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Evaluation of using Web 2.0 technologies in diabetes education for adolescent and young patients

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Preface

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Abstract

Diabetes Mellitus is a major chronic disease with multi-organ involvement and high-cost complications. Although it has been demonstrated that structured education can control the risk of developing these complications, there is a substantial room for improvement in the educational services for these patients. e-learning can be a good solution to fill this gap. A system dynamics model was developed in this study to highlight the potential return on investment in these systems.

Most of the current e-learning solutions for diabetes were designed by computer experts and healthcare professionals, but the patients, as end-users of these systems, have not been deeply involved in the design process.

Web 2.0 technologies include a series of social and technological changes in the web applications which facilitate the interaction and collaboration between users on the web platforms. These changes can improve the level of involvement of the end-users in the web-based diabetes education systems. To increase their level of interest in these systems, it is very important to understand their expectations from different characteristics of these systems and to measure their level of satisfaction considering those characteristics.

A prototype system was developed in this project and the above mentioned parameters were measured, plus an evaluation about the effectiveness of the developed prototype in a prospective pre-test / post-test study.

The value survey was conducted before the system was used. This method prevented the results being biased by the experience with the current system. This will allow the results obtained to be generalized to any other website for a similar purpose. This potential for generalization helped in building a rating model for diabetes education websites using the results of the value survey.

The evaluation of the clinical effectiveness of the developed prototype showed the improvement in HbA1C level of the participants, but the difference was not statistically significant.

An effectiveness model was built based on information system theories to measure the level of effectiveness of different characteristics of the developed prototype and highlight the roadmap for future improvement of this system.

Keywords:

Web 2.0; Diabetes Mellitus; Patient education as topic, eLearning; System dynamics; Requirement engineering; Information system effectiveness; Healthcare professionals; Adolescent; Young

Chapter 1 Introduction

Diabetes is a common chronic disease. Because of the wide range of complications, high cost of management and early onset in some types, it has been the subject of many research projects.

The CareNet project focuses on the evaluation of a prototype developed for collaborative diabetes education. In this evaluation two models are developed for rating the websites developed for diabetes education and measuring the effectiveness of their different characteristics. Also, the clinical effectiveness of this prototype was evaluated in a six month follow-up using a pre-test / post-test study.

1. 1 - Motivation and Research Challenges

Diabetes is one of the major chronic diseases with a wide range of secondary complications. There has been a considerable increase in the number of the people with this medical condition in recent years. Although disease specific education has been shown to be a useful tool to control the complications of this disease, existing resources do not appear to be sufficient to cover the increasing level of requirements. An in-depth study about alternative methods for education is essential to cover this gap.

1. 2 - Aims and Objectives

Considering the limitations of face-to-face educational systems for diabetes presented in section 2.2.3-, and the potential of the Internet to cover some of these issues, this research aims to develop a collaborative model of web-based diabetes education for adolescents and young people living with diabetes.

The objectives of this research were as follows:

- Review of the literature relating to web-based diabetes education

  In the second chapter of this thesis an in-depth review of literature relating to web-based diabetes education is presented. Also, background theories concerning the evaluation of e-learning systems are discussed. Finally Web 2.0 technologies and their effect on healthcare are presented.

- Build a model using system dynamics theory to calculate the potential benefit of the Web-based diabetes education in the UK which is presented in section 6.1. The result from this model showed the cost-effectiveness of this method of education and was a motivation for this study.

- Develop a prototype for collaborative web-based diabetes education

  In the third chapter, the process of development and usability testing of a prototype website for collaborative diabetes education is presented.

- Define a model for evaluation of the developed prototype

  The fourth chapter presents the methodology of the evaluation of this prototype using a four step protocol, including online questionnaires and clinical studies.

- Measure the importance level of different characteristics of online diabetes education from the patients' and healthcare professionals' points of view which is presented in section 5.3.
- Measure amount of usage of different parts of the developed prototype presented in section 5.4.
- Evaluate the clinical effectiveness of the developed prototype presented in section 5.6.
- Measure the level of satisfaction with the developed prototype among participants.

  The results of these evaluations are presented in section 5.8. These results include the comparison between the participants in this project and the rest of the patients in the same clinic, their initial clinical data, their perceived level of importance about different characteristics of online diabetes education systems, their amount of usage of the website during the evaluation, their clinical outcome and their level of satisfaction with the system.

- Build a framework for improvement of the existing websites for diabetes education.

  Section 6.4 presents a discussion about the results of this evaluation. In this discussion the perceived value of these systems is compared between the healthcare professionals and patients. This comparison is used to build a framework for improvement of currently existing systems which is mostly built or supervised by healthcare professionals.
- Build a model to highlight the level of effectiveness of each of the system characteristics and the future tasks to improve the system.

The results from the initial survey are used to build a rating model for diabetes education websites in section 6.5. Finally an effectiveness model is developed in section 6.7 to measure the effect of different system characteristics on its effectiveness and future actions for increasing the effectiveness of the developed prototype is proposed.

Chapter 7 covers the conclusion of the CareNet project.

The abstracts of the peer-reviewed publications from this PhD thesis are available in Appendix 9.

Chapter 2 Review of Literature

In this chapter an introduction to diabetes and its complications is presented. A systematic review is conducted to explore previous research on the application of Internet-based education for diabetes and a meta-analysis was performed to evaluate the effect of online education on blood glucose and HbA1C as main clinical metrics.

2. 1 - Introduction to Diabetes

Diabetes mellitus (DM) is one of the major chronic diseases characterized by high blood glucose level (hyperglycaemia). The factors causing this phenomenon are reduced insulin secretion, decreased glucose utilization or increased glucose production. This metabolic dysregulation will cause secondary pathophysiological changes in different parts of body. The classic symptoms of diabetes are frequent urination (polyuria), increased thirst (polydipsia) and increased hunger (polyphagia).

Diabetes is classified in two main types based on the pathogenic process which leads to hyperglycaemia. Type 1 is caused by complete or near total deficiency of insulin and type 2 is caused by heterogeneous set of factors such as variable degrees of insulin resistance, impaired insulin secretion, and increased glucose production. There were two common terms used for classification of diabetes in the past as insulin dependent diabetes mellitus (IDDM) and non insulin dependent diabetes mellitus (NIDDM). Since many people with type 2 of diabetes end up using insulin for the control of their disease, this classification is not used anymore. The other change in the classification of diabetes is based on dividing the patients according to their age of onset. In the past, there was a common view that type 1 is an early onset form of diabetes mostly seen in children and onset of type 2 would be after 40. Since 5–10% of the patients diagnosed after 30 have type 1 and there is an increasing rate of type 2 onset in children mostly in obese adolescents, this concept is not considered either.

2.1.1- Classification of Diabetes

- *Type 1 DM:*

This is an autoimmune disease characterized by the state of insulin deficiency resulting from auto-immune destruction of the pancreatic beta cells. The aetiology of this type can be immune-mediated or idiopathic.

- *Type 2 DM:*

Type 2 may range from predominantly insulin resistance with relative insulin deficiency to a predominantly insulin secretory defect with insulin resistance. Due

to increase in improper diet regimen in children the prevalence of type 2 is increasing within this population (1).

- *Maturity onset diabetes of the young (MODY):*

MODY is characterised by autosomal dominant inheritance with early onset of hyperglycaemia before the age of 25. This early onset makes these patients one of the important target groups for this study.

- *Gestational diabetes mellitus (GDM):*

This type is similar to the diabetes type 2. It is caused by metabolic changes in pregnancy. The glucose tolerance of most affected women comes back to the normal range after delivery, but there is a substantial risk (30 – 60%) for future development of DM.

Based on a UK governmental report in 2008, the rate of teenage pregnancy is 40.4 per 1000 girls aged 15-17 and 7.7 per 1000 girls aged 13-15 (2). This highlights the potential of this population group to be identified in this study.

2.1.2- Diagnosis of Diabetes

Based on the approach issued by the World Health Organization, the criteria for diagnosis of diabetes are as follows:

1. Symptoms of diabetes plus random blood glucose concentration ≥ 11.1 mmol/L (200 mg/dL) OR Fasting plasma glucose ≥ 7.0 mmol/L (126 mg/dL)
2. Two-hour plasma glucose ≥ 11.1 mmol/L (200 mg/dL) during an oral glucose tolerance test

There are many reasons for recommending diabetes screening:

1. A large number of people who meet the current criteria for DM are asymptomatic.
2. Type 2 DM may be present for up to a decade before diagnosis.
3. Up to 50% of individuals with type 2 DM suffer from one or more diabetes-specific complications at the time of their diagnosis

4. Treatment of type 2 DM may favourably change the natural history of DM

The UK National Screening Committee (NSC) has reviewed the evidence for introducing population screening programmes for Type 2 diabetes. This review confirmed that it would not be cost-effective to screen the whole population for diabetes (3). However, there are suggestions for improvement of diabetes detection by opportunistic screening in sub-groups of the population who have multiple risk factors for developing diabetes.

Risk factors for Type 2 diabetes are:

1. Family history of diabetes (i.e., parent or sibling with type 2 diabetes)
2. Obesity (BMI ≥25 kg/m2)
3. Habitual physical inactivity
4. Race/ethnicity (Black, Asian and other minority groups)
5. Previously identified impaired fasting glucose (IFG) or impaired glucose tolerance (IGT)
6. History of GDM or delivery of baby >4 kg
7. Hypertension (blood pressure ≥ 140/90 mmHg)
8. HDL cholesterol level <35 mg/dL (0.90 mmol/L) and/or a triglyceride level >250 mg/dL (2.82 mmol/L)
9. Polycystic ovary syndrome or acanthosis nigricans (A skin disease characterized by brown to black poorly defined discoloration of skin)
10. History of vascular disease

These groups may also be good candidates for online diabetes education to increase their awareness of diabetes symptoms. This would aid earlier detection and management; which may in turn lead to decreased complications at the time of diagnosis.

2.1.3- Prevalence of Diabetes

Diabetes is a common chronic disease with a high incidence in the UK. Reports from Diabetes UK using the Yorkshire and Humber Public Health Observatory (YHPHO), a population-based model for both diagnosed and undiagnosed diabetes, showed the prevalence of diabetes rose from 3.54% to 3.66% between 2006 and 2007. This increase is due to a high incidence rate of diabetes (0.33%) and more accurate practice for patient diagnosis (4, 5).

The third phase of this model showed an even greater increase in the number of people living with diabetes (2.5 million cases by 2010). This frequency means the prevalence would be 4.95%.

2.1.4- Prevention of Diabetes

Type 2 DM is preceded by a period of IGT. There are a number of lifestyle modifications and pharmacological agents that can prevent or postpone the onset of DM. The Diabetes Prevention Programme (DPP) (6) demonstrated that intensive changes in lifestyle (change in diet and exercise for 30 min/day, five times a week) for individuals with IGT prevented or delayed the development of type 2 DM by 58% compared to a control group. This effect was unrelated to age, sex, or ethnic group. The lifestyle intervention group lost 5–7% of their body weight during the 3 years of this study.

2.1.5- Complications of diabetes

Complications of diabetes are the main reasons for the increasing cost of care in diabetes management. Diabetes complications are classified in two groups.

1. *Acute complications of diabetes:*
    A. *Diabetic Ketoacidosis (DKA):* This complication may give initial clues for diagnosis of type 1 DM, but it mostly appears in individuals with established diabetes. Its symptoms are nausea and vomiting, thirst and polyuria, abdominal pain, shortness of breath and fruity odour on the patient's breath.

B. *Hyperglycaemic Hyperosmolar State (HHS):* The prototypical patient with HHS is an elderly individual with type 2 DM, with a several week history of polyuria, weight loss, and diminished oral intake with resultant mental confusion, lethargy, or coma.
C. *Hypoglycaemia:* Recurrent hypoglycaemia is considered to have a negative effect on cerebral function especially in children diagnosed under the age of five.

Following treatment for these complications, the physician and patient should review the sequence of events that led to these complications to prevent future recurrences. In this review the most important factor is patient education about the symptoms, its precipitating factors, and the management of diabetes during a concurrent illness.

2. *Chronic Complications of DM:*

The chronic complications of DM affect many organ systems and are responsible for the majority of morbidity and mortality associated with this disease.

A. Vascular complications
    a. Micro-vascular
        i. *Eye disease:* DM is the main cause of blindness between the ages of 20 and 74 (1).
        ii. *Neuropathy:* This problem is present in about 50% of patients with long-term type 1 and type 2 DM (1).
        iii. *Nephropathy:* Diabetic nephropathy is the main cause of end-stage renal disease which is the main reason for morbidity and mortality in DM (1).
    b. Macro-vascular
        i. *Coronary artery disease:* Cardiovascular disease is increased in individuals with type 1 or type 2 DM. The

Framingham Heart Study (7) showed up to five times increase in congestive heart failure, coronary artery disease, myocardial infarction, and sudden death in DM.

ii. *Peripheral arterial disease:* Hypertension can aggregate other complications of DM, especially cardiovascular disease and nephropathy.

iii. Cerebro-vascular disease: is another chronic vascular complication of diabetes affecting blood vessels in brain.

B. Non-vascular complications

a. *Gastrointestinal:* The most common GI symptoms are delayed gastric emptying (gastroparesis) and altered small and large bowel motility (constipation or diarrhoea).

b. *Genitourinary:* Diabetic autonomic neuropathy may cause genitourinary dysfunction including cystopathy, erectile dysfunction, and female sexual dysfunction.

c. *Dermatological:* The most common skin manifestations of DM are delayed wound healing and skin ulcerations. DM is the main cause of non-traumatic lower extremity amputation.

d. Infections: Infectious diseases are more common and more severe in people with DM.

Chronic complications are related to the duration of the hyperglycaemia and mostly start about 10 years after patient develops instances of it. This long asymptomatic period will result in most patients being diagnosed by its complications. These complications are irreversible and will have a huge financial impact on the healthcare system. There is evidence that reduction in chronic hyperglycaemia prevents or delays retinopathy, neuropathy, and nephropathy. This is good evidence for the requirement of a long-term motivation for better disease management in people living with diabetes.

2.1.6- Screening for Diabetes

Screening in diabetes has two aspects. It can be done to detect diabetes in high risk populations and also in people living with diabetes for detection of pre-symptomatic complications of diabetes to stop or slow down future problems (1).

Diabetes Detection Screening Criteria are:

- Age over 50 years
- Overweight (BMI > 25)
- Family history of Diabetes
- Hypertension
- Angina or myocardial infarction
- Circulatory problems
- History of foot or leg ulcer
- African or South Asian ethnicity

Complication Detection Screenings are:

- Diabetic eye screening: This should be done annually
- Foot Screening: An annual test should be done for the presence of neuropathy, ischaemia or deformity.
- Diabetic Renal Screening: annual test for all people living with diabetes over the age of 12.
- Screening for lipid anomalies: Total cholesterol, HDL, LDL and Triglycerides should be measured annually.
- Cardiovascular risk assessment: can be done by the UK Prospective Diabetes Study (UKPDS) Risk Engine in people with type 2 of diabetes.

These screening indicators are good guides to target people with potential risks and reinforcement of knowledge about the complications of diabetes.

2.1.7- Management of Diabetes

Two main research projects have been conducted to study the effect of intensive diabetes management on clinical outcome of diabetes.

The Diabetes Control and Complications Trial (DCCT) (8) proved that reduction in chronic hyperglycaemia can prevent most of the type 1 DM complications. This large multicentre clinical trial randomly allocated more than 1400 people with type 1 DM to either intensive or conventional diabetes management; and measured the development of retinopathy, nephropathy, and neuropathy in them for ten years. Individuals in the intensive diabetes management group received multiple injections of insulin each day with extensive educational, psychological, and medical support. Participants in the conventional diabetes management group received two insulin injections each day and nutritional, educational, and clinical evaluation four times a year. The goal in the first group was normoglycaemia whereas the goal in the latter group was prevention of symptoms of diabetes.

Some of the glucose molecules in blood bind to haemoglobin (the protein that carries oxygen in red blood cells). This combination is known as haemoglobin A1C (HbA1C). The HbA1C test shows the level of diabetes control in the last few months. Individuals in the intensive diabetes management group had a lower HbA1C (56 mmol/mol) than participants in the conventional diabetes management group (76 mmol/mol).

The DCCT demonstrated that improvement of glycaemic control reduced nonproliferative and proliferative retinopathy (47% reduction), microalbuminuria (39% reduction), clinical nephropathy (54% reduction), and neuropathy (60% reduction). Most of the individuals in this project were young and had a low risk of cardiovascular disease. They had a non-significant trend in reduction of macrovascular events during the trial. The results of the DCCT predicted that individuals in the intensive diabetes management group would gain 7.7 additional years of vision, 5.8 additional years free from end-stage renal disease, and 5.6 years free from lower extremity amputations. If all complications of DM were combined, individuals in the intensive diabetes management group would experience 15.3 more years of life without significant microvascular or neurological complications of DM in comparison with the control group. This means an additional 5.1 years of life expectancy for individuals in the intensive diabetes management group.

The UKPDS (9) studied more than 5000 individuals with type 2 DM for more than ten years. This study utilized multiple treatment regimens and monitored the effect of intensive glycaemic control and risk factor treatment on the development of diabetic complications. Newly diagnosed individuals with type 2 DM were randomized to intensive management using various combinations of insulin, sulfonylurea, or metformin; or in other group, conventional therapy using dietary modification and pharmacotherapy with the goal of preventing complications of diabetes. Individuals in the intensive treatment arm achieved an HbA1C of 53 mmol/mol compared to a 63 mmol/mol HbA1C in the standard treatment group. The UKPDS demonstrated that each percentage point reduction in HbA1C, based on the National Glyco-haemoglobin Standardization Programme (NGSP) percentage unit, was associated with a 35% reduction in microvascular complications. Similar to the DCCT project, there was a continuous relationship between better glycaemic control and limiting the development of complications.

