the school bus, and still needing to finish their homework before school the next day. In addition some had tuition after school and arrived home very late. This finding is supported by the study conducted by Yusuf on stress, stressors and coping among 90 secondary school children in a few secondary schools in Malaysia. This study indicated that lack of time to do revision, frequent tests, examination, too much content to be learnt, too many assignments given by teachers and a packed learning schedule are in the top ten rank of stressors (Yusof MSB, 2010). As a student their day is fully occupied. They only have extra time during Saturday and Sunday, and some of them still go for tuition during the weekend.

The HCP indicated that the web programme was feasible to use in the clinic setting to teach the children and adolescents with T1D and their caregivers. They could use the programme to teach the children about diet, to monitor and review their patient’s blood glucose and dietary intake and to support them when they faced any problems related to T1D. In addition, the HCP believed that the programme would be more beneficial for patients as a self-education and self-management system, not only for newly diagnosed patients but also for patients who had T1D for many years. They also commented that the current programme could be used for children and adolescents below and above 10 to 14 years old and with patients from other hospitals.

An interesting finding was the HCPs belief that accessing patient information (monitoring blood glucose and dietary intake) and answering queries was not onerous to their workload as they could share this workload among themselves. Indeed it was thought that the programme might reduce discussion time with patients in the clinic because the HCP were able to review patients’ results in advance of the clinic and as a result this might reduce patient waiting time in the clinic. This result disagrees with the finding of a study conducted by Sara (2012). In that study, the HCP commented that accessing patient information was time consuming and sometimes redundant. They were also concerned that engaging with the patient portal would decrease the time they could spend with patients. A possible explanation for this might be that this study has been conducted among a large sample population of 854 adults patients T1D and T2D and 64 health care providers in Canada after using an online diabetes self-management patient portal compared to our study which involved just a small number of T1D paediatric patients in one hospital in Malaysia. The current study found that the valued being able to view patients' blood sugar and dietary intake trends by just clicking a button without the need for a paper-based diabetes diary. This finding is in agreement with Sara (2012) findings which showed the health care providers also appreciated the ability to view patients' blood sugar and allowed them to manage patients without in person appointments.

6.8.2 Barriers to programme use

The majority of participants, children and HCP in this current study found the web programme easy to navigate and user-friendly; there were no difficulties identified during the log on and they enjoyed using the programme. However, one child and a few mothers indicated that they had some difficulties while using the programme. Barriers included difficulty sending a question to the HCP, patients being unable to enter their previous blood glucose data, and not knowing how to start a discussion or conversation in the forum component. Some of the HCP indicated they had problems when there was no internet access in the hospital but this happened only occasionally. Responses to the information and language used were encouraging. The majority agreed that the language and information in the programme were easy to understand and acceptable to the aged group 10-14 years old. Although a few of the children and adolescents indicated that there was some information they were not able to understand. Moreover, another important finding was that the HCP indicated access to information via the web programme was easy that this current website was not like ordinary websites and the information was reliable and more trustworthy than from a generic search engine (example Google). It is interesting to note that children, adolescents and HCP believed the *Food Library* and *Diabetes Diary* were the most useful feature of the programme but felt it was important that the other features were maintained as well.

The HCP viewed patients' interaction with the programme positively. However, not many participants uploaded their blood glucose results or asked questions of them regularly. In order to encourage patients' to upload their blood glucose results regularly, the HCP suggested building a system which enables patients to connect their BG meter to the programme so that it might reduce the burden of uploading the BG readings manually every day. They also suggested it was necessary for the parents to be included in the programme so that parents could send questions to their HCP. The HCP also indicated use of the *Forum* section among patients was minimal. Some HCP expressed the belief that one way to encourage use of the *Forum* or *Discussion Board* among children and adolescents with T1D would be to get them to know each other first through introduction at the clinic or through the diabetes camp. In addition including parental involvement in the forum section might improve use of that section among parents. However, the HCP suggested parents should have their own username and password.

6.8.3 Regimen adherence

Research has indicated that optimal regimen adherence is difficult to achieve for many young people with T1D. Results from previous studies found adolescents had poor regimen adherence including lack of dietary skills and dietary adherence problems (Delamater *et al.*, 1988; Schmidt *et al.*, 1992), infrequent glucose monitoring and blood glucose data not routinely being used to make appropriate changes in the regimen (Delamater *et al.*, 1989) as advised by the clinician and insulin being omitted (Neumark-Sztainer *et al.*, 2002).

It is interesting to note that in this study, self-efficacy was increased after the intervention and there was a significant difference between pre and post-test scores. Most of them also had high scores, indicating high self-efficacy. The results of this qualitative study also showed that all of the participants reported that their self-confidence was increased after using the web programme. Most of the participants felt confident that they would be able to manage their diet, insulin and monitor their blood glucose. However, a few of the participants had difficulties in managing diet, insulin, monitoring blood glucose and doing exercise and for some participants, the confidence level decreased once the blood glucose increased even though they had controlled their diet and injected the correct dose of insulin. All of the mothers agreed that managing their children’s T1D is not an easy task. However, with experience and support from the HCP they were able to cope and manage their children’s T1D. When first diagnosed all mothers and participants experienced difficulty adjusting to the diagnosis. Encouragement and support from HCP increased their confidence level and coping skills. These findings further support the idea of Alan (Alan *et al.*, 1990) who proposed that good coping and adjustment of children in the month just after diagnosis were predictive of better regimen adherence over 4 years of having T1D.

Most of the mothers also agreed that diet management is one of the most difficult tasks especially when their children eat at school or when they eat outside. Peer pressure when at school was also another factor that contributed to lack of regimen adherence. La Greca (2002) reported in their study, that social support especially peer support has been found to be associated with greater adherence for dietary and exercise behaviours (La Greca *et al.*, 2002). In the current study, all of the participants performed and managed their T1D themselves with their mothers' assistance and supervision. They controlled their food intake, injected themselves and monitored their own blood glucose. However, they still required parental support and monitoring to improve their self-confidence and adherence. These findings corroborate the ideas of Ellis (Ellis *et al.*, 2007) and Skinner (Skinner *et al.*, 2000), who suggested that a higher level of adherence has been associated with greater family support including parental monitoring (Ellis *et al.*, 2007) for T1D care in studies with adolescents.

6.8.4 Glycaemic control

In this study, the majority of the participants monitored their BG four times a day as recommended by the HCP. However, most of them did not record the result everyday giving the reason of insufficient time. A few participants made a record in the web programme every day, the remaining made a record on Saturday or Sunday. One participant did the monitoring only once a day when she felt her blood sugar was in control and three to four times a day if uncontrolled. What is surprising is that she was able to achieve good glycaemic control with HbA1c 7.2% after the intervention. The reasons for less frequent monitoring were pain from too much finger pricking and difficulties in getting blood glucose strips. One participant monitored only two times per day every day and the cost of the blood glucose strip was the reason for less frequent monitoring. In Malaysia, blood glucose strips are very costly with the cost RM1.50 to RM2.00 (Ringgit Malaysia) per strip. Parents spent an average of RM6.00 to RM 8.00 per day just for the strips. They also have to buy the strips either in the hospital or from the Malaysia Diabetes Association which is often quite a distance from their home. Blood glucose strips are not available in all pharmacies. Availability of blood glucose strips is also one of the factors contributing to infrequent monitoring. Insufficient time and being busy with school homework were given as factors contributing to missing insulin injections.

6.8.5 Nutrition knowledge

The results of this study show that participants' nutrition knowledge was improved after six months. The paired t-test showed that this result was statistically significant ($P= 0.012$). Results from the qualitative interview also indicated that they were able to describe a healthy diet for a diabetic patient and had made changes to their dietary intake and food choices based on information from the web-based programme. However, most participants had difficulties in answering food labeling questions from the Nutrition (NKS) test, and from the interview, some of them also reported that they were unable to understand the information about food labels. This finding guides improvement of the information on food label. Previously, participants and mothers received T1D education mostly from the hospital and diabetes camp. The majority of participants and mothers agreed that it is important to have the skills and knowledge on managing the diet and insulin to achieve normal glycaemic control.

6.8.6 Challenges and effects of diabetes in life

In this study, diet management was found to be one of the biggest challenges of living with T1D. That is, participants needed to change their food intake and food choices. It is interesting to note that in this study T1D affected some of the families in a positive way with the whole family adopting a healthy life style, consuming a healthy diet and becoming more physically active. Support from other family members and relatives were important so that they did not feel isolated. Most of the mothers and participants were willing to share their experiences and discussed with other families what it is like, having children with T1D. The current study also found that there is lack of awareness among some teachers regarding the ability and safety of T1D children when participating in physical activity.

6.8.7 Dietary intake

Nutrition education is currently an important component of standard diabetes care. The focus of nutrition education for children and adolescents with T1D and their families is on optimising metabolic control through dietary choices (Silverstein *et al.*, 2005b). Findings from this study demonstrated that the percentage of energy from carbohydrate, protein and fat met the current nutrient recommendations for children and adolescents with T1D. The finding of the current study is consistent with other studies (Lodefalk and Aman, 2003; Wilson and Smith, 2003; Overby *et al.*, 2007; Pais *et al.*, 2010) who found that for all participants in their study, intakes fell within the normal distribution ranges for all macronutrients. However, our finding was not consistent with findings of one study (Mayer-Davis *et al.*, 2006) which was conducted in United States of America where children and adolescents with T1D aged 10-15 years old and 10-22 years old consumed more than 35% of calories from fat.

Although the results from this study differed from some published studies as mentioned earlier, it was consistent with the study conducted by Zalilah et al (2006). In this study which was conducted among 618 non-diabetic Malaysian school children aged 11-15 years old they were found to consume 32-34%, 51-53% and 14-16% of energy intake from fat, carbohydrates and proteins respectively (Zalilah *et al.*, 2006), suggesting that the diet of this sample of Malaysian children with T1D was similar in composition to that of non-diabetic Malaysian children. However, data from the Malaysian Adult Nutrition Survey (MANS) found that the macronutrient intakes of Malaysian adults was somewhat different, at 28%, 59% and 14% for fat, carbohydrate, and protein (Mirnalini *et al.*, 2008).

ISPAD Clinical Practice Consensus Guidelines, 2009 for children and adolescents with diabetes (Smart *et al.*, 2009b) suggested that dietary recommendations for children with T1D are based on healthy eating recommendations suitable for all children and adults and therefore the whole family should consume sufficient servings of fruits, vegetables, fibre, whole grains, and low fat dairy. In addition special attention should be given to fat and saturated fat recommendations for children and adolescents with T1D because they are at increased risk for cardiovascular disease, and there is evidence that atherosclerosis can be well-established by adolescence (Berenson *et al.*, 1998; Jarvisalo *et al.*, 2002).

Although the percentage of carbohydrate was within the recommended range, the type of carbohydrate did not meet the guidelines. Results showed that even though the intake of fibre, fruits and vegetables was increased after six months, intake was still lower than the recommendation. The present findings seem to be consistent with other research which found that children and adolescents with T1D consumed inadequate amounts of fibre, grains, fruit and vegetables (Mayer-Davis *et al.*, 2006; Overby *et al.*, 2007). The SEARCH study conducted in the United States of America with a sample of 1511 youth with T1D aged 10-22 years indicated that the mean intake of fruit and vegetables was only one and a half servings a day and for wholegrain products less than one serving a day (Mayer-Davis *et al.*, 2006). A study conducted among Norwegian children and adolescents aged between 12 and 13 years found average fruit and vegetable consumption to be 2.7 servings per day (Overby *et al.*, 2007).

The results of current study also indicated that participants' mean fibre intake was lower than recommended. There were similarities between the low fibre intake in this study and that described by Overby et al (Overby *et al.*, 2007). In their study, participants' fibre intake did not reach the amount recommended in the ISPAD guidelines (Smart *et al.*, 2009b). Diabetic patients are recommended to eat a high fibre diet to improve blood glucose control. Studies conducted by Buyken et al (1998) and Overby et al (2007) showed the association between a high fibre diet and decreased HbA1c levels (Buyken *et al.*, 1998; Overby *et al.*, 2007). The studies conducted by Overby et al. (2007) among 550 children and adolescents with T1D (aged 2-19 years old) found that adolescents with a low intake of fibre had higher HbA1c (Overby *et al.*, 2007). This is an important finding, as there is a growing body of evidence to support the theory that the incidence of non-communicable diseases and other health outcomes are associated with the diet. The World Health Organisation recognises that diets which are relatively high in fruits, vegetables, and fibre, are likely to decrease the risk of cardiovascular disease and certain cancers, while diets high in fat, salt, and sugar, are likely to increase adult risk factors for high blood pressure and dyslipidaemia, particularly when combined with physical inactivity (Nishida *et al.*, 2004; Brunner *et al.*, 2007).

6.8.8 Social support

Social support is regarded as a crucial factor for adolescents with a chronic disease (Lagreca *et al.*, 1995; Price, 1996; Kyngas *et al.*, 2000). It has been found to promote coping with chronic disease (Graetz *et al.*, 2000) and compliance with health regimens (Dunbar-Jacob *et al.*, 2000; Kyngas and Rissanen, 2001). The most important members of the supportive network are family, friends and health care providers (Dunbar-Jacob *et al.*, 2000; Kyngas and Rissanen, 2001). Family variables, such as positive family climate and open relationships between the family members, provide valuable support for adolescents (Millerjohnson *et al.*, 1994; Lagreca *et al.*, 1995; Kyngas, 2000). Close peer relationships are another important source of support for chronically ill adolescents at a time when they have to tackle both developmental tasks and disease-related challenges (Millerjohnson *et al.*, 1994; Kyngas *et al.*, 1998). While parents continue to play the role of primary caregivers, friends and peers provide emotional support by accepting their ill friend with his or her physical limitations (Kyngäs, 2004). Many chronically ill adolescents feel different from and socially more restricted than, their same-age peers (Tijhuis *et al.*, 1998; Graetz *et al.*, 2000). The emotional support from friends is largely oriented towards helping the adolescents to feel accepted (Lagreca, 1992; Kyngas *et al.*, 1998). For example, peers may assist with the daily diabetes management by providing reminders to test the blood glucose level or to take insulin (Lagreca, 1992; Kyngas *et al.*, 1998).

The children and adolescents in this study appeared to gain support from all family members, especially their mothers. Support from mothers was very important in order to assist them in managing their T1D. The majority also had good support from friends at school. Some of the children and adolescents stated their friends would remind them when they needed an insulin injection, or refrain from buying sweets in their presence. Findings from this study indicated that not all of the children and adolescents used the *Discussion Board* or *Forum* component to share their views and problems. However, a few of the children and adolescents used the *Discussion Board* to ask questions in relation to management of their T1D. This allowed peers who were able to manage their T1D very well to provide advice to others who were having problems. This shows the feasibility of this programme as a support programme among children and adolescents with T1D.

6.8.9 Suggestions for improvement to the web programme

In this study, there were several suggestions from children, parents and HCP for improving the programme. These included building a system that would enable patients to connect their blood glucose meter to the programme, creating a link between the web programme and health care professional's personal email, frequent up-dates to the information were suggested such as adding new findings in diet and T1D research and new information, as well as providing the system in another language and allowing parents access to the forum. One participant and one mother suggested the use of instant messaging such as Face book or twitter in order to allow real-time peer dialogue and also listing the names of all patients on the *Forum*. Participants and their mothers provided several recommendations for improvement to the web programme. Two participants and two mothers recommended more colour, pictures, sound, music and graphics and the ability to enter previous data into the *Diabetes Diary*.

6.9 Conclusion

This study was undertaken to design and evaluate a web-based diet and diabetes education programme to be used by children and adolescents with T1D in the UMMC, Malaysia. This research offers an evaluation of a web-based programme in a real-life setting. Although the current study was based on a small sample of participants and was dedicated to the T1D children and adolescents in the UMMC, Malaysia aged 10-14 years, the findings suggests that access to a web-based programme provided additional benefit to the patient and their parents in terms of improving regimen adherence, diabetes knowledge, dietary intake, self-efficacy and communication and support from the HCP. This study also gives a lot of information about children and adolescents' experiences, attitudes, and the challenges they face in managing their T1D and their dietary intake. The results of this study are also of potential value to health professionals involved in the care of children and adolescents with T1D. Focus on increasing dietary fibre, improved information on food labelling, insulin management and hormonal changes should be targeted in diabetes education for this population. The involvement of patients with T1D and the HCP involved in their care ensures that the web-based diet and diabetes education programme satisfies both of the end users. As an overall conclusion the study demonstrated the feasibility of this web education programme used as an education, diabetes management and support programme for children and adolescents with T1D and their HCP in UMMC. This study can become a baseline data set for a future randomized control trial (RCT) study among T1D population in Malaysia.

Chapter 7 Overall discussion

7.1 Introduction

This chapter serves as a conclusion to this thesis and begins with a synopsis of the major findings of this study. Discussion of the research implications for practice and strengths and limitations of the study are also presented. The chapter concludes with the future directions of this research.

7.2 Summary of findings

The main purpose of this study was to develop a web-based diet and diabetes education programme to improve dietary management and to provide support for children and adolescents with T1D in UMMC, Malaysia. This study used both qualitative and quantitative data collection methods. Participants were Malaysian children and adolescents aged 10-14 years with T1D who were living in Malaysia (n=64), their parents (n=12), the clinicians (n=3) and non-diabetic Malaysian children and adolescents aged 10-14 years living in Newcastle (n=12). The results of this study demonstrate the feasibility of this web-based diet and diabetes education programme for children and adolescents with T1D in the UMMC, Malaysia.