2.1.8- Education for people living with diabetes

Most routine diabetes care processes such as carbohydrate intake control, blood glucose metering, and insulin injection in type 1 and diet control and weight-watching in type 2 are done by patients themselves. Control of certain complications such as foot problems can be performed by the patients in addition to scheduled visits to clinics. Empowering the patients with enough knowledge about these tasks can play a crucial part in diabetes care. This goal is achieved by patient education.

Among the different models of diabetes patient education, structured models are considered to be the most effective. The National Institute for Clinical Excellence (NICE) defines structured education as “a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individual’s clinical and psychological needs, and adaptable to his or her educational and cultural background” (10). Also standard 3 of the National Service Framework (NSF) states that: “all children, young people and adults with diabetes will receive a service which encourages partnership and decision-making, supports them in managing

their diabetes and helps them to adopt and maintain a healthy lifestyle" (11). The key criteria for the structured programme agreed by the Patient Education Working Group are underpinned by the philosophy that it will be available through different media, it should be person-centred, evidence-based, dynamic, and flexible to the needs of the individuals and users should be involved in ongoing development.

Diabetes UK have provided guidance on the topics that should be covered by any education programmes for people living with diabetes (12). These topics come under the following headings:

- Nature of diabetes
    - significance and implications of a diagnosis of diabetes; the impact of diabetes
    - aims and different types of treatment
    - relationship between blood glucose levels, dietary intake and physical activity
    - short- and long-term consequences of poorly controlled diabetes
    - nature and prevention of long-term complications
    - Importance of annual surveillance for complications.
- Day-to-day management of diabetes
    - importance of a healthy lifestyle, especially physical activity, a balanced diet and not smoking
    - importance of self-management
    - self-monitoring – glucose monitoring or urine testing
    - interpreting the results of self-monitoring and tests of long-term blood glucose control
    - adjusting insulin dosage (for those on insulin)
    - importance of systematically using different injection sites (for those on insulin)

- storage of insulin; disposal of sharps
- importance of regular foot care, choice of footwear, foot hygiene, the role of podiatry
- importance of oral hygiene and regular dental check-ups

- Specific issues
  - hypoglycaemia (for those on insulin or hypoglycaemic agents): warning signs, likely causes, role of alcohol, the need to have rapidly absorbable carbohydrate available and the particular care required if undertaking high-risk activities, such as driving or working with dangerous machinery
  - other illness – 'sick day' rules must be given to all people living with diabetes; (see box opposite)
  - immunisations, such as for flu or pneumococcal pneumonia, should be offered to all people living with diabetes
  - pre-conception advice (for women of childbearing age) – the importance of excellent control at the time of conception as well as during pregnancy
  - importance of regular eye examinations – both visual acuity and fundal examination
- Living with diabetes
  - importance of carrying personal identification, such as Medic-Alert, and a warning card including the name, contact address and telephone number of a person who can help them
  - driving: notification of the DVLA and insurance company and the importance of avoiding hypoglycaemia while driving
  - holidays
  - implications of diabetes for employment, life insurance and travel insurance
  - implications for education: liaison with nurseries and schools about

children and young people living with diabetes is essential

- making best use of healthcare services: what care to expect; when to contact local services for what; how to get more information (NB people with diabetes are entitled to receive an annual free eye examination by an optometrist/ophthalmic medical practitioner; those receiving treatment with either tablets or insulin are exempt from paying prescription charges)
- accessing benefits, such as the Disability Living Allowance for children with Type 1 diabetes, if applicable
- contacting other people with diabetes
- information about Diabetes UK and local support groups

- 'Sick day' rules
  - importance of continuing to take insulin or tablets – in fact they may need to increase the dose
  - testing urine or blood for glucose at least four times a day
  - if on insulin, testing urine for ketones
  - drinking plenty of liquids
  - if not well enough to eat, replacing normal meals with carbohydrate-containing drinks
  - contacting GP if in any way unsure about what to do, especially if being violently sick

In the UK, there are two commonly used programmes for diabetes education; Dose Adjustment for Normal Eating (DAFNE) (13) for type 1 and Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) (14) for type 2.

2. 2- Diabetes in adolescents and young people

Adolescence is a formative period of human life that has a fundamental impact on a person's future personality. In the people living with diabetes, this period has important features that distinguishes them from other younger or older patients.

2.2.1- Epidemiology

The majority of adolescents with diabetes have type 1 DM. The prevalence of both type 1 and type 2 diabetes has increased amongst the youth of less than 18 years of age (15). Diabetes type 1 most often develops during childhood, particularly around the age of puberty. Although the reason for the increase in type 1 diabetes is not well understood, much of the increase in type 2 diabetes among youth can be explained by the increase in the number of children who are at risk of being overweight or obese. The overall risk of other siblings getting type 1 according to one diagnosed child is low, but statistics are less encouraging if the child happens to be one of the unlucky 8-16% (DR3+DR3 or DR4+DR4 in major histocompatibility complex (MHC)) (1). The problem is that full MHC typing is very expensive to contemplate as a routine investigation.

2.2.2- Specific Issues

There are three specific issues in the management of diabetes in adolescent and young people that make it significantly different and more complex than diabetes management in adults.

- *Clinical:* The period of adolescence is bound with profound alterations in the metabolism as a result of physiological adaptation to the puberty. This characteristic of adolescence commonly manifest as a deterioration of glycaemic control. Improved management and control of diabetes at this age can reduce the incidence and delay the impact of associated microvascular and other long-term complications. It also has shorter-term benefits, including improved academic performance and school attendance, reduced hospital admissions and greater satisfaction with services. In the UK, hospital admissions for type 2 patients below 18 years of age increased by approximately 45% between 1996-1997 and 2003-2004. This compares with a 63% rise in patient admission for obesity in the same period (16).
- *Psychological:* Adolescence and youth is bound with some social changes such as school examinations, experiments with sex, alcohol and drugs,

starting work and leaving home. This is the period for gaining independence and increasing in self-esteem. Because of the self management involved in diabetes, this period is the best time for patient education to accept self responsibility for care. The other group is the parents of children who should receive education and support to accept allowing their children to be responsible for themselves. One of the accepted methods for transfer of responsibility in this group is the supportive networks of professionals who look at the problems of diabetes from different perspectives in a holistic approach. Cost-effective interventions exist that improve the outcomes for adolescent and young people whilst reducing long-term expenditure. Services need to be designed in response to local needs assessments, in partnership with adolescent and young people, ensuring that they can meet the specific needs of the local population. In every case, however, services should be developed and delivered in a coordinated and integrated way that is focused on the needs of children and young people and meet the "You're Welcome" quality criteria, which help services to be young-person friendly (17).

- *Organizational:* The other important aspect of this group is the transfer from a family based paediatric service to a larger and less personal adult diabetes service. In this new environment the adolescents may encounter many patients at the late stage of the disease suffering from complications of diabetes such as blindness, wheelchair-bound and amputees which emotionally is very traumatic. For the above mentioned reasons many centres have established special transition clinics for the adolescents living with diabetes to provide a more smooth transition at this age. Other projects which have been conducted in the UK are the out of clinic activities such as summer camps for these people.

2.2.3- Education

The NICE guidance on "Diagnosis and Management of Type I Diabetes in Children, Young People and Adults" (18) recommends that: "Children and young people with

type 1 diabetes and their families should be offered timely and ongoing opportunities to access information about the development, management and effects of type 1 diabetes." The guidance adds that "the method of delivering education and content will depend on the individual and should be appropriate for the child's or young person's age, maturity, culture, wishes and existing knowledge within the family".

<table>
<tr><th colspan="6">Individual states with frequency</th><th rowspan="2">Overall Frequency</th></tr>
<tr><th>Course Awareness</th><th>Course Attendance</th><th>Course duration</th><th>Course Interest</th><th>Course Offer</th><th>Reason for Rejection</th></tr>
<tr><td rowspan="11">+
(28%)</td><td rowspan="4">+
(40%)</td><td>< 1 Day
(43%)</td><td></td><td></td><td></td><td>4.7%</td></tr>
<tr><td>1 Day
(8%)</td><td></td><td></td><td></td><td>0.8%</td></tr>
<tr><td>2-4 Days
(37%)</td><td></td><td></td><td></td><td>4.2%</td></tr>
<tr><td>> 5 Days
(12%)</td><td></td><td></td><td></td><td>1.3%</td></tr>
<tr><td rowspan="7">-
(60%)</td><td rowspan="7"></td><td rowspan="6">+
(34%)</td><td rowspan="4">+
(26%)</td><td>Time Inconvenience
(31%)</td><td>0.5%</td></tr>
<tr><td>Don not like group training
(22%)</td><td>0.3%</td></tr>
<tr><td>Location inconvenience
(13%)</td><td>0.2%</td></tr>
<tr><td>Unknown
(34%)</td><td>0.5%</td></tr>
<tr><td>-
(74%)</td><td></td><td>4.3%</td></tr>
<tr><td colspan="2">-
(66%)</td><td>11.2%</td></tr>
<tr><td>-
(72%)</td><td colspan="5"></td><td>72%</td></tr>
</table>

Table 2.1: Diabetes education among children with diabetes in the UK

The statistics show that the coverage of education for the young people living with

diabetes is unsatisfactory. The results in the Table 2.1 are extracted from a report on child members by Diabetes UK in 2006 (19).

The previous table shows a considerable shortcoming in structured education because of lack of awareness and courses on offer or inappropriate time and place. Also according to the specifications of diabetes in adolescents mentioned in this chapter, it can be concluded that there is a need for new methods of disease education for this group.

Adolescents are considered as a computer-native generation. They are more familiar with computer technology in comparison with the previous generations and can adopt this technology more easily. Internet-based diabetes education can be a good alternative for current traditional education model.

2. 3 - Systematic Review and Meta-analysis

2.3.1- Introduction

Rationale

As previously mentioned, there are several trials regarding the effect of structured education on diabetes control. There is no commonly agreed method for delivery of this service via the Internet, but high availability of broadband services and increased knowledge about using Internet-based services is a good opportunity for investing in this method of healthcare. Limits in the resources for providing the required education have encouraged the healthcare providers to invest in these methods. This review aims to identify the Internet-based projects for diabetes education and investigate the evaluation studies for measuring their level of effectiveness.

Objectives

Articles that presented results of randomized clinical trials, pre-test/post-test interventions, qualitative studies or reports of the websites developed for diabetes education were included in the review.

2.3.2- Methods

Protocol

This review is based on the methodology proposed by the PRISMA Group (20). Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) is the updated version of the "QUality of Reporting of Meta-analysis" (QUOROM) which covers both meta-analysis and systematic reviews.

Eligibility criteria

The studies which focused on a diabetes education programme for patients; used the Internet as the communication medium and written in English were included in this review. Because of the limited number of studies, no participant age limit was applied.

Information sources

The Cochrane Database of Systematic Reviews (CDSR) and nine scientific resources were searched for relative articles. The searched resources were:

1. Emerald (http://www.emeraldinsight.com/)
2. Eric (http://www.eric.ed.gov/)
3. Informa world (http://www.informaworld.com/)
4. Proquest (http://www.proquest.co.uk/en-UK/)
5. Pubmed (http://www.ncbi.nlm.nih.gov/pubmed/)
6. Science Direct (http://www.sciencedirect.com/)
7. Web of Science (http://www.isiknowledge.com/)
8. Wiley (http://www.interscience.wiley.com/)

Search

The query string used for these searches was:

"diabetes AND (education OR "Patient Education as Topic") AND (internet OR web)"

Initially the resources were searched for review articles and then for other types of articles.

Study selection

Selection of the studies was done through the scanning of the abstracts, checking the articles in list of the references of the selected articles and searching for other publications from the authors of the selected articles. Also journals related to the subject of the review were specifically checked.

Data collection process

Results from all of the sources were exported to reference management software, EndNote v.13; repeated records were identified by the build-in duplicate checker of the software.

Data items

The data items collected during the review were:

- Electronic source
- Journal
- Author
- Publication Year
- Method of evaluation
- Project name
- Control group
- Type of diabetes included
- Sample size
- Follow-up duration
- Age range of participants
- Content of education
- Organization funding the study
- Country of study
- Evaluation of Knowledge transfer
- Clinical evaluation
- Evaluation of satisfaction
- Evaluation of improvement in quality of life
- Findings
- Limitations

Risk of the bias in individual studies:

The studies were checked for adequate information, allocation concealment, blinding (self-reported outcome or objective outcome), incomplete outcome data and selective reporting.

Summary measures

Among the clinical data blood glucose and HbA1C were the most commonly reported tests. These two tests represent the short-term and long-term control of the diabetes and were chosen for meta-analysis. Also results about knowledge transfer and user satisfaction are summarized.

Synthesis of results

Because of the low number of studies included in the meta-analysis, I^2 was used for measuring the heterogeneity of the results. The I^2 test is the preferred method for measuring inconsistency in met-analysis. Some of the advantages of using this test are as follows:

1. Its interpretation is intuitive; it gives the percentage of total variation across studies due to heterogeneity.
2. It is simple to calculate
3. It does not depend on the number of studies.
4. It can be interpreted irrespective of the type of outcome data (Dichotomous, quantitative, time or event)

Risk of bias across studies

Risk of the publication bias and selective reporting within the studies was investigated. The methods of intervention were compared to ensure that only the results from comparable interventions are included in meta-analysis.

2.3.3- Results

Study selection

Six review articles were identified about the overall use of the computer systems for diabetes education. Only one of the reviews was about web-based interventions and the other reviews were generally looking at computer-based diabetes education which reported some studies about the Internet-based systems (see Table 2.2).

The review from Wantland which generally looked at the Internet-based interventions was not specific to diabetes. It was conducted in 2004 and did not include the recent projects. Also the list of resources searched in this review was limited. The related articles referenced in those reviews were included in the current review.

Author	Year	Title
Krishna S (21)	1997	Clinical trials of interactive computerized patient education: Implications for family practice
Visser A (22)	2004	Perspectives on education and counselling for diabetes patients
Wantland DJ (23)	2004	The effectiveness of Web-based vs. non-Web-based interventions: A meta-analysis of behavioural change outcomes
Boren SA (24)	2008	Computerized Learning Technologies for Diabetes: A Systematic Review
Cooper HA (25)	2009	Technology-based approaches to patient education for young people living with diabetes: a systematic literature review
Kaufman N (26)	2010	Internet and information technology use in treatment of diabetes

Table 2.2: Systematic reviews about computer-based patient education

The reviewed characteristics in these articles were:

1. Type of the studies
2. Knowledge and behavioural change outcomes
3. Demographic Characteristics
4. Duration of intervention

In the second step, previously mentioned electronic resources were searched for relevant articles with the same query string. This search resulted in 3105 abstracts. 37 abstracts were available in more than one of the searched databases. The remaining 3068 abstracts were initially reviewed for the relevance of the article to

this review.

Because of the large number of articles resulting from the search in electronic resources, RefViz software was used to group the articles to clusters. 26 groups were identified by RefViz. The galaxy view and the matrix view of the identified articles are depicted in Figure 2.1 and Figure 2.2 respectively. The main keywords of those groups are presented in Table 2.3.

This tool helps in easy classification of the articles and quicker identification of the papers related to the subject of interest. The inclusion criteria for this review were studies which used the Internet as the medium to deliver education to people living with diabetes. In this process 2994 abstracts were excluded.

The reference lists of the remaining 74 articles were scanned for further articles. No new articles were found in this process. Also the mentioned resources were searched for any other article published by the authors of the selected papers. No new article related to the subject of this review was identified.

“Diabetes Educator” journal was specifically searched for relevant articles with the query string of “web or internet”. Initially 158 articles were found, but no related article could be added to the previous list (Diabetes Educator is cited in PubMed).