Participants and their mothers described the programme as useful, accessible, beneficial to them managing their T1D and as a support programme. This programme increased children and adolescents' knowledge related to diet and T1D (p=0.012). Results of the questionnaire data showed that participants' nutrition knowledge was improved after the intervention and results from the qualitative interviews supported this. The information from the programme helped them to better manage their T1D including managing their dietary intake. Knowledge is often seen as a necessary, but not sufficient, condition for behaviour change to occur, and this may be particularly true for behavioural skills-related knowledge (Reynolds *et al.*, 1999). For example children and adolescents with T1D probably have knowledge in terms of the importance of proper diet, proper techniques of insulin injection and frequent monitoring of blood glucose in order to achieve optimal blood glucose level. However, in order to put that knowledge into practice they must have high self-efficacy to cope with the daily routine required for the optimal management of their T1D for their whole life. Evidence suggests that the combination of knowledge and high self-efficacy is more likely to lead to behaviour change, in the management of their own T1D (Reynolds *et al.*, 1999).

This web based programme may improve children and adolescents' self-efficacy. The qualitative results suggest that their self-efficacy was increased after using the programme and the results from the quantitative study from the questionnaire (p=0.001) were similar. Most of the participants felt confident that they would be able to manage their T1D including diet, insulin and monitoring of their blood glucose. In this study, support from the clinician was found to be one of the important factors in increasing participant's self-confidence and coping skills. Children and adolescents with T1D and also their parents required continuous support from a HCP for the management of T1D. Children and adolescents with T1D required regular parental support and monitoring to enhance and maintain their self-confidence and adherence in order to self- manage their T1D. Several studies have shown that support from family and friends (a precursor to self-efficacy in SCT), has been associated with better nutrition behaviours such as consuming a healthy diet (Ford *et al.*, 2000; Steptoe *et al.*, 2004). Several studies have also shown that social support is an important social cognitive determinant of healthy dietary habits (Anderson *et al.*, 2007) especially in college students (Sallis *et al.*, 1999; Rovniak *et al.*, 2002; Strong *et al.*, 2008). Rovniak et al (2002) and Anderson et al (2007) suggested that although knowledge and self-efficacy might improve, targeting social support may have enhanced the impact of the intervention on behaviour change through self-efficacy (Rovniak *et al.*, 2002; Anderson *et al.*, 2007).

However, in this study the support from peers with T1D was evident. It is somewhat surprising that online interactivity with peers was not popular among participants in this study. The participants commented on the benefit of the *Online Peer Support* or *Discussion Board*, however, the *Discussion Board* was used primarily by only four participants. There are several possible explanations for this result, lack of time and busy with school homework and some of them preferring instant messaging like Face book and twitter, additionally perhaps the remaining children and adolescents felt uncomfortable posting information to the *Online Discussion Board*. A more focused online discussion, for example, with a specific topic assigned each week, might engage a larger fraction of adolescents with T1D.

HCP indicated that the web programme was feasible to use in the clinic setting to teach children and adolescents with T1D and their parents. They could use the programme to help them teach about diet, to monitor and review their patient's blood glucose and dietary intake, and also to support them when they faced any problems related to T1D. In addition, the HCP believed that the programme may be more beneficial for patients as a self-education and self-management system. This programme proved beneficial not only to newly diagnosed patients but also patients who had had T1D for several years.

The web-based diet and diabetes education programme was favourably received not only by children and adolescents with T1D in Malaysia but also by children and adolescents without diabetes in Newcastle. They commented that the web provided a lot of information which they felt was appropriate for children and adolescents with T1D and healthy children as well. The language used in the programme was easy to understand, except for certain information which was changed before the final Phase of the study (Phase three). The children and adolescents in this study also preferred bright and colourful photos. The use of multimedia and animation in the education components may attract the children and adolescents to continue using the web. Several authors suggested that computer multimedia increases attention and continuity of active participation, and leads to improved learning. Furthermore, computer multimedia provides interesting videos, sounds and lighting, colours and immediate feedback, which can promote the intrinsic motivation of children (Mayer and Gallini, 1990; Chen *et al.*, 2013).

7.3 Refined model of web-based diet and diabetes education programme

This study has found that for improvement of diabetes management among children and adolescents with T1D in Malaysia the proposed model in Figure 23: is a good starting point. This finding corroborates the ideas of Bandura (1986) who suggested that environmental factors (nutrition programme, social support) and personal factors (self-efficacy, knowledge) interact with each other and predict changes in behaviour (diabetes management). Figure 23 shows the final model for diet and diabetes management among children and adolescents with T1D in UMMC, Malaysia.

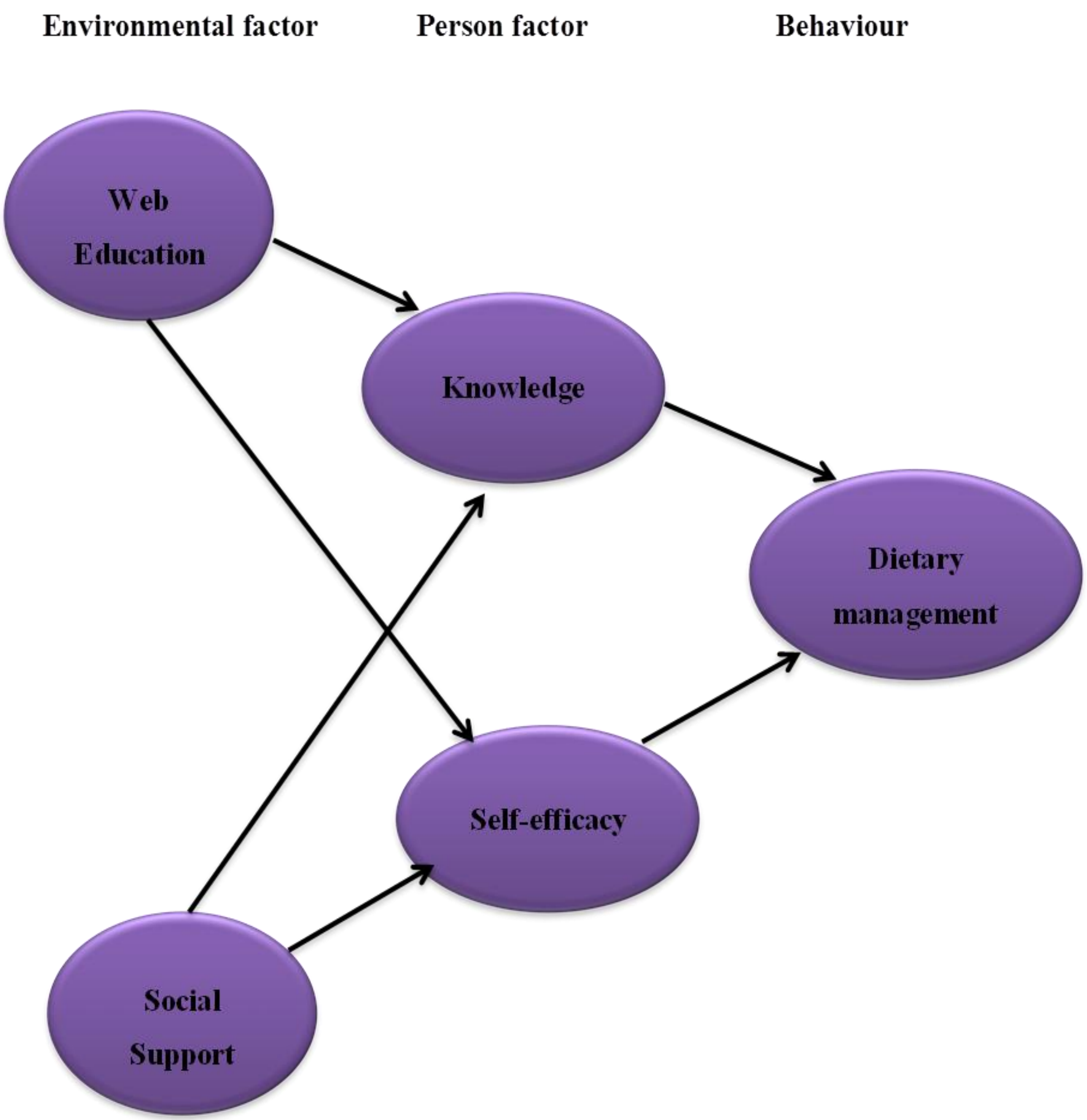

Figure 23: Final model for diabetes management among children and adolescents with T1D in Malaysia.

Based on this model, both environmental factors (web education and social support from clinicians and parents) and personal factors (diet and diabetes knowledge and self-efficacy) interact continuously each other and have been shown to be important in triggering behaviour changes, in this study improvement on diet and diabetes management among children and adolescents with T1D. This web based programme was an important tool in improving the knowledge and self-efficacy to manage diet and diabetes. After using the web, participants knowledge improved and they felt confident managing their diet, insulin, and monitoring BG. This study also showed that children and adolescents with T1D in UMMC, Malaysia always required continuous support, monitoring and supervision from parents in increasing and sustaining their self-confidence and adherence. Support from parents, especially mothers, was important to assist them in managing their diet and diabetes. In addition to that, mothers and children also needed continuing support from HCP, so that they were able to cope and manage diabetes in their life. Encouragement and support from HCP increased their confidence level and coping skills. Mothers, children and adolescents with T1D also obtained information from HCP related to T1D.

This web programme provided support through the *E-Consultation* and the *Forum* components. However, only a few of the children and adolescents with T1D used these components. If more children used the components, there may have been an interaction between the web education and social support in the final model. The finding of the current study was consistent with previous studies which showed that interventions targeting SCT variables produce promising results in modifying behaviours including dietary behaviours (Sallis et al., 1999; Schnoll and Zimmerman, 2001; Rovniak et al., 2002; Suminski and Petosa, 2006) and diabetes related outcomes, such as diet adherence and self-monitoring of blood glucose among patients with T1D (Hays and Clark, 1999; Glasgow et al., 2002). SCT provides a reciprocal model in which behavioural or personal factors, as well as environmental influences interact continuously. SCT has been particularly effective for developing nutrition education programmes for children and adolescents (Hoelscher *et al.*, 2002).

Implications of the findings

7.3.1 Implications for practitioners

This web-based diet and diabetes education programme can be used not only by patients and parents at home for the management of T1D, especially dietary management, but might support and improve the current T1D education system in the UMMC, Malaysia and assist HCPs in teaching, managing and monitoring their patients in the clinic and at home. This programme might be used by other children and adolescents with T1D and also HCPs in other hospitals in Malaysia.

7.3.2 Implications for policy makers

Another important practical implication is that if the web-based programme is to be used at home by all children and adolescents with T1D in Malaysia, limited access to the internet may pose a problem, particularly in rural areas. However, the 9th Malaysia Plan (2006-2010) by the Malaysian Government targeted the setting up of 70 district internet centres and 100 sub-district centres. Projects such as Pusat Internet Desa or Rural Internet Centre (RIC) were carried out by the Malaysian government to provide ready access to information and communication technology (ICT) (Alias *et al.*, 2010). As of 2010, forty two Rural Internet Centres (RICs) each with its own website and network of members are now available in Malaysia. The telecentre project initiated in April 2000 stands as one of the largest government initiatives to bridge the rural-urban digital divide through free community-shared ICT facilities and internet access (Alias *et al.*, 2010). The Malaysian government aims to set up such centres that will eventually reach an estimated 2.8 million members of rural communities (Nor Iadah *et al.*, 2008). Hopefully with that initiative and support from the Malaysian government, children and adolescents with T1D living in rural areas would not face any problem in accessing the internet.

7.3.3 Implications for research

This study has contributed to the existing literature by providing a study on the impact of nutrition and diabetes interventions on the knowledge, self-efficacy and diet and diabetes management among children and adolescents with T1D. The approach has been consistent with recommendations in nutrition education research to examine environmental variables, to combine theoretical concepts into potentially effective models, and to build models based on prior work in nutrition education and theories from non-nutrition areas (Achterberg and Clark, 1992).

This research looks at two factors involved in behaviour change among children and adolescents with T1D in Malaysia. These were based on Social Cognitive Theory by Bandura (1986) and were environmental and personal factors. This study has provided evidence that the nutrition education programme and social support may improve self-efficacy and knowledge and may lead to positive changes in diet and diabetes management among children and adolescents with T1D in UMMC, Malaysia. The system should be tested in other hospitals in Malaysia, not only in urban areas but also in rural areas, in order to examine whether the programme is effective in improving diet and diabetes management among children and adolescents with T1D in other hospitals in Malaysia. The system should also be tested among a wider age range of children and adolescents with T1D.

7.4 Strengths and limitations of the study

7.4.1 Strengths

This study is not without its strengths. The lack of currently available successful educational and support programmes for children and adolescents with T1D especially in South East Asian countries has led to the need to identify and investigate novel approaches. This is the first web-based diet and diabetes education programme available in Malaysia to use not only at home but also in the clinic setting. This programme is intended to support and enhance the education programme in the UMMC, Malaysia. If this programme is successful in UMMC, it is envisaged that this could be introduced in all hospitals in Malaysia. This programme is intended for use by all races in Malaysia: Malay, Chinese and Indian alike. The programme took into consideration the food consumed by children and adolescents of the different races which are predominant in Malaysia. There is a paucity of research on the impact of an education programme in the management of T1D in children and adolescents in Malaysia. There is also very limited research on dietary intake among children and adolescents with T1D in Malaysia.

In the current study, parents were not present during the interview to provide comfort and freedom to the children and adolescents so they would speak freely without any interference from parents. The views and opinions expressed were genuinely from children and adolescents, not from their parents. Parental presence was felt to be comforting to participants, but it may also affect the child's ability to speak freely without parental influence. Parental presence in the interview is important to consider when interviewing children. Some researchers have chosen to let the parent remain present in the interview, whereas others interviewed children alone (DeForge *et al.*, 2001; Carnevale *et al.*, 2006). Parents who remain present in the interview can be both comforting and inhibiting to the children. In one study children and siblings describing their experiences with assisted ventilation in the home were depicted as generally silent in the presence of their parents (Carnevale *et al.*, 2006). The researchers cited difficulties with obtaining private access with the children because most parents preferred to be present in the interview (Carnevale *et al.*, 2006). In contrast, a study conducted by Goodwin et al (2004) indicated that parents remained present for all interviews in a study with children, who required wheelchairs, to increase the comfort of both child and parent (Goodwin *et al.*, 2004).

In this study the researcher chose home as a location for the interview based on participants' preferences, therefore they felt comfortable during the interview session. The location of the interview is of particular significance when children are research participants. Home, school, office clinics, and hospitals have been the setting for interviews, with the home being the most often cited interview setting with children. The home can be considered a place of comfort for the children and adolescents, it might decrease anxiety and facilitate the interview (Spratling *et al.*, 2012). The location of the interview is frequently described in child studies with the major consideration being convenience for the child (Spratling *et al.*, 2012). The home was described most often as the interview location (Bennett, 1991; Noyes, 2000; Kyngäs, 2004; Carnevale *et al.*, 2006; Earle *et al.*, 2006; Heah *et al.*, 2007).

By using a food diary, participants were able to record their food intake at the time of consumption, so there is no need for them to memorize all the food, and eating occasions are recorded in real time. We were provided with a detailed description of foods so it enhanced the accuracy of diet coding. This method is suitable for the assessment of foods eaten regularly.

The use of both qualitative and quantitative research methodologies in this study allowed a comprehensive evaluation. Mix methods research is recognized as offering the most comprehensive approach to evaluation (Pope & Mays 1995). The use of qualitative methods enhances understanding of the quantitative findings and allows for explanation of the findings. Investigation of children, adolescents and their parents' use of the web as well as their views and experiences, provided data on the impact and acceptability of the programme.

This study can provide information for a future randomized control trial (RCT) study among children and adolescents with T1D in Malaysia. It would be interesting to compare experiences of individuals within the same group (10-14 years) in other hospitals in Malaysia and perhaps a different age group in the UMMC and other hospitals. A large randomised controlled trial (RCT) should be conducted and include two groups. The total numbers of participants needed is approximately 100 participants for each group and could provide more definite evidence of effectiveness. In one group (intervention group), the participant would be given access to the web programme and in the control group, the participants would continue using their current education materials or the standard education in their own hospital. From this RCT we could identify the effectiveness of this web programme to improve knowledge, self-efficacy and diabetes management among children and adolescents with T1D.

It is recommended that in order to investigate the relationship between knowledge, self-efficacy, social support, diabetes management and metabolic control that an RCT is conducted and it would be feasible to conduct this in Malaysia. However different management, teaching and service provided in different hospitals should be taken into consideration and could make a difference in the results of the study. Thus it is recommended that HCPs and hospitals that want to participate in a RCT agree on the standard education provided to the control group, which would provide better statistical power for the RCT.

7.4.2 Limitations

Several limitations to this study need to be acknowledged. The sample size was restricted by inclusion and exclusion criteria and a small number of patients who refused to take part and further the findings are limited by the use of a cross sectional design. The cross sectional design lacks a control arm and thus limits the attribution of the actual impact of this programme on improving knowledge, diet intake and self-efficacy among children and adolescents with T1D. The control trial design with the inclusion of a control group would be required to identify the real impact however the significant change detected before and after intervention would suggest potential effectiveness worthy of testing further.