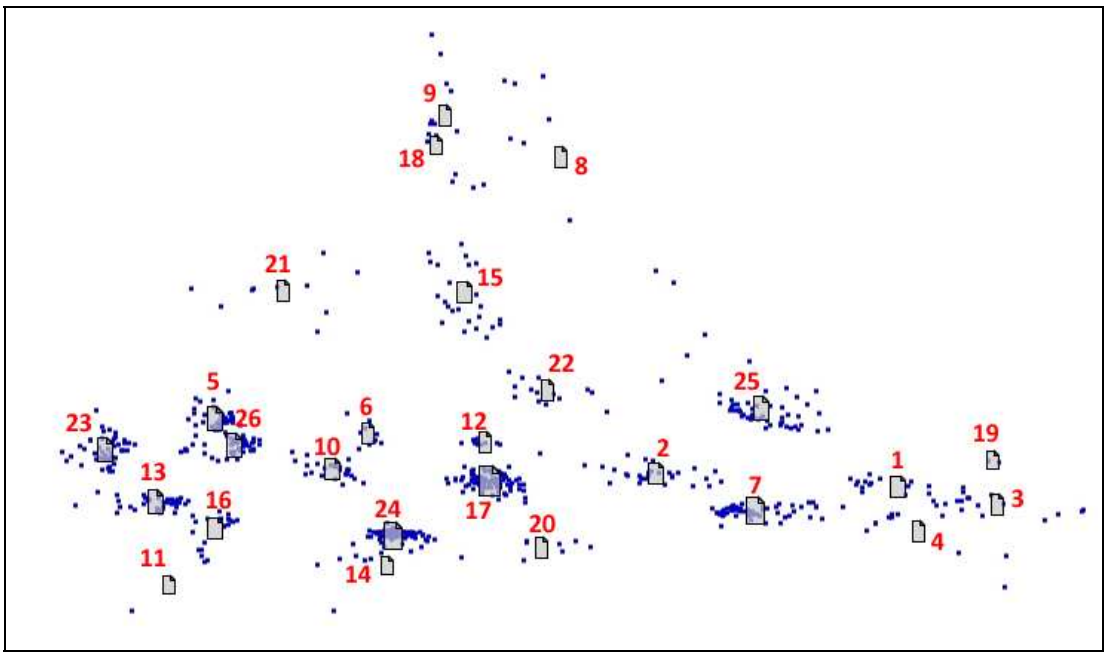

Figure 2.1: Galaxy view of the articles identified in primary search

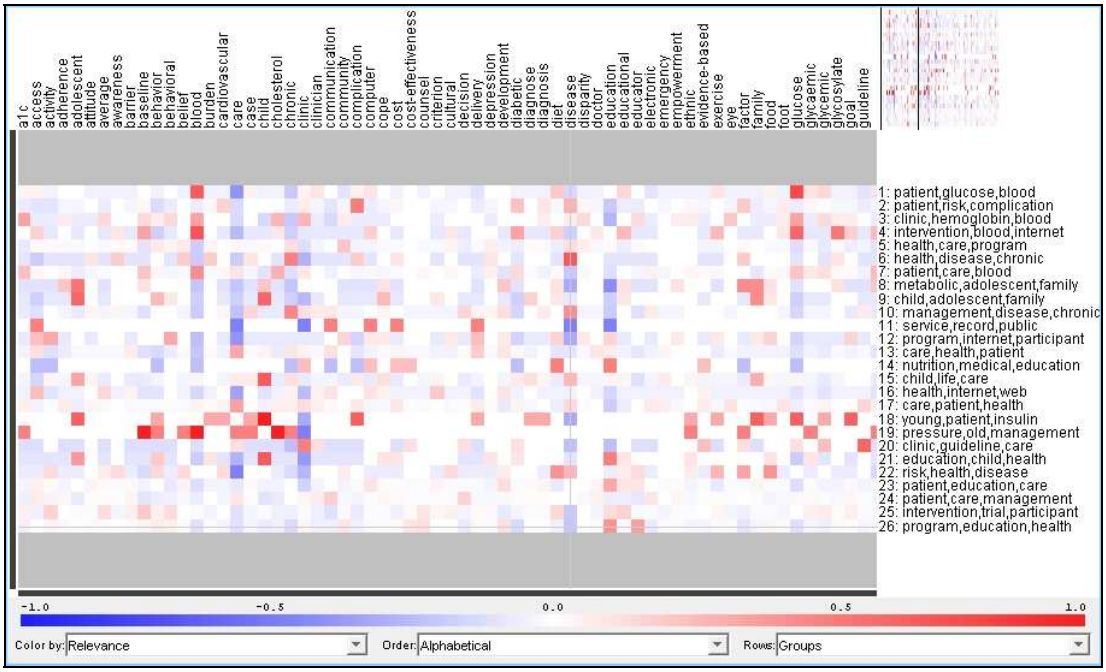

Figure 2.2: Relativity matrix of the keywords with article groups

Group	Keyword
1	Patient, Glucose, Blood
2	Patient, Risk, Complication
3	Clinic, Haemoglobin, Blood
4	Intervention, Blood, Internet
5	Health, Care, Programme
6	Health, Disease Chronic
7	Patient, Care, Blood
8	Metabolic, Adolescent, Family
9	Child, Adolescent, Family
10	Management, Disease, Chronic
11	Service, Record, Public
12	Programme, Internet, Participant
13	Care, Health, Patient
14	Nutrition, Medical, Education
15	Child, Life, Care
16	Health, Internet, Web
17	Care, Patient, Health
18	Young, Patient, Insulin
19	Blood pressure, Old, Management
20	Clinic, Guideline, Care
21	Education, Child, Health
22	Risk, Health, Disease
23	Patient, Education, Care
24	Patient, Care, Management
25	Intervention, Trial, Participant
26	Programme, Education, Health

Table 2.3: List of the main keywords identified in the grouped articles

The process of selecting the relevant articles is shown in the Figure 2.3.

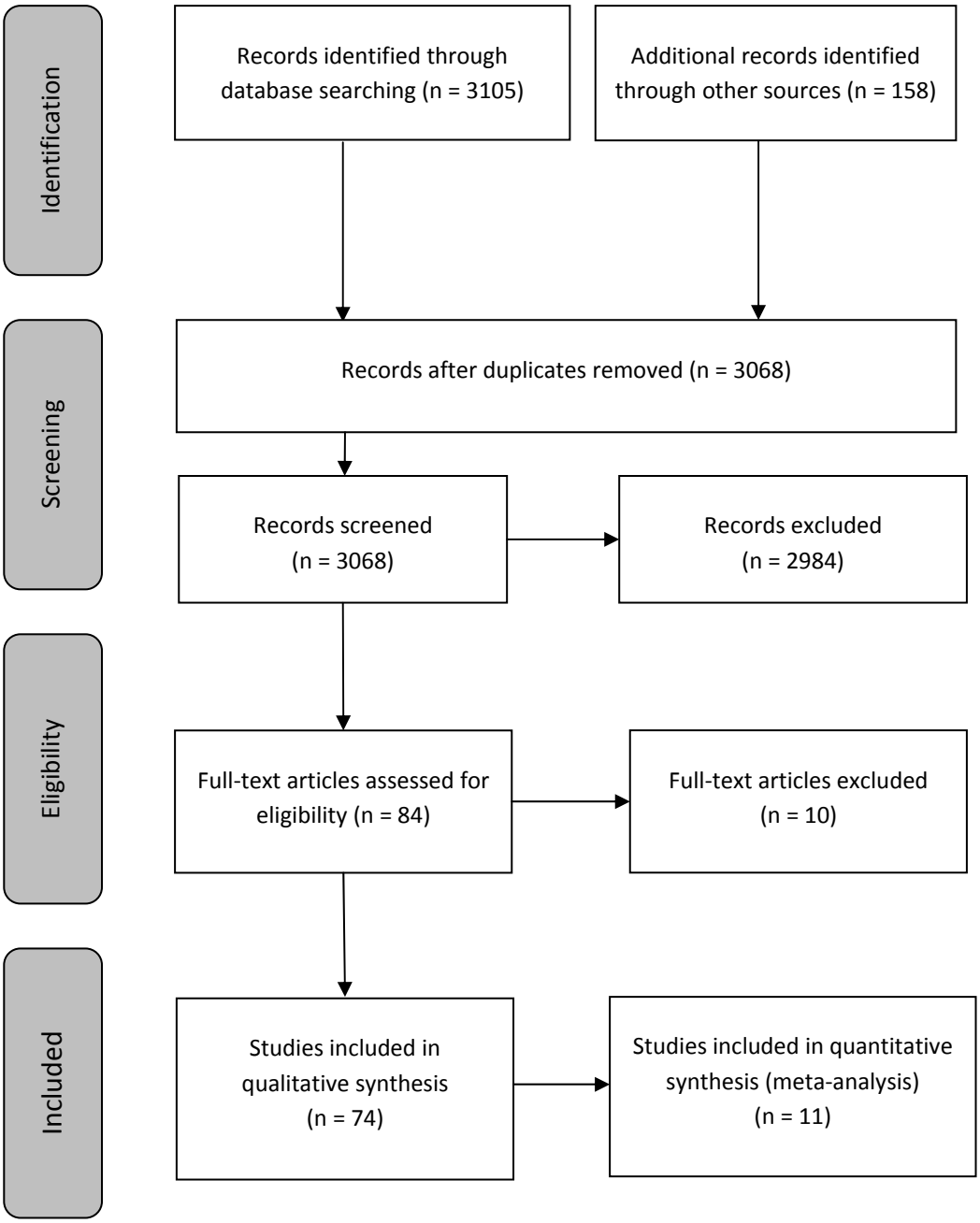

Figure 2.3: PRISMA flow diagram of study selection

Table 2.4 presents the number of identified and selected articles divided by electronic resource.

Resource	Initial articles	Selected articles
Emerald	72	0
Eric	202	0
Informa World	577	0
OvidSP	912	4
Proquest	133	12
PubMed	371	40
Science Direct	310	7
Web of Knowledge	422	5
Wiley	106	6
Total	**3105**	**74**

Table 2.4: Outcome of search for related articles in different resources

Validity of the study

The methodologies applied to evaluation projects were closely checked to ensure that the articles included in the review were using correct protocols.

Study characteristics

Papers were classified in four different groups based on their evaluation methods: Randomized Clinical Trials (RCT), pre-test/post-test comparisons, qualitative studies and system development reports. The frequency of articles in each group is presented in Table 2.5.

Type of study	Frequency
RCT	18 (24%)
Pre Test – Post Test	5 (7%)
Qualitative Results	16 (22%)
Development Report	35 (47%)
Total	**74**

Table 2.5: Type of studies in reviewed articles

There were six papers evaluating the knowledge transfer process in their studies, sixteen papers measuring the clinical outcome, seven papers measuring the satisfaction of the patients and three papers assessing the changes in quality of life among patients receiving the Internet-based education.

Measurement	Frequency
HbA1C	14
FBS, BG	11
Cholesterol	5
HDL	4
BMI	4
TG	2

Table 2.6: Clinical factors measured in reviewed articles

Measured clinical items were mainly blood glucose (BG) and HbA1C as indicators for short-time and long-time control of clinical effectiveness respectively (see Table 2.6).

Risk of bias within studies

The biggest potential risk of bias in the reviewed studies is the risk of publication bias. As presented in the next section, 35 articles reported the development of Internet-based solutions for diabetes education and 16 articles related to qualitative studies of such systems. These articles represent two thirds of the overall articles identified in this review. No evidence was found about evaluation of those systems. Also, only eight studies reported the attrition rate during the evaluation. This rate varied from 10% in NetPlay study (27) to 31% in the study by Viklund et al (28).

In most studies only the baseline and final measures of HbA1C were reported and no evidence of the previous trend in this test was presented. Change in the trend of HbA1C can reveal better clinical meaning than simple comparison of pre-intervention and post-intervention. In the Figure 2.4 this difference is presented. The picture on the left side shows clinical improvement and that on the

right side shows worsening of the clinical metric in simple comparison; but if we consider the previous trend then the meanings will become reversed.

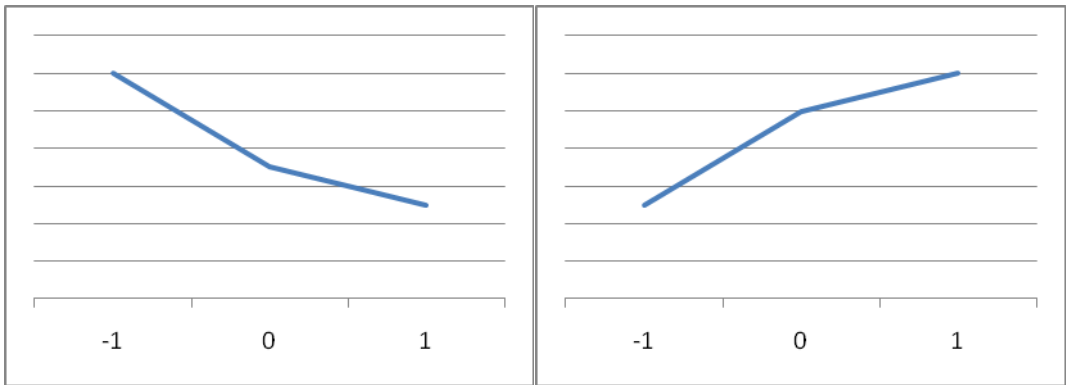

Figure 2.4: effect of previous trend in interpretation of the change in clinical measurement

Six studies included in the review measured the HbA1C in more than two instances which somehow resolved this problem (28-33).

Results of individual studies

Randomized Clinical Trials

The sample size of the RCTs varied from 10 to 1665. All of projects had participant follow-up which varied from 2 to 24 months (see Table 2.7).

Author	Project	Publication year	Country	N	Intervention	Follow-up
McKay HG (34)	D-Net	2001	USA	78	Exercise Coach	2 m
Barrera M (35)		2002	USA	160	Measuring the Diabetes Support Scale (DSS)	3 m
McKay HG (36)	D-Net	2002	USA	160	Information and peer support	3 m
Shea S (37)	IDEATel	2002	USA	1500	Access to data, video , conference with educator, chat service with other patients	12 m
Boukhors Y (38)		2003	Canada	10	Insulin dose recommendation	4 m
Tate DF (29)		2003	USA	92	Weight Loss counselling	12 m

Author	Project	Publication year	Country	N	Intervention	Follow-up
Glasgow RE (30)	D-Net	2003	USA	160	Diabetes educational resources, social networking	10 m
McMahon GT (31)		2005	USA	104	Some educational modules	12 m
Edwards A (39)		2006	UK	360	Information about benefits of tight blood sugar control	2 m
Kim CJ (40)		2006	South Korea	73	Guidelines and BG monitoring	3 m
Shea S (41)	IDEATel	2006	USA	1665	Access to clinical data, video , conference with educator, chat with other patients	12 m
Viklund (28)		2007	Sweden	32	5 x 2h course problem-based discussion in groups	6 m
Lee Ting I(32)	POEM	2007	Taipei	414	Continuous event-based education	9 m
Misoon S (33)		2009	South Korea	31	Diabetes Self-management course	3 m
Roek MG (42)	Di@log	2009	Nether-land	248	Insulin titration course	12 m
Liebreich T(27)	NetPlay	2009	Canada	49	Courses for improvement of physical activity	3m
Mulvaney S (43)	Your-Way	2010	USA	72	Enhanced support for self-management	3 m
Noh JH (44)	eMOD	2010	China	40	Comprehensive diabetes education	6 m

Table 2.7: RCT studies

Only three of the studies assessed the amount of learning on the part of the participants and thirteen evaluated the clinical outcome. Measurement of the degree of satisfaction with the course was performed in five studies and quality of life was just measured in two studies.

Author	Outcome			
	Learning Assessment	Clinical Measurement	Satisfaction	Quality of life
McKay HG (34)	No	No	No	No
Barrera M	No	No	Yes	No
McKay HG (36)	No	HbA1C, Chol, Psychological State	No	No
Shea S (37)	No	BG, HBA1C, BP, Chol, TG, HDL	Yes	Yes
Boukhors Y	Yes	FBS, BG,HbA1C	Yes	Yes
Tate DF	No	BG, BMI	No	No
Glasgow RE	No	HbA1C	No	No
McMahon GT	No	HbA1C, BP, HDL	No	No
Edwards A	Yes	No	Yes	No
Kim CJ	No	FBS, HbA1C, Physical Activity	No	No
Shea S (41)	No	FBS, HBA1C, BP, Chol, TG, HDL	No	No
Viklund	Yes	HbA1C	No	No
Lee Ting I	No	FBS, HBA1C, Chol, TG, HDL	No	No
Misoon S	No	HbA1C	No	No
Roek MG	No	HbA1C	No	No
Liebreich T	No	No	Yes	No
Mulvaney S	No	HbA1C	No	No
Noh JH	No	BG, HbA1C	No	No

Table 2.8: Parameters evaluated in RCT studies

Clinical data were included in eleven studies; only one study introduced the educational material based on the clinical data of the participants (32). In this study the courses were selected by the system coaches who were healthcare professionals. In four studies links to external material related to diabetes were provided. The detailed information about these items is presented in Table 2.8.

The content of the educational material was structured in nine trials, semi-

structured in two and not structured in seven studies. The educational material was mostly text-based and covered different aspects of diabetes disease (see Table 2.9).

Author	Education Format	Health Data	Link to external data
McKay HG (34)	Not structured	Included	No
Barrera M	Not structured	Included	No
McKay HG (36)	Structured	Included	No
Shea S (37)	Structured	Included	No
Boukhors Y	Not structured	Included	No
Tate DF	Not structured	Not included	Yes
Glasgow RE	Not structured	Included	Yes
McMahon GT	Structured	Included	Yes
Edwards A	Not structured	Not Included	No
Kim CJ	Structures	Included	No
Shea S (41)	Structured	Included	No
Viklund	Not structured	Not Included	No
Lee Ting I	Semi structured	Included, Related	No
Misoon S	Structured	Not included	No
Roek MG	Semi structured	Included	No
Liebreich T	Not structured	Not included	Yes
Mulvaney S	Not structured	Not included	No
Noh JH	Structured	Included	No

Table 2.9: Structure of RCT studies

If we divide the compartments of these studies into educatee, educator and the computer system, this review revealed that the flow of information in the channels of communication between these compartments were very different.

Because there were differences in content of communication between the compartments, a separate one-way channel is dedicated for the transfer of

information between each two compartments; resulting in five separate communication channels. The detailed information is presented in Table 2.10.

1. Channel from educatee to system:

   This channel was used for clinical data input in most of the studies and learning evaluation in three studies.

2. Channel from system to educate:

   It was mostly used for providing educational content to the educatees in all studies and graphical representation of their uploaded data in eight studies.

3. Channel from educator to system:

   The usage of this channel was specifically for supporting the patients through the process of education which was used in twelve studies.

4. Channel from system to educator :

   This connection was used to inform the educators about the status of educatees which included clinical status in seven and data about evaluation of education in two studies.

5. Channel between educatees:

   Used for social networking between the educatees; it was active in ten studies.