The small sample size limited the ability to conduct the control trial design. This study did not recruit participants from other teaching hospitals besides UMMC or others non-teaching hospitals because each hospital had different management and service provided, also used different techniques and methods of teaching and treatment. Time constraints also limited the ability to recruit patients from others hospital and also it was difficult to compare different teaching methods and treatments. This study conducted in the UMMC can serve as a baseline study for further research at other hospitals.

Hospitals in Malaysia are divided into public and private. Among the public hospitals, there are also divisions into specialist, state, and district, and overlapping with those being the teaching and non-teaching hospitals. There are only three teaching hospitals namely: Hospital Universiti Sains Malaysia (HUSM), University Kebangsaan Malaysia Medical Centre (UKMMC) and UMMC. A teaching hospital is a hospital that provides clinical education and training to future and current doctors, nurses, and other health professionals, in addition to delivering medical care to patients. They are generally affiliated with medical schools or universities (hence the alternative term university hospital), and may be owned by a university or may form part of a wider regional or national health system. Some teaching hospitals also have a commitment to research and are centres for experimental, innovative and technically sophisticated services. Teaching hospitals are under the Ministry of Higher Education, while non-teaching hospitals are under the Ministry of Health.

The sample was representative only of children and adolescents living in urban areas and did not address children and adolescents living in rural areas. Children and adolescents in rural areas might have less access to technology or internet and English proficiency may be limited. The UMMC is located in Pantai Dalam in the southwest corner of Kuala Lumpur. Kuala Lumpur is the federal capital and most populous city in Malaysia. It is among the fastest growing metropolitan regions in the country, in terms of population and economy. The majority of the patients that come to UMMC live near to the Kuala Lumpur. Patients from rural areas will get a treatment from district hospital near to their homes, unless it is necessary that they will refer to the UMMC by their clinicians for further treatment. They will go back to their hospital for follow-up treatment. Further work is required to test the intervention in a wider range of settings.

Generalisations of findings in this study can only be made with caution as the number of clinicians involved in this study was very low and may not reflect the views or opinions of other clinicians involved with children and adolescents with T1D in other hospitals in Malaysia. There were five HCP in the diabetes paediatric team in UMMC: one professor (head of department), one paediatric endocrinologist (senior lecturer), two clinical diabetes nurses and one dietician. Only one of the paediatric diabetes endocrinologists was involved with the study because the other did not regularly attend the clinic due to their busy administrative load. Another one of the clinical nurses was not included in the study as they were busy with the adult clinic as well. There was another one or two medical officers on clinical rotations and so they only worked in the clinic for two or three months, therefore, they were not included in the study (They are not permanent staff, changed every three months).

Establishing a connection with the child during the qualitative interview was critical to successful research outcomes (Spratling *et al.*, 2012). In the current study, the researcher had experience in working with children and adolescents; something which has been shown to help establish rapport with children during interviews (Spratling *et al.*, 2012). However, conducting interviews with children and adolescents proved to be a challenging task. Many of the children in this study did not talk much and did not give lengthy information about their experience of T1D management and using the web programme. On the other hand, some of them were able to give a lot of information regarding their experience. In the future, repeated contact and interviews might allow a relationship to develop between the child and the researcher (Earle *et al.*, 2006) and might help them to provide more information during an interview. However it was interesting to note the difference when conducting the interview between Malaysian children living in Malaysia and living in Newcastle. In this study, the researcher found that Malaysian children in Newcastle were more able to provide detailed information about their experience of using the web based programme compared to children living in Malaysia. A possible explanation for this might be that children in Newcastle were healthy children compared to children in Malaysia. T1D patients are more likely to be emotional, unpredictable and sensitive especially when their blood sugar is not under well controlled. As noted by Spratling et al (2012), the state of health of the child, the situation, and the sensitivity of the topic under investigation need to be considered (Spratling *et al.*, 2012).

Another possible explanation for this might be that children in Malaysia lack soft skills such as communication and analytical skills. According to Ahmad (1998), the lack of soft skills amongst Malaysian undergraduates is partly attributed to the “rote learning” style adopted by Malaysian school children who are pressured by their parents, peers, and school to excel academically as a result of the examination-based education system (Ahmad, 1998). Thus, students resort to memorising facts and figures to excel as their success in Primary and High school is constantly assessed by how many A’s they achieved in their examinations and tests which are carried out on a monthly, semester, and on an annual basis (Shakir, 2009). In the process, they fail to develop an inquisitive mind and analytical skills, as most of their time is spent attending tuition classes, extra classes, and examination workshops to better prepare them for the many upcoming examinations (Shakir, 2009). Many studies investigate the association between creative thinking skills, culture and socio-economic status. Study conducted by Saeki et al (2001) in the United States indicated that the Asian community is less creative compared to their Western counterparts (Saeki *et al.*, 2001). A previous study has reported the differences between Asian and Western thinking styles are attributable to culture (Zhang, 2002). The above reason might explain the differences between Malaysian children studying in Malaysia and in Newcastle, due to a different culture in school and different soft skills.

According to Spratling et al (2012), group interviews might engage children and decrease their anxiety. Decreasing anxiety, or helping with the fears, can facilitate interviews with children (Spratling *et al.*, 2012). A study investigating the experiences of children with

Spina Bifida who were wheelchair-bound included focus groups with children to reduce anxiety and motivate them to share their experiences (Goodwin *et al.*, 2004). However, one study showed that group interviews have been cited as problematic with child participants. Children (n=14, ages 7 to 12 years) were asked to describe their perceptions of being homeless in a phenomenological study using group and individual interviews. The authors initially conducted group interviews; however, the children became unruly, requiring the interviews to end. Subsequent interviews were completed individually with children (DeForge et al., 2001). Due to the above reason, the researcher made a decision to conduct one to one interviews instead of one group interview. Furthermore, based on experienced conducting one to one interview among Malaysian children and adolescents in Newcastle showed that children were able to explain and give detailed about their views and experiences.

7.5 Recommendation for future work

This research has raised many questions which warrant further investigation. It is recommended that further research be undertaken in the following areas: relationship between regimen adherence and metabolic control, peer-pressure or support, school environment and teacher support and to investigate the patient waiting time to see the HCP in the clinic with or without using this programme. It would be interesting to compare experiences of individuals within the same group (10-14 years) in other hospitals in Malaysia and perhaps a different age group in the UMMC and other hospitals. A large randomised controlled trial (RCT) could provide more definite evidence of effectiveness. Understanding of the predictors of diabetes management will be enhanced by an RCT which allows evaluation of the complex relationship between nutrition intervention, knowledge, self-efficacy, social support and determining both the direct and indirect effects of these factor and behaviour change among children and adolescents with T1D.

Interventions with children and adolescents with T1D should focus attention on diabetes education, knowledge, self-efficacy and also social support from the family, clinician and peers with T1D. Strengthening the programme and adding new content to include insulin and blood glucose management and to further target self-efficacy, knowledge and social support may be necessary to achieve behaviour change related to diabetes self-management. Self-efficacy could be further addressed by targeting improvement in skills such as self-blood glucose monitoring and insulin injection.

7.6 Conclusion

This study was undertaken to design and evaluate acceptability of a web-based diet and diabetes education programme for use by children and adolescents with T1D in the UMMC, Malaysia. This research offers an evaluation of the acceptability of a web-based programme in a real-life setting. Although the current study was based on a small sample of participants and was restricted to the T1D children and adolescents in the UMMC, Malaysia aged 10-14 years, the findings suggest that access to a web-based programme provided additional benefit to the patient and their parents in terms of improving regimen adherence, diabetes knowledge, diet intake information and communication and support with the clinician. This study also provides a great deal of information about children and adolescents' experiences, attitudes, and challenges in managing T1D and their dietary intake. The results of this study are also of potential value to health professionals involved in the care of children and adolescents with T1D and in the further development of the web-based diet and diabetes education programme. This study found that focus on increasing dietary fibre, improved information on food labels, insulin management and hormonal changes should be targeted in diabetes education for this population. The involvement of patients with T1D and the HCP involved with the care and management of children and adolescents with T1D ensures that the web-based diet and diabetes education programme satisfies both the end users. In conclusion this study demonstrated the feasibility of this web education programme for use as an education, diabetes management and support programme for children and adolescents with T1D and their HCP in UMMC. Further this study has demonstrated the feasibility of recruitment and retention of patients with T1D and their families in research and has tested the application of appropriate outcome measures required for further study to measure the effectiveness of this web education programme in improving glycaemic control for children with T1D in Malaysia.