Author	Educatee – System	System – Educatee	Educator - System	System - Educator	Educatee – Educatee
McKay HG (34)	Self-registration, BG (RW)	Articles related to diabetes and physical activity, BG graphs (R)	Personal support for Physical activity (RW)	Access to BG graphs (R)	Communicate with other users (RW)

Author	Educatee – System	System – Educatee	Educator - System	System - Educator	Educatee – Educatee
Barrera M	BG, Food intake (RW)	Graphical representation of their data, Periodic educational documents (R)	Review forums (RW)	Access to patient forums (RW)	Peer directed interactive forum (RW)
McKay HG (36)	Initial Assessment, BG(RW)	Articles on medical, nutritional, and lifestyle aspects of diabetes, BG graphs (R)	Dietary goal setting and follow-up advice (RW)	Access to the BG graphs (R)	Communicate with other users (RW)
Shea S (37)	BG, BP (R), Direct chat with educator (RW)	Educational material, Clinical data (R)	Video chat with patient (RW)	Clinical data (R)	Direct chat (RW)
Boukhors Y	Daily BG upload, QOL, Knowledge test, behaviour test (RW)	BG chart, Insulin dose recommendation (R)	-	-	-
Tate DF	Posting daily diary (RW)	A tutorial on weight loss and a directory of selected Internet weight loss resources (R)	Goal setting for the participants (RW)	Access to daily diaries (R)	Post messages on online message-board (RW)
Glasgow RE	BG (RW)	BG Graphs (R)	Guide patients (RW)	-	Q&A conference (RW)
McMahon GT	Automatic upload of BG and BP (R) Messaging to educator (RW)	Some educational modules (R)	Message to patients (RW)	Access to clinical data of patients (R)	-
Edwards A	Evaluating the Risks (RW)	Present the risk and benefits between tight and normal treatment	-	-	-

Author	Educatee – System	System – Educatee	Educator - System	System - Educator	Educatee – Educatee
Kim CJ	By telephone calls to operators	Guideline for behavioural change in physical activity (R)	-	-	-
Shea S (41)	BG, BP upload (R), Chat with educator (RW)	Educational material, clinical data (R)	Video chat with patients (RW)	Access to clinical data of patients (R)	Direct chat (RW)
Viklund	Search for information on the system (R)	-	-	-	Discussion sessions
Lee Ting I	e-mail (RW)	Alert e-mail, SMS about appointments (R), Clinical Data (R)	Choose the material for education (RW)	Email based on abnormal test results (RW)	-
Misoon S	-	Diabetes self-management education (R)	Provide online lectures	-	-
Roek MG	Online BG diary (RW)	Online diabetes education program (R)	-	-	-
Liebreich T	Online questionnaire, logbook (RW)	education and skills for long-term behaviour change (R)	Contact with patients via email (RW)	Access to the logbook of the patients (RW)	Contact via message-board (R)
Mulvaney S	Write diabetes related stories on the website (RW)	Access to the stories provided by other users (R)	Providing advice to the patients (RW)	Access to the stories developed by the patients (RW)	Social networking with peers (RW)
Noh JH	Online BG diary (RW)	Online diabetes education program (R)	-	-	-

Table 2.10: Interaction methods in RCT studies

(R: Read-only, RW: Read-Write)

Pre-test/post-test studies

Five pre-test/post-test studies were included in this review. Their sample size varied from 12 to 135 cases. None of these studies had follow-up (see Table 2.11).

Author	Study	Publication Year	Country	N	Intervention	Follow-up
Yoo JS (45)	TTM	2003	South Korea	28	Exercise intervention program	-
Heidgerken AD (46)		2005	USA	60	Sick day education module for counsellor of summer camp	-
Bell JA (47)	Brainfood	2006	USA	135	9 learning modules	-
Kim HS (48)		2008	South Korea	40	Diabetes recommendations via text message and Web	-
Whittemore R (49)	TeenCope	2010	USA	12	Diabetes coping skills	-

Table 2.11: Pre-test/post-test studies

Three studies assessed the amount of learning on the part of the participants. Three studies evaluated the clinical outcome. Two studies measured user satisfaction and one evaluated the change in quality of life (see Table 2.12).

Author	Outcome			
	Learning Assessment	Clinical Measurement	Satisfaction	Quality of life
Yoo JS	Yes	BG, HbA1C, Physical Activity	Yes	No
Heidgerken AD	Yes	No	No	No
Bell JA	Yes	No	No	No
Kim HS	No	BG, HbA1C	No	No
Whittemore R	No	HbA1C	Yes	Yes

Table 2.12: Parameters evaluated in pre-test/post-test studies

Author	Education Format	Health Data	Link to external data
Yoo JS	Semi structured	No	No
Heidgerken AD	Semi structured	No	No
Bell JA	Structured	No	No
Kim HS	Not structured	Yes	No
Whittemore R	Semi-structured	No	No

Table 2.13: Structure of pre-test/post-test studies

The educational material was mostly text-based and covered different aspects of diabetes. The format of the educational content was semi-structured in three studies and structured in only one of them. One study included clinical data and no link was provided to diabetes-related external materials (see Table 2.13).

Author	Educatee – System	System – Educatee	Educator - System	System - Educator	Educatee – Educatee
Yoo JS	Exercise behaviour-scale questionnaire (RW)	Guideline for behavioural change in physical activity (R)	Add guideline for behavioural change in physical activity (RW)	-	-
Heidgerken AD	Knowledge test (RW)	Sick day rule education (R)	-	-	-
Bell JA	Knowledge test (RW)	19 Educational units (R)	Feedback to the test results (RW)	Test results (R)	-
Kim HS	Upload BG measurement (RW)	Clinical data in charts (R)	Recommendations to the patients (RW)	Access to clinical data of the patients (R)	-
Whittemore R	PedsQL, Stress Questionnaire	Diabetes courses on coping skills	-	-	-

Table 2.14: Interaction methods in pre-test/post-test studies

(R: Read-only, RW: Read-Write)

Considering the channels of the communication, all studies included some educational content introduced to users. In three studies the educator played an active role giving feedback to educatees. The detail information about these communications are presented in Table 2.14.

Qualitative studies and models

In this review 13 articles were found on qualitative studies and proposed models for online diabetes education. The list of these articles and a short description about them is presented in Table 2.15.

Author	Year	Study	Description
Ralston (50)	2004	Living with Diabetes	Semi-structured interviews with nine participants of the online diabetes education. They supported the system and asked to be more involved in its further development.
Zrebiec JF (51)	2005	MSW	Tracking the activities of the system users and evaluation of user satisfaction. Average length of use was 16:44 minute and 74% expressed positive satisfaction.
Feinman RD (52)	2006	ALCF	Active Low-Carber Forums (ALCF) was evaluated with a 27-item questionnaire. Users were mostly overweight, female, interested in losing weight and in 25% of cases their family physician supported their participation in this project.
Kamel Boulos, A.V Roudsari (53)	2006	M2DM	A model for development of a web-based diabetes education system individualized based on the user needs based on semantic web.
Long JD (54)	2006		A pilot study on interactive nutrition education which caused a significant reduction in fat consumption and high user satisfaction.
Ma C (55)	2006	Violet Technology	Introduced diabetes Information Profile using psychological, educational and clinical factors.
Charron-Prochownik D (56)	2007	D-SMART	Diabetes Self-management Assessment Report Tool (D-SMART) was evaluated for usability and satisfaction in this study. It was easy to understand and 94% of participants were satisfied with it.

Author	Year	Study	Description
Gerber BS (57)	2007	STYLE	This pilot program, Self-management Training in Youth for Lifelong Effectiveness, specially tailored for adolescent and young people living with diabetes. The system utilisation of 19 participants was monitored with overall 4445 instancing the web. The participation was heavily relied on the encouragement from diabetes educator.
Eyombo (58)	2008	Stay Healthy	This paper is about a satisfaction survey with the project website. Participants preferred to learn from their doctor at the first instance and then from the site. The best predictors of a high rating to the website were better overall health status, worry and previous experience in using computers and internet to access healthcare information.
Timpka T (59)	2008		Participatory action research using design pattern. Participants were children with diabetes. Requirements were developed and integration with electronic health record was discussed.
Zickmund (60)	2008		Used focus group discussions. Interest in online services was linked to dissatisfaction with current services, inability to obtain medical information and logistic problems in the offices. Education about the privacy concerns was requested by the participants.
Ubeyli ED (61)	2009		A model for risk evaluation, data collection and education of undiagnosed diabetes was proposed.
Nordqvist (62)	2009		Healthcare professionals involved in development of the Web 2.0-based system for education of child and adolescent people with diabetes participated in this qualitative study. They expressed a positive attitude toward such systems and demanded more technical education for contribution to these systems.
Glasgow RE (63)	2010		Comparison of characteristics between participants and non-participants on demographic and clinical factors.
Perez N (64)	2010		Feasibility study of tele-medical services via text message and Internet for gestational diabetes which resulted in 62% reduction in face-to-face visits.
Nordfeldt S (65)	2010	DiabIT	Web 2.0 portals are useful for continuous diabetes education but they should be kept active.

Table 2.15: Articles reporting qualitative studies of the websites for diabetes education

Website development reports

Most of the publications on Internet-based diabetes education were limited to reports about development of these services. No evidence about the evaluation of them was identified in resources used for this review. These articles are presented in Table 2.16.

Author	Year	Study	Description
Tomky (66)	1997		A report about development of a web-based working prototype for one of the modules outlined in the National Standards.
Wu (67)	2000	Southwest Wide Web	A diabetes education column in the website of Sichuan Information Centre
Plougmann S (68)	2001	DiasNet	an Internet-based system where more emphasis is put on patient; based on DIAS decision support system used for insulin adjustment
Povlsen (69)	2002	D4Pro	This paper briefly describes the developmental process, the concepts and designs of diabetes education material for web, and makes recommendations on how it can be applied.
Starren J (70)	2002	IDEATel	This paper is about the feasibility study of IDEALTEL project which was discussed in RCT papers.
Lehmann (71)	2003	AIDA Online	A paper about the online version of Automated Insulin Dosage Advisor (AIDA)
Peace D (72)	2003	HESY	Healthy Eating is in Store for You (HESY) is a web-based programme developed through collaboration between Dietitians of Canada (DC) and the Canadian Diabetes Association.
Roberts SS (73)	2003	NDEP	A report about the National Diabetes Education Program Website.
Goldberg HI (74)	2003		A feasibility study on allowing patients with type 2 diabetes to co-manage their disease from home.
Feathers AS (75)	2004		A Study on identification of the websites for education of genetics factors in diabetes education for lay people.
Goldberg HI (76)	2004		A report on self-management support in a web-based counselling which included people living with diabetes
Ravert RD (77)	2004		A content analysis of the messages posted by adolescents with diabetes at public Web-based forums. It suggested that adolescents with diabetes visit online forums for social support, information, advice, and shared experience.

Author	Year	Study	Description
Kim Y (78)	2004		A paper about feasibility of distributed tele-care and home-based support in South Korea
Hill J (79)	2005	CAMC	A distance-education courses on diabetes in Charleston Area Medical Centre, USA
Malasanos TH (80)	2005	FITE	Telemedicine clinics supplemented by online education to provide effective care for children with diabetes.
Charron-Prochownik D (81)	2005	GIFT-D	A website for helping the families to make decision about genetic testing for type 1 diabetes
Cox D (82)	2005		Blood glucose awareness training for hypoglycaemia and hyperglycaemia
Nordfeldt S (83)	2005		A study using postal questionnaire about use of the Internet in search for diabetes-related information. The study concluded that there is a great need for development of systems combining technical and human support in Sweden.
Simon SR (84)	2005		This study was conducted to determine the effectiveness of Internet-based audit and feedback to physicians to improve care for diabetes and hypertension. The lack of participation in this Internet-based intervention suggested implications for the development of future programs that require physicians to interact with technology and improve quality of care.
Reed K (85)	2006	2Aida	Another paper about online version of AIDA project.
Thomson, GA (86)	2006	Diabetes-e	A website for continuing professional development (CPD) for health professionals and with a particular emphasis on patient input.
Clark (87)	2006	MyPyramid	An online version of the Food Guide Pyramid, released by the United States Department of Agriculture (USDA)
Yeh YT (88)	2006	POEM	Development report about a Patient-Oriented education management system for diabetes using the Internet
Andrews G (89)	2007	ClimateGP	ClimateGP is an online education system combining patient education with feedback to, and guidance from, the doctor provided by Royal Australian College of General Practitioners.
Koleszynska J (90)	2007	GIGISIM	GIGISim was developed to facilitate the online management of Diabetes mellitus.
Devlin S (91)	2007		A Web portal was developed to assist in diabetes education and self-management with feedback from the expert patients.

Author	Year	Study	Description
Whittington G (49)	2007		Preventative Diabetic Ketoacidosis (DKA) e-learning available via the web and mobile devices
Varni (92)	2008	ePedsQL	Development and validation of the electronic version for Paediatric Quality of Life Inventory (ePedsQL)
Atack L (93)	2008	PEPTalk	Measuring the satisfaction level of the participants with the developed system using think-aloud method in a usability testing laboratory
Newton K (94)	2008		Correlation statistics found a significant positive relationship between self-efficacy and positive outcome expectations and between self-efficacy and quality of life in a seven week intervention with the web-based diabetes education.
Heinrich E (95)	2009	DIEP	This project is developed using multimedia facilities to overcome short-comings of existing diabetes educations
Herrejon K (96)	2009	Your Guide to Diet and Diabetes	A report on development and usage of this website (6124 login sessions by 104 users)
Ko GT (97)	2010		Using java engine this project includes a risk predictor engine and provide related courses to participants
Ekberg (98)	2010		A design guide for developing diabetes education system using community of practice model and relation between users

Table 2.16: Articles reporting development of the websites for diabetes education

Considering all articles identified in this review, the publication year was from 1999 to 2010 with the peak in 2006 (see Figure 2.5).

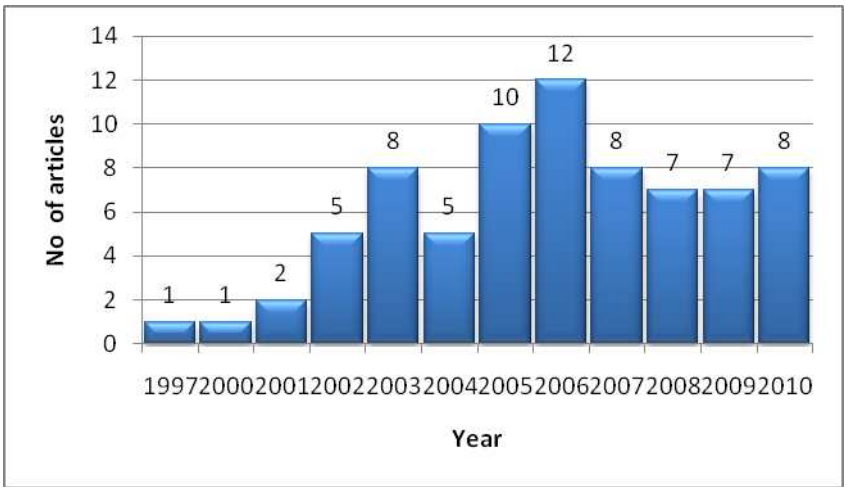

Figure 2.5: Frequency of publication by publication year in the reviewed articles

The studies were conducted in different countries. USA is standing at the top with 56% of the studies and the UK is in the fourth place having 7% of the studies (see Table 2.17).

Country	Frequency (percent)
USA	39 (56%)
Sweden	6 (8%)
South Korea	6 (8%)
UK	5 (7%)
Canada	4 (5%)
China	4 (5%)
Netherlands	2 (2%)
Australia	2 (2%)
Denmark	2 (2%)
Turkey	1 (1%)
Germany	1 (1%)
New Zealand	1 (1%)
Poland	1 (1%)

Table 2.17: Frequency of countries conducting the research for the reviewed articles

Synthesis of results

A meta-analysis was conducted on two of the major clinical factors: Fasting Blood Sugar (FBS) (Figure 2.6) and HbA1C (Figure 2.7).

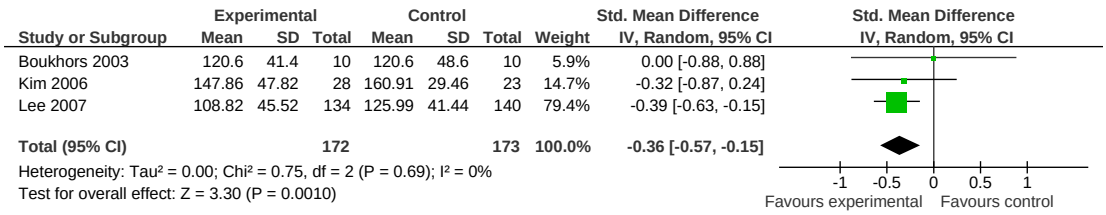

Figure 2.6: Forest plot for Meta-analysis of FBS outcomes in RCTs

Only the studies which used similar methods for intervention were included in this meta-analysis. The data from these studies were recorded in RevMan v. 5 and using the I^2 test the heterogeneity of the results was calculated.

The results of the I^2 tests in both clinical variables show very low inconsistency among the included studies. The result of the Z test for measuring the total effect in the included studies shows significant change in favour of experiments in the intervention groups.