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Appendices

Appendix 1 Consent form (Phase one)

UNIVERSITY MALAYA MEDICAL CENTRE

CONSENT BY PATIENT FOR CLINICAL RESEARCH

I...
Identity Card No...
(Name of Patient)
of ....
(Address)

hereby agree to take part in the clinical research (clinical study/questionnaire study/drug trial) specified below:

<u>**Title of Study:**</u> The development and evaluation of web based interactive diet and diabetes education program for use by children with type 1 diabetes.

the nature and purpose of which has been explained to me by
Dr. ....
(Name & Designation of Doctor)

and interpreted by ....
(Name & Designation of Interpreter)

.... to the best of his/her ability in .... language/dialect.

I have been told about the nature of the clinical research in terms of methodology, possible adverse effects and complications (as per patient information sheet). After knowing and understanding all the possible advantages and disadvantages of this clinical research, I voluntarily consent of my own free will to participate in the clinical research specified above.

I understand that I can withdraw from this clinical research at any time without assigning any reason whatsoever and in such a situation shall not be denied the benefits of usual treatment by the attending doctors.

Date: ....   Signature or Thumbprint ....
(Patient)

IN THE PRESENCE OF

Name ....)
)
Identity Card No. ....)   Signature
(Witness for Signature of Patient)
Designation ....)

I confirm that I have explained to the patient the nature and purpose of the above-mentioned clinical research

Date ....   Signature ....
(Attending Doctor)

CONSENT BY PATIENT FOR CLINICAL RESEARCH	R.N. Name Sex Age Unit

Appendix 2 Information sheet (Phase one)

HELAIAN MAKLUMAT PESAKIT

Sila baca dengan teliti, sebarang pertanyaan boleh dikemukakan kepada penyelidik atau doktor yang terlibat.

Tajuk kajian

Penghasilan program pendidikan diet dan diabetes berasakan web untuk kegunaan kanak-kanak yang mengalami penyakit diabetes tahap satu.

Pendahuluan

Program pendidikan berkenaan diabetes adalah sangat penting untuk kanak kanak pesakit diabetes selain daripada suntikan insulin, pemakanan dan juga memeriksa gula di dalam darah. Kanak-kanak suka kepada sesuatu program yang menghiburkan dan menyeronokkan. Ini dapat menarik minat mereka untuk menggunakannya, mengikuti apa yang telah dipelajari, dengan harapan dapat membantu mereka mengawal gula didalam darah.

Oleh itu, kami merancang untuk menyediakan program pendidikan berasaskan web yang bukan sahaja mengandungi unsur-unsur pelajaran tetapi juga karton, animasi, interaktif dan lain-lain untu menarik perhatian kanak-kanak menggunakannya.

Tujuan kajian?

Kami amat-amat memerlukan kanak-kanak pesakit diabetes untuk membantu kami menghasilkan program pendidikan yang bersesuaian dengan mereka dengan cara mengambil bahagian di dalam bengkel yang kami kendalikan.

Langkah-langkah yang perlu diikuti?

Di dalam bengkel ini, kami amat berharap agar:

- Anda dapat mengambil bahagian di dalam semua aktiviti yang kami kendalikan.
- Anda dapat menjawab soalan yang akan dikemukakan.
- Dapat merakamkan segala aktiviti yang akan dijalankan.

Mereka yang tidak di galakkan untuk menyertai kajian?

- Kanak-kanan diabetes yang tidak boleh membaca dan menulis.
- Kanak-kanak diabetes yang mengalami masalah kesihatan mental/

Faedah jika menyertai kajian?

Untuk peserta
Anda dapat memberitahu kami apa yang anda perlukan pada sebuah program pendidikan berkaitan pemakanan dan diabetes.

Untuk penyelidik
Bengkel ini dapat memberikan kami maklumat apakah yang kanak-kanak perlukan dari program pendidikan pemakanan dan diabetes. Oleh itu kami berharap kami dapat menghasilkan sebuah program pendidikan yang terbaik untuk semua kanak-kanak yang mengalami diabetes.

Bolehkan saya menarik balik daripada mengambil bahagian?
Kami tahu anda perlu meluangkan sedikit masa untuk mengambil bahagian di dalam bengkel ini. Kami cuba sedaya upaya untuk memastikan ianya menyeronokkan.

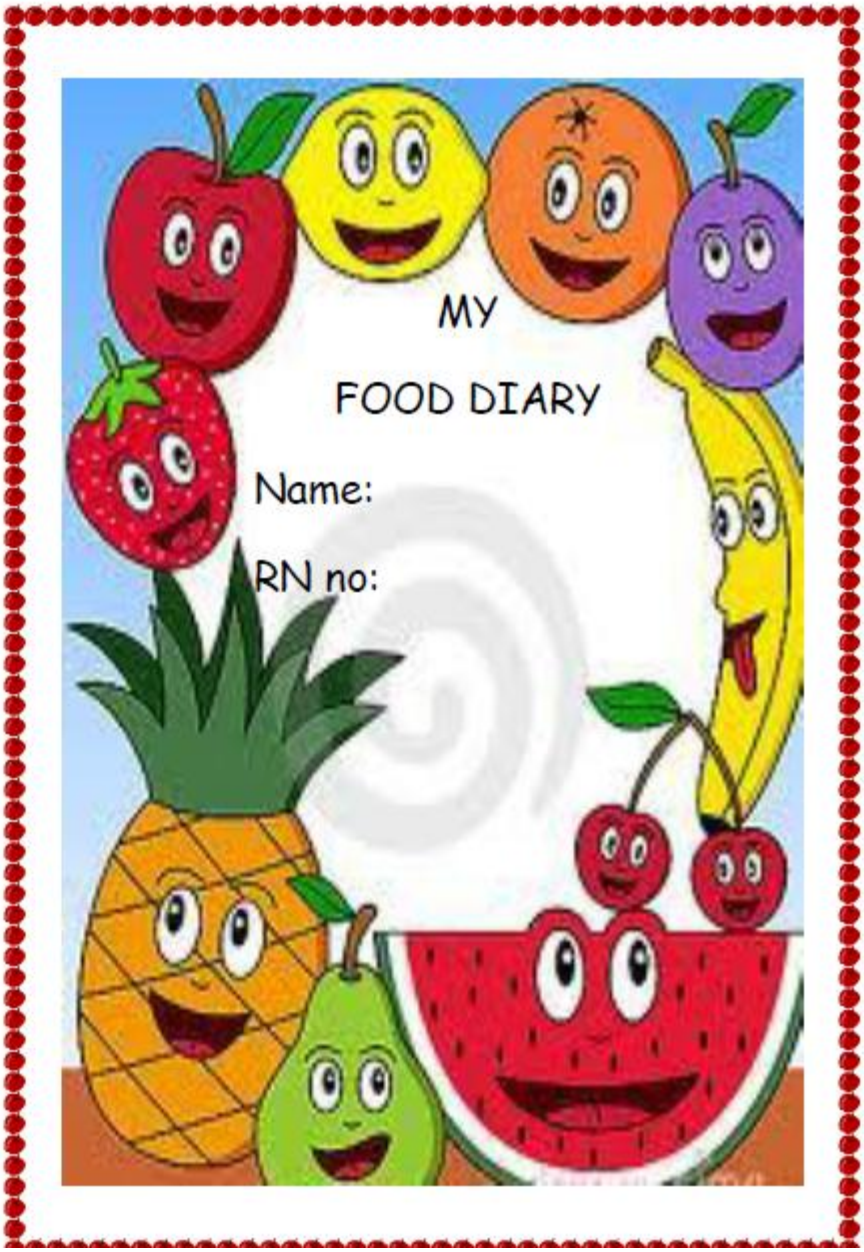
Bolehkan saya tidak mengambil bahagian dalam kajian?
Anda tidak perlu mengambil bahagian jikalau anda tidak berminat.

Siapakah yang perlu saya hubungi jikalau saya ingin kemukakan sebarang soalan sewaktu kajian?

Nama Doktor:	Muhammad Yazid Jalaluddin	Tel: 79492417
Nama Dietitian:	Mohd Huzaini Abd Halim	Tel: 79492044
Penyelidik/Dietitian:	Rokiah Ismail	Tel: +447403433394 Emel: r.b.ismail@ncl.ac.uk

BK-MIS-1116-E01

Appendix 3 3day- food diary



Appendix 4 Foods and their serving sizes

Foods	**One serving**
wholegrain products	
Bread, wholemeal	2 slices
Rice, brown, cooked	1 cup
Legumes	
Chickpea/dhal	1 cup
Green/mung bean and canned baked bean	1 cup
Bean curds	2 pieces
Milk	
Low fat milk	1 glass
Fruits	
Apple/ chinese pear/ mango/ *ciku*	1 whole
Banana, *berangan* (medium size)	1 whole
Banana, *emas*	2 whole
Durian	3 seeds
Grapes	8 small
Guava/Pear	½ whole
Mandarin Orange	1 whole
Papaya/ pineapple/ watermelon	1 slice
Prunes	4 small
Raisins	1 dessert spoon
Vegetables	
Dark green leafy-vegetables, cooked	½ cup
Fruit vegetables, cooked	½ cup
Ulam, raw	1 cup

Standard measurements used in this dietary guideline are as follows:

1 cup = 200 ml.
1 glass = 250 ml.
1 dessertspoon = 10 ml.