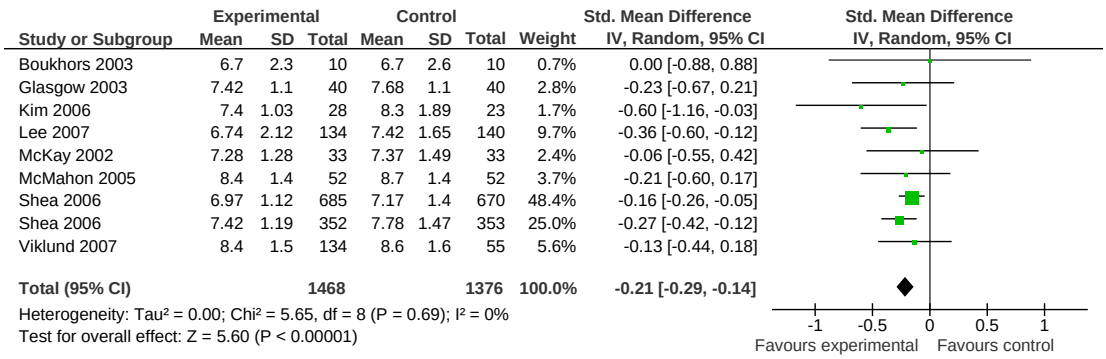

Figure 2.7: Forest plot for Meta-analysis of HbA1C outcomes in RCTs

The level of knowledge transfer was mostly measured by its impact on the change of behaviour in clinical trials. Boukhors et al. (38) measured the level of following the recommendations. Edwards et al. (39) measured the improvement of confidence in decision-making for treatment and Viklund et al. (28) used the Diabetes Empowerment Scale (DES) which is a 23-item questionnaire about problem solving, self-esteem, coping with stress and readiness to change.

Among the pre-test/post-test studies, Yoo et al. (45) provided the subjective report on readiness for exercise and physical activity. Heidgerken et al (46) and Kim et al. (48) measured the exact level of improved knowledge and both reported significant increase in answering to questions.

Measurement of satisfaction level in all studies was based on simple questions asking the users about their overall level of satisfaction with the systems. High level of satisfaction was reported in studies that measured this factor; but no evidence about the level of satisfaction with detailed aspects of the systems was reported.

Risk of bias across studies:

There is a risk of potential bias across the studies because of the difference in the content of the education materials. In most of the articles the educational content was not explained in detail. Even with the similar topics covered in some studies, comparison of content usability is very difficult. The second potential bias in some of the reviewed articles concerns the attrition rate. This parameter was reported only in eight studies. The reported rate of attrition varied from 10-31% which is a wide range. The third risk for bias is the amount of usage of those services and the amount of learning from them. The information about these factors was not clearly provided in the articles.

2.3.4- Discussion

Summary of evidence

The articles presenting the studies developed for Internet-based diabetes education are mostly limited to developmental reports. Only 31% of them included any evaluation of their effectiveness. Among those evaluations, different attributes were measured such as the amount of transferred knowledge, clinical improvement, satisfaction and the change in quality of life. The duration of the follow-ups was limited in most of the studies. The result from meta-analysis of the clinical parameters shows a significantly positive outcome. Other parameters such as transferred knowledge, satisfaction and change in quality of life had positive outcomes as well.

These studies did not evaluate the level of values and satisfaction with diabetes education as an e-learning system. They mostly delivered the content material of diabetes education via electronic communication channels rather than using the extended features that e-learning can provide. Tailoring the education towards the real-time evaluation of patient needs was very limited.

According to patient empowerment concepts that attracted a lot of attention in recent NHS policies (99), such educational systems should be more tailored toward the needs and requirements of patients and the best way to achieve this goal is to

further involve patients and consider their views regarding these systems. In e-learning systems it has been shown that user satisfaction is a key factor in system effectiveness (100). End-users were not very much involved in the development of systems and their expectation from the systems was not measured properly.

The format of education was not structured in most of the reviewed studies which is an important short-coming in them. Utilisation of existing resources on the Internet can be a key factor to enrich these systems and speed-up their development. These resources were only utilized in five studies.

Limitations

The biggest limitation in this review is the low number of reports with negative findings such as attrition rate.

Funding

This review did not have any external source of funding and the reviewer had no financial interest in favour of any of the reviewed articles.

2. 4 - Summary

Although there were some possibilities for bias in the reviewed articles, the general trend in these studies shows improvement in control of clinical measures in diabetes. To find the answers to the issues mentioned about user values, a survey was carried out at the beginning of the CareNet study to measure the level of importance of different characteristics of diabetes e-learning from the patients' point of view.

All of the included articles in this review were presenting the websites which were developed by or in collaboration with healthcare professionals. The healthcare professionals collaborating in the CareNet study were asked to complete the same value survey completed by patients. Comparison between their point of view and the results from the patient survey can be used as a requirement engineering model for improving the existing diabetes education websites.

Chapter 3 Research Plan and Methodology

In this chapter an in-depth discussion about e-learning and some of the background theories for its evaluation are presented.

Then Web 2.0 as an emerging concept for enriched web-based systems is introduced and the effect of these new technologies on healthcare and especially diabetes education is discussed.

Finally the plan for system design, implementation and the qualitative and quantitative evaluation of the developed system is explained.

3. 1 - Background

The review of the literature in the previous chapter showed that web-based diabetes education can help to overcome the limitation of the current diabetes education. Web-based education is an e-learning method. So in the following section e-learning is discussed in more detail and the theories about measuring and improving its effectiveness are presented.

3.1.1- E-Learning

- ***Definition***

E-learning is defined as the use of electronic technologies for the purpose of education. This system can be applied using different channels of communication. These channels are generally divided to two groups:

- Asynchronous Channels: In this group the communication between the educator and educatee is not real-time and there is a delay in the interactions just as with e-mail.
- Synchronous Channels: In this group educator and educatee have a real-time interaction such as Skype.

There are several technologies that can be used for e-learning like:

- Telephone line
- Radio channels
- Electronic documents
- Simple or Interactive CD or DVD ROMs
- Internet based applications
- Simple or Interactive TV
- Mobile Technology

The first e-learning systems used electronic media to deliver educational content to learners; such as computerized documents, educational CD or DVD ROMs, TV

programmes and simple educational websites. In recent years there has been a shift in the mode of computerized education from one-way knowledge feeding to interactive communication between the two parties involved in the educational process. This can be seen in Interactive CDs or DVD-ROMs, Interactive TV and educational websites that keep a profile of the learners and provide two-way communication between the system or educator and the educatee. The Internet is the most powerful medium for this purpose. It provides a variety of communication systems such as e-mail and the web. They are enriched by hyperlinks to other online resources and contain different types of data such as text, audio and video. Mobile computing has expanded the portability of this process from computer side to everywhere.

It can vary from the educational system implemented in an Intranet of a school, university or a company to distance-learning systems developed for the Internet.

The major components of an e-learning system can be considered as:

- Educator: The important issue about the educator is the knowledge about the subject and the knowledge regarding the best methodology for delivery of that knowledge in an educational context.
- Content and material: The main issue surrounding the content is the values that are expected to be delivered.
- Educatee: Important factors concerning the educatee are evaluation of knowledge delivery, its effect on the educatee and their satisfaction with this process
- Communication channel: This aspect of education defines the principles of the mode by which the knowledge can be delivered in terms of media such as text, voice and video, the facilities that these channels can provide in terms of one-way or two-way communication and also synchronous or asynchronous connections.

Based on the results presented in the review of literature chapter, there is a need for an alternative solution to cover the gap between the existing diabetes educational systems and the current requirements. E-learning has a strong potential for this purpose, which is presented below in the form of a SWOT analysis. This method was developed by Albert Humphrey at Stanford University to evaluate the internal and external factors favourable or unfavourable for achieving the objectives (101).

Strength:

1. These systems can potentially facilitate communication between users on a large scale to help them learn from each other and raise the global level of knowledge.
2. The users of the e-learning system can manage their learning schedule on a flexible basis and it does not interfere with their daily life.
3. A larger group of patients can be supervised by a health education coach.
4. This system can facilitate competition between patients to encourage them in gaining benefit from the system.
5. These systems can provide the opportunity for co-operation between healthcare centres.

Weakness:

1. There is considerable need for the experts in both fields of computer science and health to link this potential.
2. For people who do not have access to the Internet or do not have the required knowledge, these systems may not be very useful. By releasing some of the limited resources that are available for patient education, those people may gain more opportunities to use traditional systems.
3. Healthcare professionals need training on how to deliver their education in this system and interact with the patients via computer systems.
4. Simple conversion of educational content to a computerized version is not a good solution for e-learning. For complete utilization of e-learning features,

the educational content must be transformed to different media. These transformations consume time and effort; but starting earlier can bring about a better commencement.

Opportunities:

1. E-learning can gain benefits from the wide coverage of the Internet in the UK (61%).
2. Considering the very busy environment of healthcare, these systems can facilitate communication between healthcare providers and consumers.
3. Recent trends on enrichment of Internet-based applications such as Rich Internet Applications (RIA) have provided good opportunities for these systems to be more interactive and powerful simulating all the potential that exists in desktop-based applications.
4. Especially for the young generation, this is a well known method as they are considered computer-natives and have a good experience in working with Internet-based systems and an e-learning environment.
5. The shift towards a younger age in type 2 of diabetes can place more emphasis on the above requirement (102).
6. There is a good initiative on mobile computing that can extend the accessibility level of these systems.

Threats:

1. The major point of concern with these systems is the risk of unreliable information introduced into them. This issue should be addressed in system design and levels of access to the system; so that these systems can become more reliable than the existing blogs over which there is no control of content validity and which are being referenced by many people.
2. For better communication between the educator and educatee toward a virtual environment, good responsibility of the educators is required for successful operation of the system.

Considering the results from internet-based educations systems and the added values of the RIS solutions discussed in the SWOT analysis, the application of e-learning is feasible for education of adolescents and young people living with diabetes.

- ***Background theories***

User acceptance is a key factor for effective administration of the new technologies. To achieve this purpose, the features of new systems must be compatible with the requirements of their users. These needs are influenced by their values, beliefs and attitudes toward such systems.

Value Theory:

The definition of value is mostly discussed in the field of psychology. Prof. Milton Rokeach from Washington State University in 1973 described the theory of human value as an underlying factor for human attitudes and behaviour (103). Posner and Munson suggested that value describes what individuals consider important (104).

Rokeach described beliefs as “Any simple proposition, conscious or unconscious, inferred from what a person says or does” (103). He classifies beliefs in three categories.

1. Descriptive or external: e.g. diabetes is a chronic disease
2. Evaluative: e.g. the trust of patients in relation to special methods of treatment
3. Prescriptive: e.g. belief in the requirement for new methods of diabetes care

Based on this definition, values in the current diabetes educational system would be enduring principles that learners use to evaluate the importance of this system and its characteristics. High levels of these principles are important factors in adherence to and usage of the system which will play an important role in its long-term effectiveness.

Values are classified in two groups:

1. *Intrinsic (Terminal) values:* are the ones that are appreciated by their holders because of their own importance.
2. *Extrinsic (Instrumental) values:* are the ones that are used as a tool to achieve intrinsic values.

The importance of classification of these values in diabetes education is that so far the terminal values such as gaining a life similar to healthy people are impossible to achieve and the educational systems must work on extrinsic values such as the means of living a life style as close as possible to that of healthy people.

Rokeach believes that the number of values each person has is more limited than the number of attitudes. He suggested that values are the most important criteria used by people to evaluate objects, ideas and actions. He also emphasized the requirement for studying human values to predict their behaviour.

He describes attitudes as a set of beliefs formed mainly by past experience which may alter in different situations or in the passing of time based on the experience that a person gains. The limited effect of diabetes education described in the Return on Investment section can also be explained by his definition of different types of attitudes. Rokeach classified them as attitudes toward an object and the ones toward a situation. Because the objects and objectives of diabetes care do not change during this course of follow-up, we must concentrate more on situational changes. Comparing the duration of patient intensive follow-up which lasts six month in most educational models and the timing of the decrease in efficacy of the education which starts after first year, it shows that the decrease in performance is mostly because of the changes in the situational attitude caused by decrease in rigorous support in the beginning of the trial. This theory shows that measuring the extrinsic values of the people with diabetes in relation to e-learning for diabetes education can be a good tool for defining the requirements for such systems as it would be related to their attitude towards the system.

User Satisfaction:

The other aspect of diabetes education which was considered an important factor in many articles was patient satisfaction.

Patient satisfaction can be considered in two different ways:

1. Satisfaction with their quality of life: which was evaluated in previous researches and valid questionnaires are developed for this purpose. This can be affected by a variety of different confounding factors in a patient's environment.
2. Satisfaction with the education system: this aspect was not evaluated in a systematic way and is one of the items evaluated in this study.

According to IS Effectiveness Theory (105), user satisfaction is one of the important aspects of system effectiveness. There are two main theories about satisfaction of users with information systems:

1. *User Information Satisfaction (UIS):*

   Introduced by Ives et al., UIS was based on psychological research measuring employee satisfaction as the sum of attitudes towards a variety of characteristics affecting the situation (106). The questionnaire had 36 items, each evaluating a pair of value and satisfaction for one aspect of information systems. However, Gatella and Lederer suggested that UIS is not a reliable instrument (107).

2. *End-User Computing Satisfaction (EUCS):*

   Introduced by Doll and Torkzadeh (1988), who tried to go beyond the evaluation of satisfaction with specific applications and developed a more generalized model covering the normal population rather than information system professionals (100). They used a shorter 12-item questionnaire with Likert-type scaling items that covered five important aspects of information systems which are content, accuracy, format, ease of use and timeliness.

Computing was divided to two separate roles in the past:

1. *Primary role:* is the role of the users who use the system output for their decision process
2. *Secondary role:* is the role of the users who contribute in data entry and report generation. This group has more interaction with the system.

It should be mentioned that considering the existing trends in usage of the Internet and Web 2.0 technologies in which users contribute more in content production, there is a trend toward a third group that is involved in both roles as both generator of data and user of the reports from shared generated data. EUCS covers this third role as well.

This model proved to be a useful tool in a comparative study by Sedden and Yip in 1992 (108) which can be used to predict system effectiveness. Continuing the work from Doll and Torkzadeh, Levy performed a comprehensive review of the literature and identified forty-eight characteristics for a general e-learning system (109).

IS Effectiveness:

System effectiveness is evaluated by usage, satisfaction and impact of the system. In this concept the nearest theory to the subject of this study is the theory of Technology Mediated Learning (TML) proposed by Alavi et al (110). She proposed her model based on two previous theories (111):

1. *Media Richness Theory:* Defined by Daft and Legend (112) which suggests that the richer the delivery medium is, the higher the learner's perception of learning, skill enhancement and satisfaction will be.
2. *Time, Interactions and practice Theory:* Proposed by McGarth (113), this theory explains that with longer time dedicated to learning and with more interaction between learners; higher learning, skill enhancement and satisfaction will be achieved.

She also added the effect of emotional climate in the environment of learning to the factors affecting the outcome. Her study showed that collaborative learning via a computer is more efficient than collaborative face-to-face learning. She concluded that three aspects should be considered in educational system effectiveness: learning, satisfaction and skill development. The skill development in this study is measured by the effect of education on the control of the HBA1C level in educatees.

3.1.2- Web 2.0

Web 2.0 is an emerging concept about the evolution of Web as the new platform of communication and collaboration. Considering the TML theory, it can increase the effectiveness of the web platform with both enriched media and increased interaction of the users. This medium can be used to improve many of the short-comings in communication between the providers and consumers of healthcare.

- ***Definition***

The World Wide Web was created in 1989 by Sir Tim Berners-Lee at the European Organization for Nuclear Research (CERN) in Geneva, Switzerland and was published in 1992. The concept of the web was based on hyperlinks which were used by browser application to connect distributed resources across the Internet. The initial web pages were static documents using Hyper-text Mark-up Language (HTML) that included hyperlinks to each other. These pages were produced by web content developers in HTML language and published by web administrators.

After that, the Dynamic HTML (DHTML) standard was introduced in 1993. The added features in DHTML were:

- *Cascading Style Sheet (CSS):* which allowed a more enriched user interface by controlling the format of HTML elements
- *Scripting:* which provided the mechanisms to interpret user actions and produce client-side changes in the page.
- *Document Object Model (DOM):* a platform-neutral and language-neutral interface allowing programs and scripts to dynamically access and update

the content, structure, and style of documents. The introduction of the DOM allowed the content of the database systems as back-end to be published on the web and the input of the users to be stored in the back-end database.

As previously mentioned, the initial websites were developed and managed by a specific group of people but were available for the public to “Read”. This is the reason that in defining generations of the web, some scholars describes the main feature of Web 1.0 as “Read”. During this period, the main activity on the web space was providing content and facilitating hyperlinks by web authors.

At the end of this generation of the web, a requirement gradually rose to increase the content of information on the web by increasing the creativity, sharing and collaboration of users via the web as a two-way communication channel. This generation was described as Web 2.0; the main feature of which was described as “Read-Write”. The background idea for this concept dates as far back as the 1960s and JCR Licklider’s thoughts on using networked computing to connect people in order to boost their knowledge and their ability to learn (114).

The future generation of the web technology, called Web 3.0, involves transforming the web into a huge database, including artificial intelligence in the web, Service Oriented Web, Semantic Web and 3D graphics. The main feature described in this generation is the Executable Abstraction Layer which permits users to publish user contributed code; converting user functions to “Read-Write-Execute”.

The concept of "Web 2.0" began with a conference brainstorming session between O'Reilly and MediaLive International and was proposed by Dale Dougherty the “Memo Map” of which is presented in Figure 3.1.