Appendix 5 Information sheet (Phase two)

A pilot study to develop a web-based diet and diabetes education program for children with type 1 diabetes

WHAT’S IT ALL ABOUT?

This is a study to develop a web-based program for diet and diabetes education.

We are recruiting school children aged 10-14 years to help us improve the program. You no not need to have diabetes to be able to take part.

WE NEED VOLUNTEERS TO HELP US

We would like you to browse this program in your home for two days. You can use this program after your school and at your own convenient time.

When you are using the program, we would like you to give us comments on what you think of the program and how easy it is to use into the feedback form which is part of the program (with the help of your parent / guardian).

After two days, we will call you just to make sure you have finished and that you have given your comments in the feedback forms which are located at the end of each section of the program.

We will ask some children to take part in a follow-up interview about the program. We will

£10 ELDON SQUARE VOUCHER

As a thank-you for taking part you will receive a £10 gift voucher for shopping in Eldon Square.

There is of course no obligation to take part and you can withdraw from the study at any time. The information you give will be used to make the program better but we will not use your name in any of our reports. If you would like to take part please:

- Complete the enclosed consent form
- Return it to the researcher in the pre-paid envelope provided

Any questions or for more information on the study, please contact Rokiah Ismail on 07403433394 or 0191 2227739.

Appendix 6 Consent form (Phase two)

CONSENT FORM

ID no.

I have read the Recruitment Letter explaining how my child will be involved in the study and have had time to consider it.

I understand that participation is voluntary and that my child is free to withdraw at any time, without giving any reason.

Name of child …………………………………… Male / female* Date of birth __ / __ / ____

Class ……………………………………………..

School ……………………………………………..

I agree/do not agree* to my child taking part in the study

______________________	______________________		___________
Signed (parent/guardian)	Name of parent/guardian	Date	

I agree/do not agree* to take part in the study

______________________	______________________		___________
Signed (child)	Name of child	Date	

I agree/do not agree* for my child to be interviewed

______________________	______________________		___________
Signed (parent/guardian)	Name of parent/guardian	Date	

I agree/do not agree* to be interviewed

Signed (child)	Name of child	Date

*please delete as appropriate

Name:
Mr/Mrs/Ms………………………………………………………………………….……………………

Address..……………………………………………………………………………….……………

……

Postcode
………………………………………………………………………………………………………

Telephone no. (day)
……………………………………………………..……………………………………………..

Mobile ……………………………………………………………………………………………….

Please return form to Rokiah Ismail: Human Nutrition Research Centre, Newcastle University, 1st floor Leech Building, Framlington Place, NE2 4HH using the pre-paid envelope provided.

Phone: 0191 222 7648 Text: 07403433394

Appendix 7 Parent letter (Phase two)

Dear Parent / Guardian

We are looking for children aged 10-14 years old to take part in a study to help us develop a web-based diet and diabetes education and support program for use by children with type 1 diabetes in University Malaya Medical Centre, Malaysia.

Before we can conduct this study among diabetic children, we need to conduct the study among children who do not necessarily have diabetes but are living in Newcastle with the aim to test acceptability and satisfaction of the system and gain feedback from the children.

We are delighted to say that your child name was identified from the list of Newcastle Malaysia Committee and eligible to take part in this study. This study will only take two days to complete and should not interfere with school time and work. I will arrange to meet with you and your child at a time of your convenience in your own home. Your child is free to leave the study at any time without the need to give any reason.

We will ask some children to take part in a follow up interview.

There is an information sheet attached to this letter which explains more about the study and a consent form.

If you and your child are interested in participating in this study or you would like to know more, please contact me (Rokiah Ismail) at the below address, call me on the phone number below or email me with your contact details.

Yours sincerely,

Rokiah Ismail
PhD student
Human Nutrition Research Centre,
Newcastle University,
1st floor, Leech building,
Framlington Place,
NE2 4HH
Tel. 0191 222 7648
Email: r.b.ismail@ncl.ac.uk

Appendix 8 Information sheet (Phase three)

Please read the following information carefully, do not hesitate to discuss any questions you may have with your Doctor.

Study Title

The development and evaluation of web based interactive diet and diabetes education program for use by children with type 1 diabetes.

Introduction

Diabetes education is important for children with type 1 diabetes beside insulin injection, diet and check blood sugar. Children need to have education programs which are enjoyable and fun so they will use them and then follow what they have learned and this may help them to improve their blood sugar.

We aim to develop an education program which not only has the important information they need but is also fun to use.

What is the purpose of this study?

We need children with type 1 diabetes to participate in this study to help us develop a web program which will be suitable for them.

What are the procedures to be followed?

With the help or your parent or guardian we would like you to:

- Use the web program at home for six months.
- Answer questionnaire about diabetes education program, self-efficacy and nutrition knowledge.
- Tell us what you think about this program and how easy it is to use into the feedback form which is part of the program.
- To keep a record of everything you eat and drink for three days at the first month, three months and six months into the diet diary section of the web program.
- To record your blood sugar into the glucometer diary section of the web program.
- To use the forum section to communicate or sharing problem or story with other children.
- To send a question related to diabetes to your consultant.

After six month we will call you just to make sure you have finished and that you have given your comments in the feedback forms which are located at the end of each section of the program.

Who should not enter the study?

- Children with diabetes who cannot read or write.
- Children with diabetes who also have mental health problems.

What will be benefits of the study?

To you as the people taking part
You can help us in the development of the diet and diabetes education program. We will be making this fun for the children taking part and we hope that you will enjoy being involved.

This program may help you learn more about diet and diabetes, you can ask question to your diabetes team, and share your experience with other diabetic patients. By this it might help you improve your diabetes and how you feel.

To the investigator
This study will give us information about what children need from a diet and diabetes education program which we help us develop the best possible program to be available for all children with diabetes.

What are the possible drawbacks?
Taking part in the study will take some of your time. We will try to make this as enjoyable as possible.

Can I refuse to take part in the study?
Yes, you can refuse to take part and this will have no effect on your treatment. If you agree to take part you can leave the study at any time without having to give a reason for this.

As a thank-you for taking part you will receive fifty (RM 50) cash money.

Who should I contact if I have additional questions during the course of the study?

Doctor's Name	Muhammad Yazid Jalaluddin	Tel: 03-79492417
Investigator	Rokiah Ismail	Tel: +447403433394

Appendix 9 Parent letter (Phase three)

Newcastle
University

mydiabetes

Dear Parent / Guardian

We are looking for children aged 10-17 years old to take part in a study to help us develop a web-based diet and diabetes education and support program for use by children with type 1 diabetes in University Malaya Medical Centre, Malaysia.

We are delighted to say that your child name was identified from the list of University Malaya Medical Centre patient with type 1 diabetes and eligible to take part in this study. This study will take six months to complete but it should not interfere with school time and work. I will arrange to meet with you and your child at a time of your convenience in University Malaya Medical Centre paediatric diabetes clinic. Your child is free to leave the study at any time without the need to give any reason.

We will ask children to take part in a follow up interview.

There is an information sheet attached to this letter which explains more about the study and a consent form.

If you and your child are interested in participating in this study or you would like to know more, please contact me (Rokiah Ismail) at the below address, call me on the phone number below or email me with your contact details.

Yours sincerely,

Rokiah Ismail
PhD student
Human Nutrition Research Centre,
Newcastle University,
1st floor, Leech building,
Framlington Place,
NE2 4HH
Tel. +44 0191 222 7648, Mobile +447403433394
Email: r.b.ismail@ncl.ac.uk

Appendix 10 Consent form (Phase three)

Newcastle University

mydiabetes

CONSENT FORM

ID no.

I have read the Recruitment Letter explaining how my child will be involved in the study and have had time to consider it.

I understand that participation is voluntary and that my child is free to withdraw at any time, without giving any reason.

Name of child ………………………………….. Male / female* Date of birth __ / __ / ____

Class ……………………………………………..

School ……………………………………………..

I agree/do not agree* to my child taking part in the study

______________________	______________________	____________
Signed (parent/guardian)	Name of parent/guardian	Date

I agree/do not agree* to take part in the study

______________________	______________________	____________
Signed (child)	Name of child	Date

I agree/do not agree* for my child to be interviewed

______________________	______________________	____________
Signed (parent/guardian)	Name of parent/guardian	Date

I agree/do not agree* to be interviewed

Signed (child)	Name of child	Date

*please delete as appropriate

Name:
Mr/Mrs/Ms……………………………………………………………………………………………

Address.……………………………………………………………………………………………

……………………………………………………………………………………………………

Postcode..……………………………………………………………………………………………

Telephone no. ……….……………………………………………………………………………..