The general components of Web 2.0 concepts from the perspective of Tim O’Reilly are as follows (115):

1. The Web As Platform
2. Harnessing Collective Intelligence
3. Data is the Next Intel Inside

4. End of the Software Release Cycle
5. Lightweight Programming Models
6. Software Above the Level of a Single Device
7. Rich User Experiences

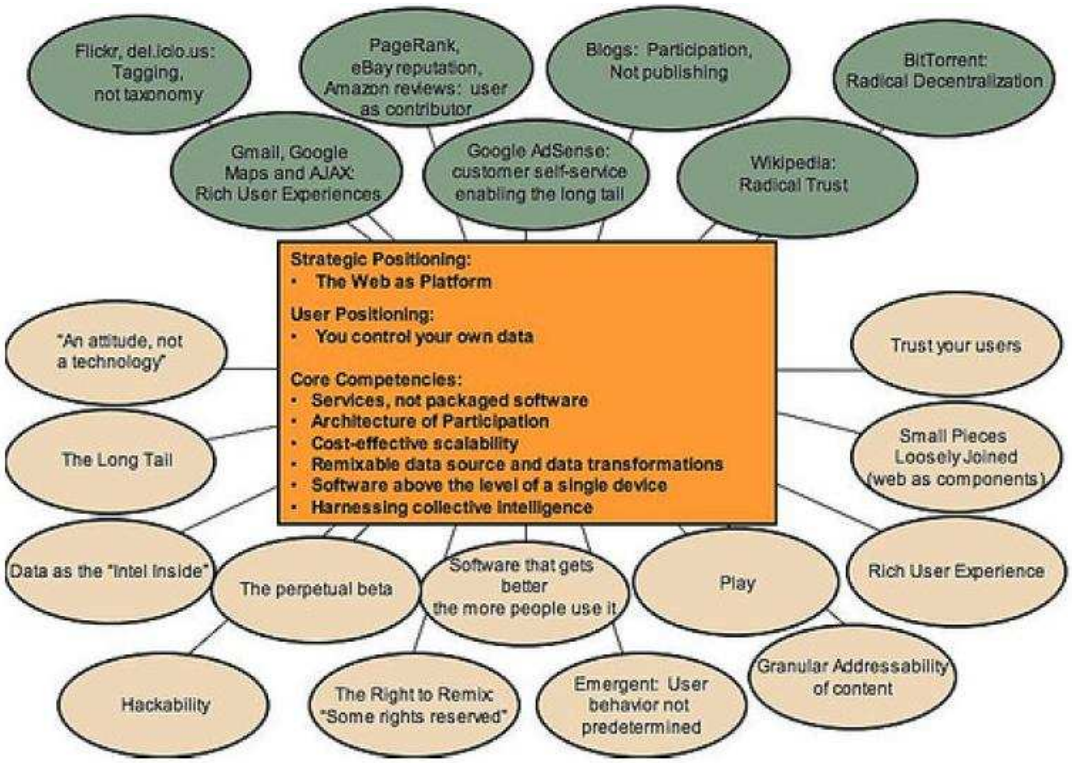

Figure 3.1: Web 2.0 Memo Map

Troy Angrignon defines Web 2.0 as a group of economically, socially, and technologically driven changes in attitudes, tools, and applications that are allowing the web to become the next platform for communication, collaboration, community, and cumulative learning (116).

- ***Web 2.0 technologies***

There are several heterogeneous but familiar technologies that are associated with this new trend in the web.

1. *Blogs*

   Proposed first by Jorn Barger (1997), these are websites with regular

comments, descriptions of different events and other material such as images and videos. The entries are mostly displayed in reverse chronological order. Yochi Benkler defines blogs as a weighted conversation between a primary author and secondary comment contributors, communicating to an unlimited number of readers (117). Each post is tagged and the reader can navigate to similar posts based on these tags.

There are three types of links in blogs:

a. *Permalink:* This is a unique persistent link to a post generated by blogging system.

b. *Trackback:* When enabled can generate a link between two posts on two different blogs that has a cross comment.

c. *Blogroll:* This is a list of other blogs found useful by the owner of a particular blog and are published as a favourite list.

2. *Wikis:*

A Wiki is a single or set of web pages that are easily edited by anyone who is allowed to access them (118). They are streams of conversation, revision, amendment, and truncation. In wikis users edit a single content not commenting on it like blogs. Also they have two more options which are history and rollback. History provides access to a previous version for each entry and rollback enables the user to undo changes that are made to each entry and enable a previous version for that item.

3. *Tagging:*

A tag is a keyword considered for any digital content such as a web page (Del.icio.us by Joshua Schachter, http://delicious.com), a picture (Flickr, http://flickr.com), video (YouTube, http://youtube.com) or a sound (Odeo, http://odeo.com). In contrast to traditional subject indexing, metadata are generated not only by experts but also by creators and consumers of the content. Usually, freely chosen keywords are used instead of a controlled

vocabulary. Folksonomy is the collection of the tags generated by individuals for their personal use. Although it increases the flexibility; open tagging can have four main problems. These problems are plurals, polysemy, synonymy, and depth (specificity) of tagging.

- *Plurals* and parts of speech and spelling can undermine a tagging system. For example, if tags Cat and Cats are distinct, then a query for one will not retrieve both, unless the intelligent search system has the capability to perform such replacements built into it.

- *Polysemy* refers to a word that has two or more similar meanings like hospital which means activity or place for lodging guests and has another meaning as place for treating the ill.

- *Synonymy* means different words with similar or identical meanings. This presents a greater problem for tagging systems because inconsistency among the terms used in tagging can make it very difficult for a searcher to be sure that all the relevant items have been found.

- *Depth (specificity) of tagging* means how specific should the user (classifier) be in translating a concept into tag(s)? Web resources can be tagged to varying levels of specificity, from very broad subjects taken only from the title and abstract to the paragraph level. The number of tags related to a web resource in the system defines the depth of tags.

4. *Multimedia Sharing:*

This sharing is used for different kind of media such as pictures, video and sound. Low cost digital media technologies and expansion of storage capacities have helped this service to grow exponentially.

5. *Podcasting:*

   Podcasting uses audio technologies such as mp3 sound format to store and share sound files as an on-demand service. The introduction of the portable devices such as iPod by Apple helped the growth of this service. Recently this technology has merged with video-on-demand service named vidcasting or vodcasting. Podcasts are announced via RSS feeds to subscribers so that they can be informed about the new files available.

6. *RSS:*

   RSS stands for Really Simple Syndication. It produces XML-based data that websites use to exchange their update information. The latest version of this system is RSS 2.0. It is used in blogs and podcasts for announcement of their updates. The new generation of the RSS feeds is called Atom which is an http-based protocol, developed under an open source model from Internet Engineering Task Force and supports content encoding.

7. *Mash-ups:*

   Mash-ups are the new generation of web portals as web applications that integrate data from different resources. The difference between these two technologies lies in XML content, ability to perform the process both on client-side and server-side, different models of data aggregation and ability to integrate with RSS feeds. Mash-ups are classified in three forms:

   a. *Consumer Mash-ups:* are focused on the presentation of the gathered data from different resources in a single interface to user. The use of Google Maps in cartographic data representation is a good example of this.

   b. *Data Mash-ups:* are focused on the collection of similar data from different resources. Yahoo Pipes is a good example in this group.

   c. *Business Mash-ups:* This type is the combination of the two above types.

3.1.3- Health 2.0

Web 2.0 technologies have attracted very great attention in healthcare. This high level of interest has resulted in new definitions such as Health 2.0 or Medicine 2.0. They have been considered as powerful tools to revolutionize the healthcare systems in HealthCamp 2006 and a semi-annual conference has being held on this topic since 2007 (119).

The traditional definition of Health 2.0 is mostly focused on the technological aspect of it as Matthew Host describes it as "The use of social software and light-weight tools to promote collaboration between patients, their caregivers, medical professionals and other stakeholders in health". He expanded this definition in 2008 to four dimensions as follows:

1. "Personalized search that looks into the long tail, but cares about the user experience
2. Communities that capture the accumulated knowledge of patients, caregivers and clinicians; and explain it to the world
3. Intelligent tools for content delivery and transactions
4. "Better integration of data with content; all with the result of patients increasingly guiding their own health" (119)

Dr. Ted Eytan defines Health 2.0 as "Health 2.0 is participatory healthcare. Enabled by information, software and community that we collect or create, we the patients can be effective partners in our own health, and we the people can participate in reshaping the health system itself." (119).

Dr. Eysenbach adds scientific and research aspects for the definition of Medicine 2.0 as "Medicine 2.0 applications, services and tools are web-based services for health care consumers, caregivers, patients, health professionals and biomedical researchers that use Web 2.0 technologies as well as semantic web and virtual reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration and openness within and between these user groups."(120).

Apomediation is defined as "A new scholarly socio-technological term that characterizes the process of disintermediation (intermediaries are middlemen or "gatekeepers", e.g. health professionals giving relevant information to a patient, and disintermediation means to bypass them), whereby the former intermediaries are functionally replaced by apomediaries, i.e. network/group/collaborative filtering processes. The difference between an intermediary and an apomediary is that an intermediary stands in between (latin: inter- means "in between") the consumer and information/service, i.e. is absolutely necessary to get a specific information/service. In contrast, apomediation means that there are agents which stand by (latin: apo- means separate, detached, away from) to guide a consumer to high quality information/services/experiences, without being a prerequisite to obtain that information/service in the first place." (120)

Van De Belt et al. (121) conducted a systematic review about different definitions of Health 2.0 and Medicine 2.0. This review revealed the following seven topics linked to Health 2.0.

1. *Patient empowerment:* in most of the definitions from patient federations Health 2.0 was considered as a tool to empower patients via increasing their participation in healthcare process.

   Some of websites in this category are:

   - T1 Kids from JDRF (www.t1kids.org.uk)
   - Online Blood Sugar Tracking (www.sugarstats.com)
   - Ask a Doctor Online Now (health.justanswer.com)

2. *Web 2.0 / Technology:* In this group the technical issues around Health 2.0 was considered as the main point. This linkage was mostly presented among ICT professionals working in the health sector.

   Good examples include:

   - Health 2.0 Accelerator (h2anetwork.org)
   - Health 2.0 Organisation (health20.org)
   - New York Healthcare Technology Organization (nyhto.org)

3. *Professional empowerment:* Health 2.0 was considered an important tool for collaborative learning among students and graduates in different courses of health sciences such as medicine, dentistry and nursing.

   Some examples are:

   - Tiro Med (www.tiromed.com)
   - Ask Dr Wiki (www.askdrwiki.com)
   - DocCheck (www.doccheck.com)

4. *Social Networking:* social interaction among patients and professionals was another dimension of Health 2.0 identified in this review. Transparency and openness was a special point of interest in this concept.

   Some of the good examples in this group are:

   - TUDiabetes (www.tudiabetes.org)
   - MDJunction (www.mdjunction.com)
   - NHS Choice Blogs (talk.nhs.uk)

5. *Collaboration:* By using these new tools, healthcare professionals can collaborate from different geographical locations. Many of the tele-medical services can help to provide specialist services in deprived areas. The richness of this new medium can increase the efficacy of these services.

   Following are some examples in this group:

   - BMJ Rapid Response (www.bmj.com/cgi/eletters?lookup=by_date&days=1)
   - Grunt Doctor (gruntdoc.com)
   - Eye on DNA (www.eyeondna.com)

6. *Change in healthcare:* Some of the healthcare theoreticians aim to use these new tools for a big reform in healthcare. They hope to use this new trend for more involving the patients in the care process.

   Some of the examples in this group are:

   - Online Health Advice on Patient UK (www.patient.co.uk)
   - Patient Opinion (www.patientopinion.org.uk)
   - NHS Choice (www.nhs.uk)

7. *Health information and knowledge:* The last topic related medical information sources and libraries to these emerging technologies. They can increase the availability of user-owned resources via open-access knowledge sharing.

   This concept is not limited to published knowledge. It can encompass the open access to anonymised health data that can be mashed-up for large scale inter-organizational data analysis and produce medical knowledge in a way that was not possible before.

   Some examples are:

   - Map of Medicine (healthguides.mapofmedicine.com/choices/map/)
   - NHS Choice Videos (www.nhs.uk/Video/Pages/medialibrary.aspx)
   - NIH Videocasting and Podcasting (videocast.nih.gov)

3.1.4- Application of Web 2.0 for the diabetes education

Although some of the studies discussed in the systematic review had a certain level of interactivity between the participants such as chat-rooms in the papers by McKay et al. (34, 36), Barrera et al. (35), Shea et al. (37, 41), Tate (29), Liebreich (27) and Mulvaney (43), those services were a parallel facility to the main education provided by the system. The effect of those services on the outcome of the intervention was not evaluated. The other issue in those studies was lack of utilization of external resources available on the Internet. These resources were only provided in the studies by Tate et al. (29), Glasgow et al. (30) and Liebreich (27). Web 2.0 applications have three important features that empower them to be useful for diabetes education. These features are:

1. *Collaboration and Interactivity:* This concept increases the level of access for users to enrich the educational content on the web and for this reason it is considered a “Read-Write” version of web in contrast to the previous systems in which users were only allowed to “Read” the content provided by webmasters and web content providers. This feature changes the users to contributors of the system content. Because of the requirement for special medical knowledge, this contribution cannot be extended to the medical

content for the patients, but according to the Value - Satisfaction model patients can contribute in the way the data are presented in the system via training the system with their clinical data and value judgments. Also the medical certified members, termed "Health e-Coach" can interact with the patients in this system and help them with their education. This platform can use the channel of communication with users to collect the information required for developing a model of the perceived effectiveness in computerized diabetes education.

2. *Rich Internet Application (RIA):* The "Web as a platform" concept of Web 2.0 will allow for building a framework for users to interact more with the system, gives them the ability to have their own personalized interface, upload their own data and receive personalized education based on their requirements and preferences.

3. *Competition for Improvement:* One of the main concepts in this model is to provide an environment for the users to compete against each other in relation to contribution to the system and improvement of their health status. This is the trend that has been used in many of the Internet based computer games and social networks and has attracted many adolescents.

Adolescents with diabetes are a specific group of diabetic patients with special conditions and requirements who need more attention to help them prevent future high costly complications. Because of the high incidence of this disease, the trend of type 2 toward younger people and higher life expectancy of this group, their cost of diabetes care increases significantly. A collaborative Internet-based e-learning system may be a suitable solution for problems in this specific group.

Currently two other major studies are available on using Web 2.0 for diabetes education. The first study is a study conducted at Linköping University in Sweden available via the DiabIT website (www.diabit.se). The second study is a social network developed in USA with worldwide members named TUDiabetes (tudiabetes.org). Members of this network recently started a campaign to submit

their HbA1C regularly for further analysis. Timpka et al. (59) and Ekberg et al. (98) from the DiabIT study have published two papers about designing a Web 2.0-based system for chronic disease management in children and adolescents. They have included education modules in those systems with special interest in providing free-text discussions between members, cross referencing between information resources, user-profiling and providing information to users based on their health profile.

They described functional and non-functional design elements of these systems. They used podcasting, weblog and wiki services in their model. They classified their system into three main modules:

- Patient empowerment
- Family empowerment
- Disease-specific clinical services

Also the provision of interoperability with electronic health records is considered in their system.

In this PhD study, a web-based system was developed based on the Web 2.0 model and the outcome of this system on the knowledge transfer, satisfaction with the system and clinical improvement was evaluated.

3. 2 - System Design and Specifications

The software for this study was initially designed in UML 2.0 to provide a complete prospect of the capabilities of the system. Because of using Web 2.0 technologies in this system and the important role of the users in it, UML 2.0 is a very good design environment because its Use Case diagrams can provide a complete perspective of the interactions between users and the system.

3. 3 - System development

The software was developed on Dot Net framework as an ASP.Net web application. The reason for choosing this platform as the programming language was the

flexibilities that this platform provides for RIS programming and the familiarity and experience of the principal investigator with it.

The version of the framework used for the system was version 2.0.50727. The reason for selecting this version was its personalization and role management capabilities and the Asynchronous Javascript And XML (AJAX) extensions that are developed for client-side programming in this version. The back-end database was developed in Microsoft SQL Server 2005.

3. 4 - System validation

- *Internal validity:* Straub defines internal validity as the probability of the observed effects being caused by or correlated with a set of non-hypothesized or unmeasured variables (122). All the possible corresponding factors from the literature were included in the system evaluation. Also the value survey was designed as a semi-structured survey to let the users be able to add other items.

- *External validity:* Cook and Campbell define external validity as the level at which the results of a study can be generalized (123). They believe that two types of generalization exist. The first one is generalization to a particular target of persons, settings and time and the second across particular persons, settings and time. The initial aim of this study is the first option to the same age group but there would be some suggestions for future research concerning the second group for external validity.

- *Instrument validation:* Straub defines instrument validation in two parts (122):

    1. *Content validity:* In this study the content of the e-learning system is built on the requirements proposed by NICE. Also to increase the content validity of the questionnaire, this study tries to use the most valid resources from previous researches on designing information systems evaluation instruments.

2. *Construct validity:* High validity in this section is shown by correlation between the items measuring the same concept. Kerlinger and Lee proposed testing the linear correlation between the results from item score with the overall group score to which that item belongs (124).

- *Instrument reliability:* Straub defines reliability as measurement of system accuracy (122). This feature will be measured by a Cronbach's α test. Overall high correlation between the questionnaire items will show the reliability of this tool. Also because this evaluation is based on a self-administered procedure, it will not be at risk of interviewer bias. The users complete their forms directly; so the risk of operator bias in data entry is eliminated as well (125).

3. 5 - Data collection

Data collection will be performed via online forms and monitoring the data about utilisation of the system. The HbA1C data will be collected by the principal investigator from the clinical record of the participants to ensure its reliability.

3. 6 - Research Questions

The research questions of this study are as follows:

1. What is the potential impact of the web-based diabetes education?
2. Is there any demographic difference between the adolescent and young people interested in online diabetes education with the ones who are not interested?
3. How much is the importance level of different characteristics of the web-based collaborative diabetes education system for the adolescents and young people living with diabetes and for the healthcare professionals?
4. How much is the level of satisfaction with the developed prototype regarding the system characteristics of the diabetes web-based education?

5. Is there any relationship between the level of contributing to the system and rating the educational content with their clinical improvement?
6. How much is the perceived effectiveness of the system characteristics of diabetes web-based education in the developed prototype?

3. 7 - Methodology for evaluation

Based on the suggestion from Keeney and Raiffa (126), the development of the model for evaluation of information systems consists of three phases: review of literature, primary model development based on the review and checking the validity of the developed model. Because of the clinical nature of this study, another step is added to that model to evaluate the clinical outcome of the patients for measuring the effectiveness of the e-learning evaluation (see Figure 3.2).

1. In the first phase, the initial model was developed using the review of the literature and other resources available.

2. In the second phase, the developed model is checked qualitatively. In this phase the users' opinion about the values of each aspect of the system was measured. To collect the data required for this section, a web-based semi-structured survey was conducted. The level of importance of items was compared between patients and healthcare professionals. Also the initial clinical state of the users about the quality of their life will be evaluated.

3. In the third phase the validity of this model was quantitatively checked. In a Web 2.0 environment most of these modifications are controlled via interaction of the users with the system and their usage level of personalization features. At the end of this phase, user satisfaction level with the system characteristics was measured. In this phase, the collected data were analyzed to identify and exclude any irregularities such as outliers. These results will be used in analysis of the effectiveness of the Web 2.0-based diabetes education using a value-satisfaction grid.

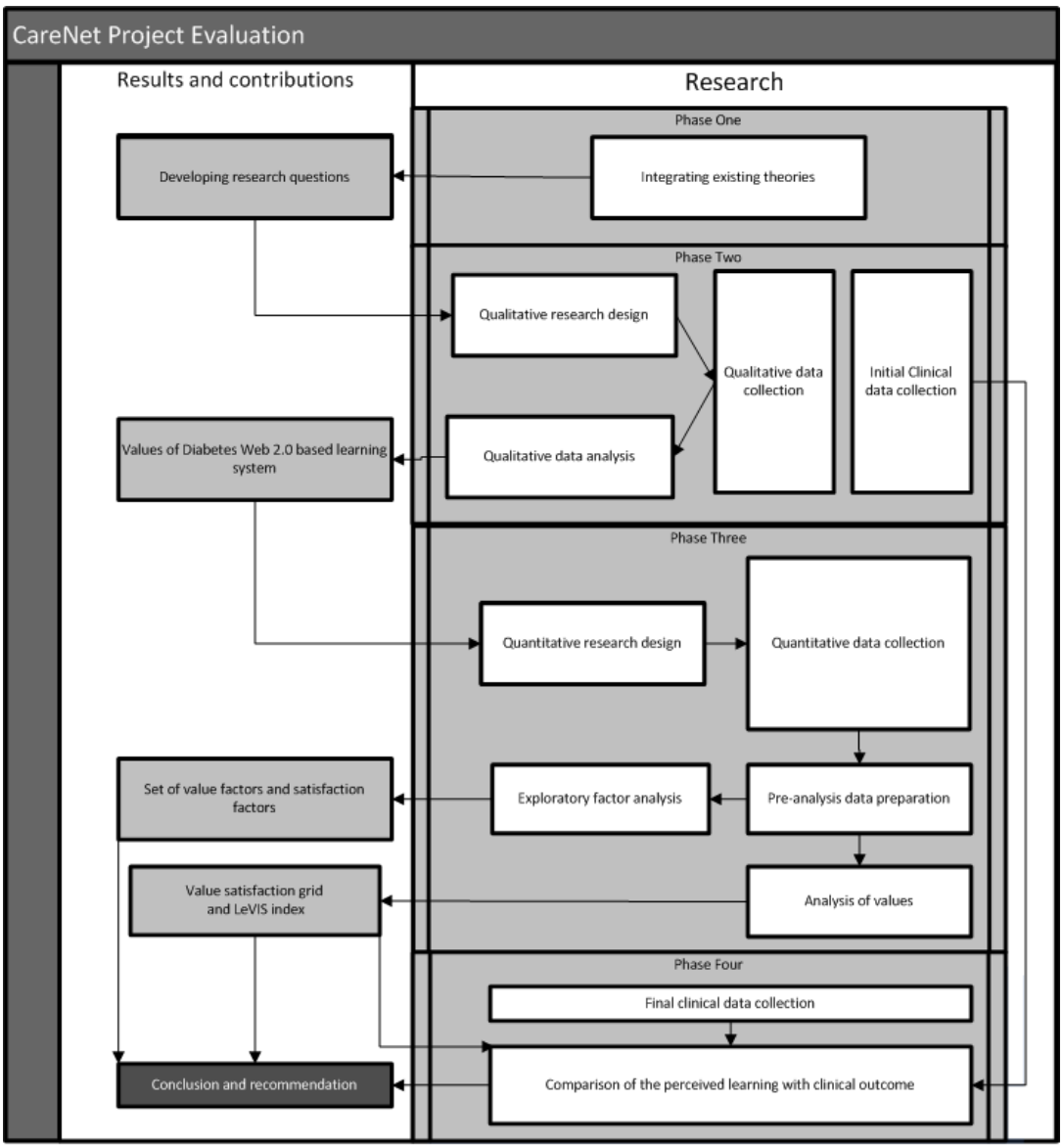

Figure 3.2: CareNet evaluation process cross-functional flow chart

4. In the last phase a pre-test/post-test analysis was performed to evaluate system effectiveness with the clinical outcome of the patients.

There are two methods for measuring the values: ranking and rating. Ng (127) showed that rating the values is better than ranking them. His explanations for this were based on the possibility of the same level of preference on two values, problems with factor analysis, regression or any other multivariate analysis of the ranked data and the distance between the levels which can be better presented in rating.

3.7.1- Qualitative evaluation

In this phase the values of the system were compared using the answers from participants and healthcare professionals. These values were measured using an online survey tool integrated into the CareNet website. Some of the items in the list of values produced by Levy were related to parallel face-to-face education in academic education (128). This list of values was compared to diabetes e-learning and thirty three compatible items were selected for the CareNet study. Webster and Hackley classified these characteristics in four dimensions (129). A variable was added to each dimension for the overall value of each dimension. Following are the value items that are considered in this study:

1) *Content*

C1 - Availability of educational content

C2 - Amount of material in the site

C3 - Interesting subject matter

C4 - Difficulty of subject matter

C5 - Availability of other content (objectives assignment)

C6 - Enjoyment from the education

C7 - Quality of the content in the system

C8 - Ease of use

C9 - Similarity of interface across the system

C10 - Gathering information quickly

C11 - Organization of the system

CO - Overall view about the content of system

2) *Human Coach*

H1 - Amount of coach –learner interaction

H2 - Amount of learning from coach

H3 - Quality of coach-learner interaction

H4 - Freedom of learning

HO - Overall view about the coach of system

3) *Learner*

L1 - Amount of learning from the system

L2 - Amount of interaction with other learners

L3 - Comfort with online learning and technology

L4 - Internet and computer skills

L5 - Self-discipline and time management

L6 - Reduced travel cost and time cost

L7 - Family support

LO - Overall view about the learner in system

4) *Technical and support:*

T1 - Quick answer from technical support by e-mail

T2 - Quality of technical support

T3 - System operation time (up-time)

T4 - Reduced system errors

T5 - System security

T6 - Accessibility of the content

T7 - High network ability and low Internet traffic

T8 - Learning flexibility

T9 - Different system tools

T10 - Access of all courses from one area (Dashboard)

T11 - Taking quizzes remotely

TO - Overall view about the technical support of system

After granting access to each user, they were asked about their perceived level of importance for each system characteristic and if they had any additional suggestions.

Based on the results from this part, the final model of system effectiveness was built. Also in this phase the initial HbA1C level of the participants was measured.

3.7.2- Quantitative evaluation

The quantitative phase of this study was conducted by monitoring the system usage. Data about their interaction with the system were gathered. Users were offered the option to propose external links for each section and these links were made available for other users after checking their relevancy and accuracy by the principal investigator. Other users were asked to rate these approved external links. This system used star-based rating for these modules.

For each education topic the users were proposed an initial test to evaluate their basic level of knowledge. After finishing the section they were offered another test for measuring their uptake level. They could also see their level of knowledge and progress in comparison to other users to augment the competition.

3.7.3- Final evaluation

In the final section the clinical data and satisfaction level of users were measured. This data were compared to corresponding initial data gathered to evaluate their relation with the amount of learning.

3. 8 - Collaborating centres

This research was designed as a multi-centre study. Three NHS trusts were considered as potential collaborating Participant Identification Centres (PICs) for this study. The collaborating trusts and their collaborating consultants were:

1. Mayday Healthcare NHS Trust
    - Dr Richard Savine (Adult Diabetologist)

- Dr Susanna Hart (Paediatric Diabetologist)

2. Barnet and Chase Farm Hospitals NHS Trust
    - Dr Sabina Russell (Adult Diabetologist)
    - Dr Vaseem Hakeem (Paediatric Diabetologist)
    - Dr Chris Baynes (Adult Diabetologist)
3. Birmingham East and North Primary Care Trust (BEN PCT) PAK Health Centre
    - Dr Waqar Malik (Adult Diabetologist)

Initial meetings with the consultants in each site were held and the process of recruiting patients and their follow-up was arranged. The participating consultants agreed to introduce potential patients to the principal investigator. In each centre one of the diabetes specialist nurses was appointed as the contact point for providing the HbA1C level of the participants at the time of recruitment and after a follow-up period.

Also required arrangements were put in place to facilitate the attendance of the principal investigator in the related clinics to talk with potential participants and answer the questions that they might have.

3. 9 - Summary

This PhD study is designed as a pre-test / post-test evaluation for clinical effectiveness and knowledge transfer of a website for collaborative diabetes education, with an initial survey measuring the importance level of different system characteristics and final survey for measuring the level of satisfaction with those characteristics.

Chapter 4 System Development

In this chapter the process of design, developing the CareNet website and the Web 2.0 technologies used in this study is explained. Also the result of the usability testing on the developed website is presented.

4. 1 - Platform

Microsoft Visual Studio platform was chosen for development of this study. The reasons for this choice were:

1. The integration features of this platform provided with operating system, database and application layer
2. The powerful programming environment for web application programming (ASP.Net)
3. Microsoft is the most commonly used platform in the NHS which will give us the opportunity for future compatibility in the NHS environment if they consider using this system.
4. Previous experience of the principal investigator with this platform

City University has a licence agreement for using Microsoft systems for education and research purpose as part of Microsoft Developers Network Academic Alliance (MSDNAA) which provided the licensing requirements for this application.

This study is developed as a multi-tier web-based application so that the system could be accessible to the research participant via the Internet.

The website is hosted on one of the City University servers for using the security and data backup services provided by the University.

4. 2 - Operating System

The website is hosted on Microsoft Windows Server 2003 with Service Pack 2 and Microsoft IIS Server.

This server has two network interfaces:

1. Intranet interface: is only accessible from inside the university network and all the controlling and management interfaces of the website are only accessible from this interface to increase the security of the system.
2. Internet interface: is accessible from any computer linked to the Internet and serves the web application to the research participants.

4. 3 - Database System

The database of this study was developed on Microsoft SQL Server 2005 service pack 3. This choice was because of compatibility and integration with the development environment (Microsoft .Net) and the powerful programming features for functions and stored procedures to provide the fast system response required in Web 2.0-based systems.

4. 4 - Web Development

The web project was developed in Microsoft Visual Studio .Net 2005 using ASP.Net 2.0.50727 and Visual Basic.Net 2.0 programming language.

Also Microsoft AJAX 1.0.20229 library was used for development of the user interface. This library can provide partial post-backs to the server which will increase the system performance.

NPlot 0.9.10.0 (http://www.nplot.com/), an open-source charting library, was used in the project. This library can produce charts which can demonstrate fine fluctuations such as changes in blood glucose data. The charts in this library had the required properties for adding backgrounds to show the normal range of tests. Also this library produces the charts on-the-fly (memory-based) rather than caching them on the server's hard disk which will increase the performance of the system.

This project was developed in code-behind mode. This mode allows separation of the behaviour logic from the web interface. This separation helps the programmer with more organized code and also increases the performance of the developed website. The developed project was compiled using the built-in Microsoft complier to maximize the system performance.

4. 5 - Web 2.0 technologies used in CareNet

In the initial meetings with healthcare professionals in the collaborating hospitals, they expressed their concern about the risk of wrong advice between the participants in this study and mentioned that they would agree to collaborate in this study if this risk was prevented in the system. Recruitment of the participants

from the healthcare systems could provide us with chance for recruiting more participants; because this study was tailored for a specific age group. This requirement resulted in some limitations in technologies used in this study. Blogs and Wikis were excluded from this phase of the study, because they were based on free-text collaboration. Instead of standard RSS technology a mail generator engine was developed in the system to inform the participants about the updates in the website.

The technologies used in the CareNet and their applications were as follows:

1. *Resource sharing*

   The educational items in the system were provided to the participants by the links to validated resources on the Internet. The participants had the option to propose other resources that they had found useful. Those links were planned to be checked by the principal investigator and be shared with other users after ensuring their relevancy and correctness.

2. *Tagging:*

   An abstract ontology of diabetes education was developed in the system to give the users the option to tag the resources that they are proposing. Those tags were linked with education topics in the system to relate the proposed resources with them.

3. *Multimedia Sharing:*

   A list of selected videos from YouTube was included in the system. These videos were randomly presented to participants whenever they logged in to the system.

4. *Information sharing:*

   The participants had the option to delegate to other users a read-only access to their clinical information.

Also users had the option to rate the resources provided to them using a star-based rating module. The average of the previous ratings for each external resource was presented to them in each educational topic.

5. *Mash-ups:*

   The system had a dashboard home page which was used to give the summary of their activity in the system. One of the gadgets in this dashboard was designed to show the users their rank in the system compared to other users. This rank included the amount of learning, contribution to the system and clinical improvement.

A logo was designed for the CareNet study to reflect the concept of this system.

This logo, as shown in Figure 4.1, consists of two main parts:

- The blue part is a symbol for a person living with diabetes whose head is similar to the sign for World diabetes day and the Rod of Asclepius (the god of medicine and healing in ancient Greek religion) in the body of the patient showing their responsibility for their own care in this system.
- The green part represents the care managers which surrounds the patient to show their supporting role. This part is presented in green which reflects well-being.

Figure 4.1: CareNet Logo

4. 6 - CareNet features

CareNet consisted of different tools and services to provide the participants with the opportunity to utilize them and for the principal investigator to analyse their preferences and amount of usage.

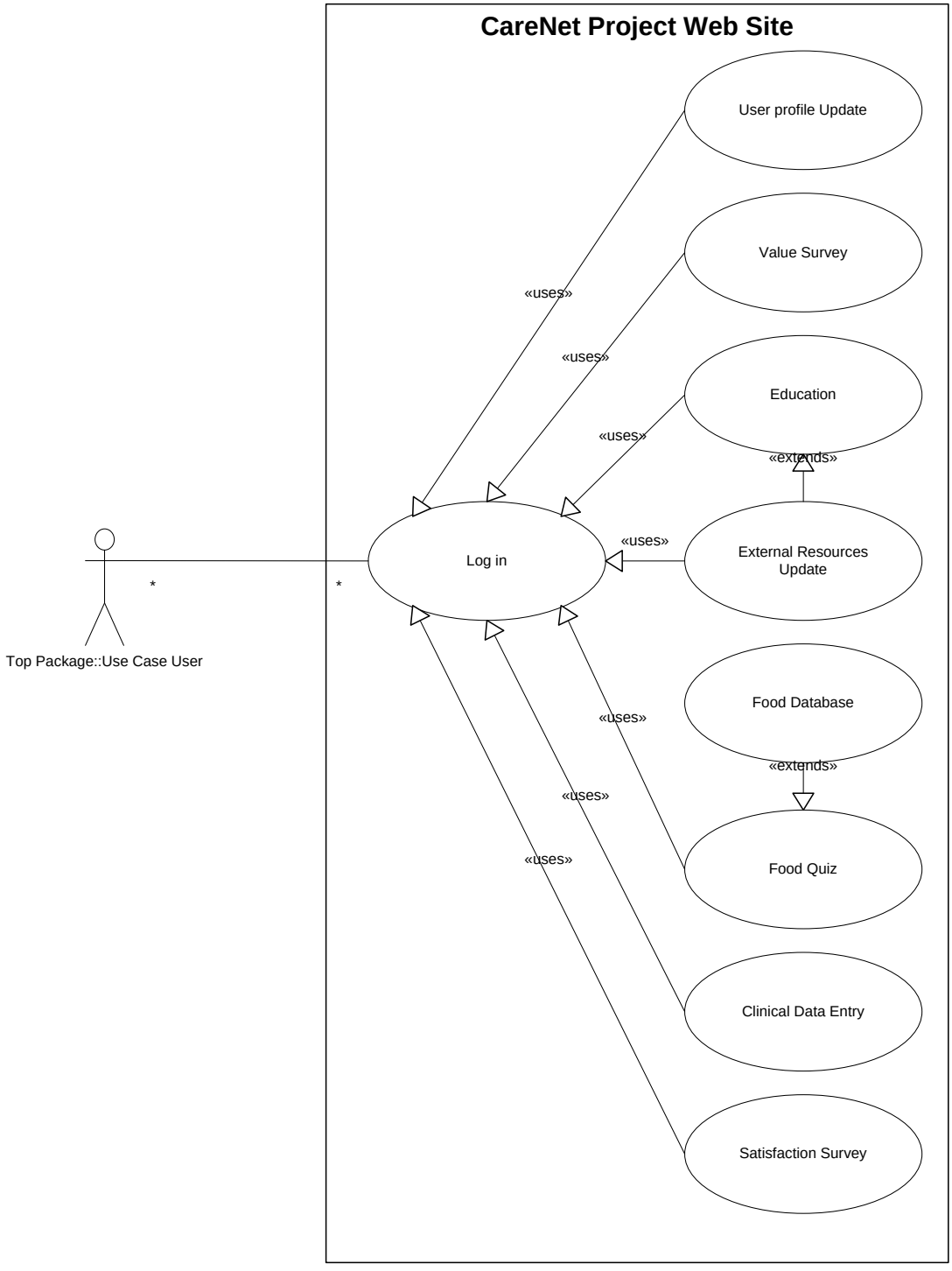

Figure 4.2: CareNet use case diagram

The modules developed for the CareNet study are linked to each other as shown in Figure 4.2. The authorization to all modules in the CareNet study is controlled by the login module. External resources are used in educational courses and food information in food database is used to build food quizzes.