Mobile ……………………………………………………………………………………………..

Please return form to Rokiah Ismail: Human Nutrition Research Centre, Newcastle University, 1st floor Leech Building, Framlington Place, NE2 4HH using the pre-paid envelope provided.

Phone: 0191 222 7648 ***Text: 07403433394***

Appendix 11 PDSMS

Newcastle University

hnrc molecules to public health

my diabetes

Perceived Diabetes Self-Management Scale (PDSMS)

Instruction: Please read the following questions. After each question, please make a check in the circle to show how much you believe you can or cannot do what is asked now.

PDSMS items	**1 Strongly Disagree**	**2 Disagree**	**3 Neutral**	**4 Agree**	**5 Strongly Agree**
1. It is difficult for me to find effective solutions for problems that occur with managing my diabetes.					
2. I find efforts to change things I don't like about my diabetes are ineffective.					
3. I handle myself well with respect to my diabetes.					
4. I am able to manage things related to my diabetes as well as most other people.					
5. I succeed in the projects I undertake to manage my diabetes.					

PDSMS items	**1 Strongly Disagree**	**2 Disagree**	**3 Neutral**	**4 Agree**	**5 Strongly Agree**
6. Typically, my plans for managing my diabetes don’t work out well.					
7. No matter how hard I try, managing my diabetes doesn’t turn out the way I would like.					
8. I’m generally able to accomplish my goals with respect to managing my diabetes.					

Adapted from Wallston et al (2007) with permission.

Appendix 12 NKS

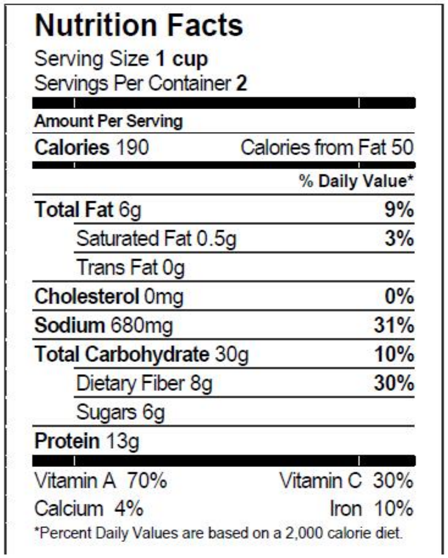
TYPE 1 DIABETES NUTRITION KNOWLEDGE SURVEY

The following questions are about general nutrition and nutrition related to diabetes. For each question, choose what you think is the best answer. Select only ONE answer for each question.

1. Which of the following are benefits of eating fruits and vegetables?	**A** **Good source of fibre**	**B** **Low in fat**	**C** **Good source of vitamins and minerals**	**D** **All of these**
2. Which of the following foods is high in fibre?	A Corn flakes	B Kidney beans	C Potato chips	D White bread
3. Which of the following foods contains heart healthy fats?	A Beef	B Nuts	C Cheese	D Butter
4. Which of the following contains more than 15 grams of carbohydrate?	A 1 small (4 oz) apple	B 12-15 grapes	C 1 cup fresh strawberries	D 1 cup (8 oz) orange juice
5. Which of the following foods provides the most vitamins and minerals?	A French fries	B Baked sweet	C White rice	D Potato chips

		potato		
6. Which of the following is NOT a whole grain food?	A Brown rice	B White bread	C Whole wheat bread	D Oatmeal
7. Whole grains are healthier than processed or refined grains because:	A They are higher in fiber	B They are naturally richer in nutrients	C Blood sugars rise more slowly after eating them	D All of these
8. If you ate 15 grams carbohydrate of each of the following foods, which would cause your blood sugar to rise the slowest?	A Oatmeal	B White bread	C Biscuit, cream cracker	D All the same
9. If you ate 15 grams carbohydrate of each of the following foods, which would cause your blood sugar to rise the fastest?	A Apple	B Apple juice	C Applesauce	D All the same
10. A juice labelled 'No added sugar':	A Is a "free" food	B Contains no sugar	C Contains carbohydrate	D None of these
11. Which of the following is NOT an example of a "free" food?	A 3 slices of cheddar cheese	B 12 oz can of diet soda	C ½ cup broccoli	D ½ cup cucumber slices

Use the Nutrition Facts label (right) for AMY'S KITCHEN CHILI to answer questions 12-15.



Nutrition Facts
Serving Size **1 cup**
Servings Per Container **2**

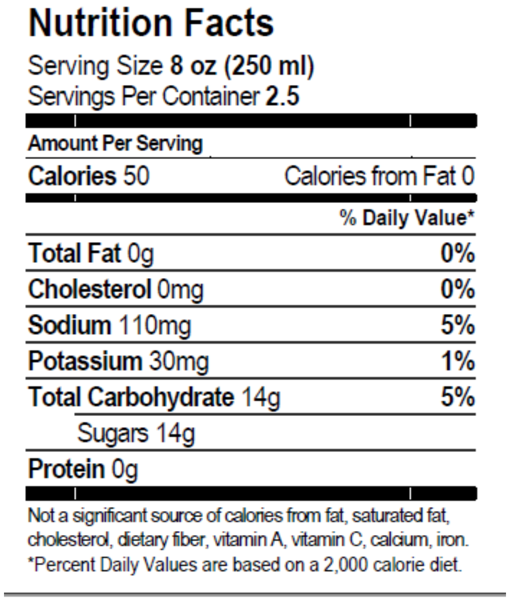
Amount Per Serving
Calories 190 Calories from Fat 50

	% Daily Value*
Total Fat 6g	**9%**
Saturated Fat 0.5g	**3%**
Trans Fat 0g	
Cholesterol 0mg	**0%**
Sodium 680mg	**31%**
Total Carbohydrate 30g	**10%**
Dietary Fiber 8g	**30%**
Sugars 6g	
Protein 13g	

Vitamin A 70% Vitamin C 30%
Calcium 4% Iron 10%
*Percent Daily Values are based on a 2,000 calorie diet.

12. How many cups are in this can of chili?	**A** **½ cup**	**B** **1 cup**	**C** **2 cups**	**D** **4 cups**
13. How many grams of fiber are in 1 cup of chili?	A 6 grams	B 8 grams	C 16 grams	D 30 grams
14. How many total grams of carbohydrate are in 1 serving of chili?	A 14 grams	B 22 grams	C 30 grams	D 60 grams
15. How many grams of carbohydrate would you use to calculate an insulin dose for 1 serving of chili?	A 6 grams	B 14 grams	C 22 grams	D 30 grams

Use the Nutrition Facts label (right) for GATORADE to answer question 16-18



Nutrition Facts

Serving Size **8 oz (250 ml)**
Servings Per Container **2.5**

Amount Per Serving

Calories 50	Calories from Fat 0
	% Daily Value*
Total Fat 0g	**0%**
Cholesterol 0mg	**0%**
Sodium 110mg	**5%**
Potassium 30mg	**1%**
Total Carbohydrate 14g	**5%**
Sugars 14g	
Protein 0g	

Not a significant source of calories from fat, saturated fat, cholesterol, dietary fiber, vitamin A, vitamin C, calcium, iron.
*Percent Daily Values are based on a 2,000 calorie diet.

16. How many servings are in this bottle of Gatorade?	**A** **1 serving**	**B** **2.5 servings**	**C** **5 servings**	**D** **8 servings**
17. How many grams of carbohydrate are in 1 serving of Gatorade?	A 14 grams	B 28 grams	C 35 grams	D 70 grams
18. How many grams of carbohydrate are in this bottle of Gatorade?	A 14 grams	B 28 grams	C 35 grams	D 70 grams

Questions 19-23 are about the number of carbohydrate in different foods. For the food listed in each question. Choose the <u>ONE</u> answer the best matches or is closest to the number of carbohydrate in that food.

19. 1 cup (8 oz) low fat milk	**A** **6 grams**	**B** **8 grams**	**C** **12 grams**	**D** **20 grams**
20. 1 cup cooked spaghetti (white, not whole wheat)?	A 20 grams	B 30 grams	C 45 grams	D 65 grams
21. ½ cup corn?	A Less than 5 grams	B 5 grams	C 20 grams	D 30 grams
22. Small lettuce salad (3/4 cup) with carrots, cucumbers, tomatoes, onion (no dressing)	A Less than 5 grams	B 10 grams	C 20 grams	D 30 grams
23. 1 cup cooked green beans	A Less than 5 grams	B 5 grams	C 10 grams	D 15 grams

Adopted from Rovner and Associates (2012) with permission