4.6.1- Security

CareNet uses form-based security. The authentication process in the CareNet website is based on a username and password. The login page is depicted in Figure 4.3.

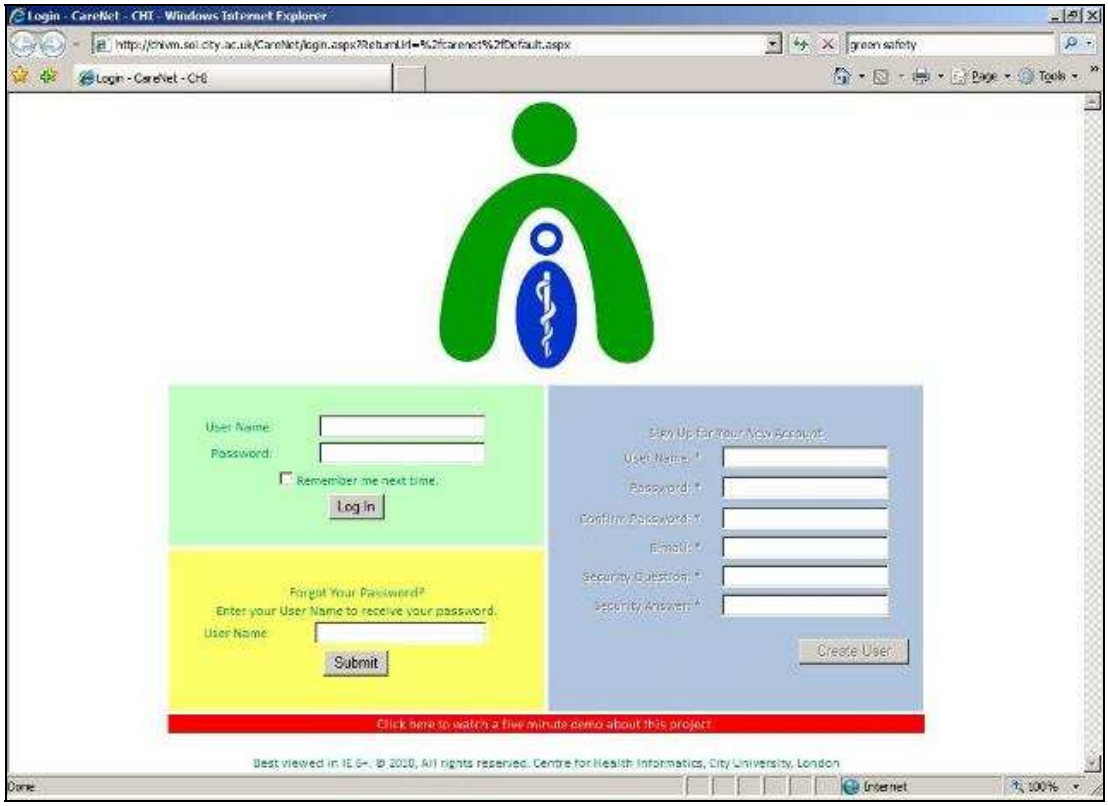

Figure 4.3: CareNet Login page

This information was emailed to participants after signing the consent from in clinics. The authentication information is stored in the back-end database in an encrypted table. Invalid attempts to login to the system are recorded and in case of three consecutive invalid attempts the account is locked by the system. The authorization process is shown in Figure 4.4.

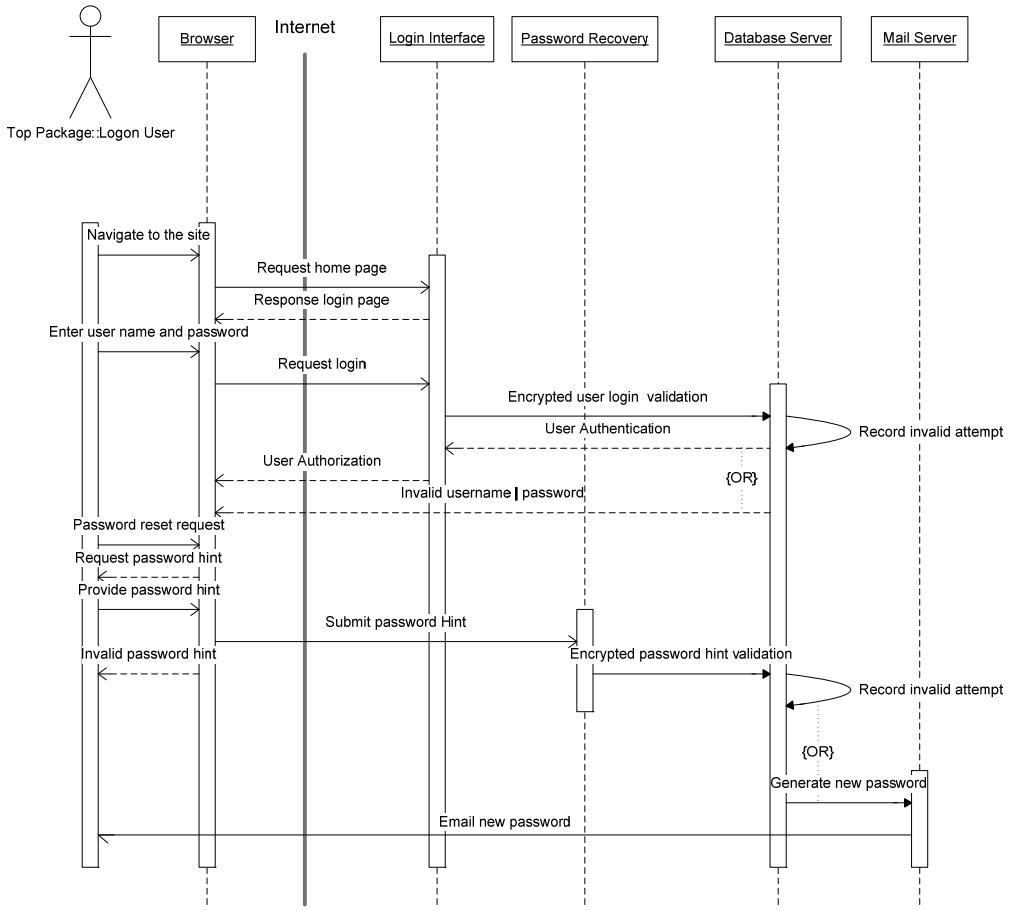

Figure 4.4: Sequence diagram for CareNet authentication process

If the password is lost, the participant can request a new password by providing a secret number which was included in the welcome email. The system will email them a new password using their email address which was used to register them in the system.

4.6.2- Navigation panel

This is an ASP.Net accordion panel located on the left side of all CareNet pages, which allows the participants to navigate between different sections of the CareNet (see Figure 4.5). It has four main sections including education, clinical data, evaluation and system. It also has a link to the homepage and log off button for increased security while using public computers.

Figure 4.5: CareNet navigation panel

4.6.3- Dashboard page

This is the default page that users see after logging into the CareNet website, as depicted in Figure 4.6. In this page they can see a summary of their activities in the system. Also a collection of diabetes related videos from YouTube are linked to the system. One of these videos is randomly shown each time a user browses this page.

The dashboard page uses ASP.Net web-part technology which allows the participants to customize it according to their own preference.

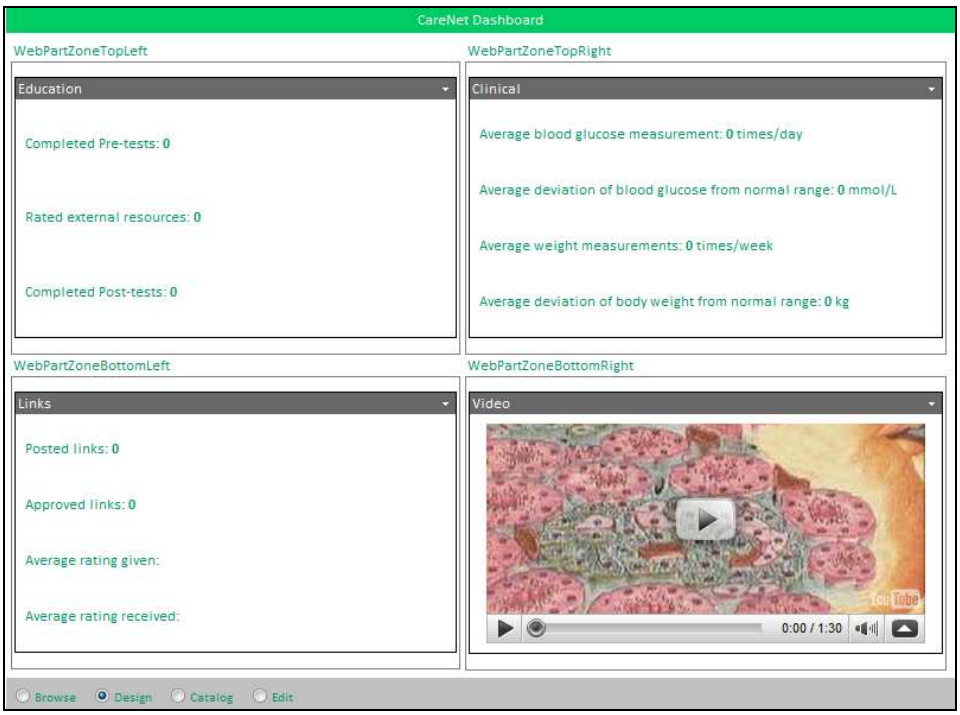

Figure 4.6: CareNet dashboard

4.6.4- Education panel

This panel, shown in Figure 4.7, provides the links to educational topics for diabetes proposed by Diabetes UK. Each topic is linked to pre-test, course material and post-test.

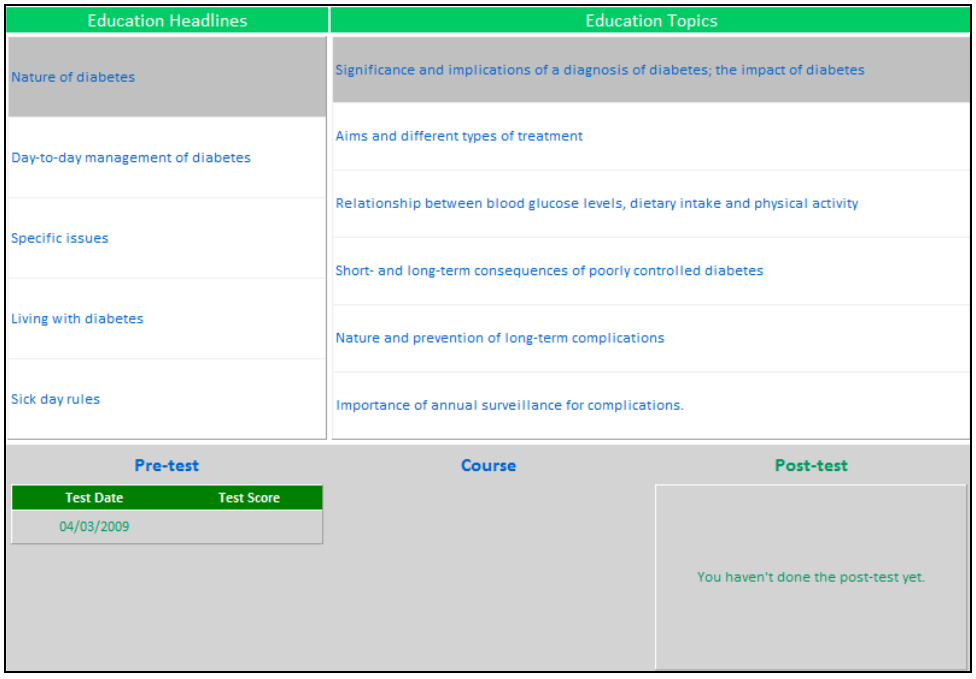

Figure 4.7: CareNet education panel

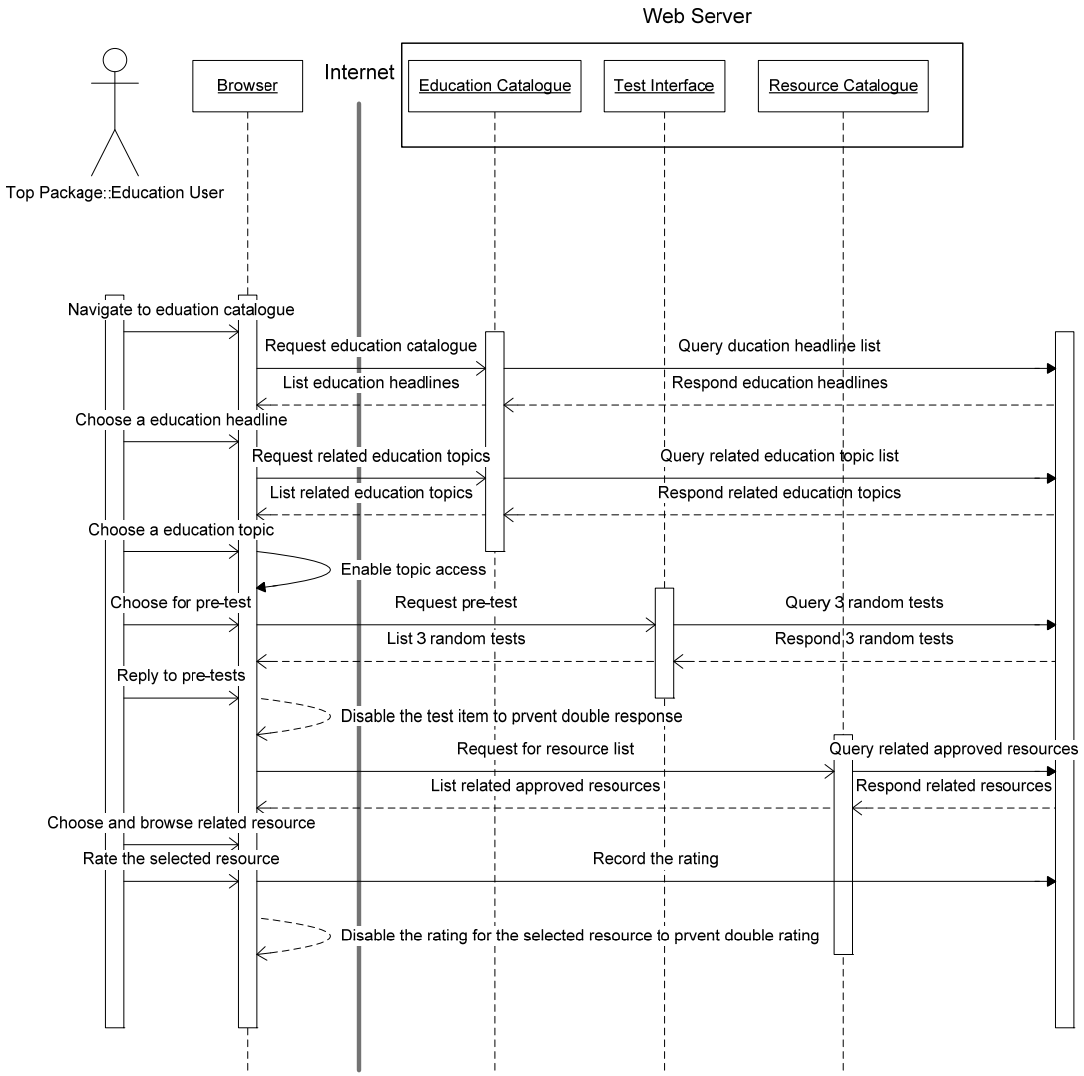

Figure 4.8: Sequence diagram for using education section of CareNet

To use the education module, as indicated in Figure 4.8, the participant is asked to select an education headline first. Then the user should select an education topic. This selection enables a link to the pre-test section for that topic. After navigating to the pre-test page, answering to all questions on that page and saving the finalized answers, the participant is automatically redirected to the course for that topic. In the course section the participant is offered a few useful links to the information about that topic. The participant is asked to click on the link which will open that resource in a new page. After reading the information in that external resource the participant is asked to rate the level of usefulness for that resource using a star-

based rating system. At least one rating is required to obtain access to the post-test section.

4.6.5- My external resources

In this part users can add the link to any resource on the Internet that they found useful. The schema is shown in Figure 4.9.

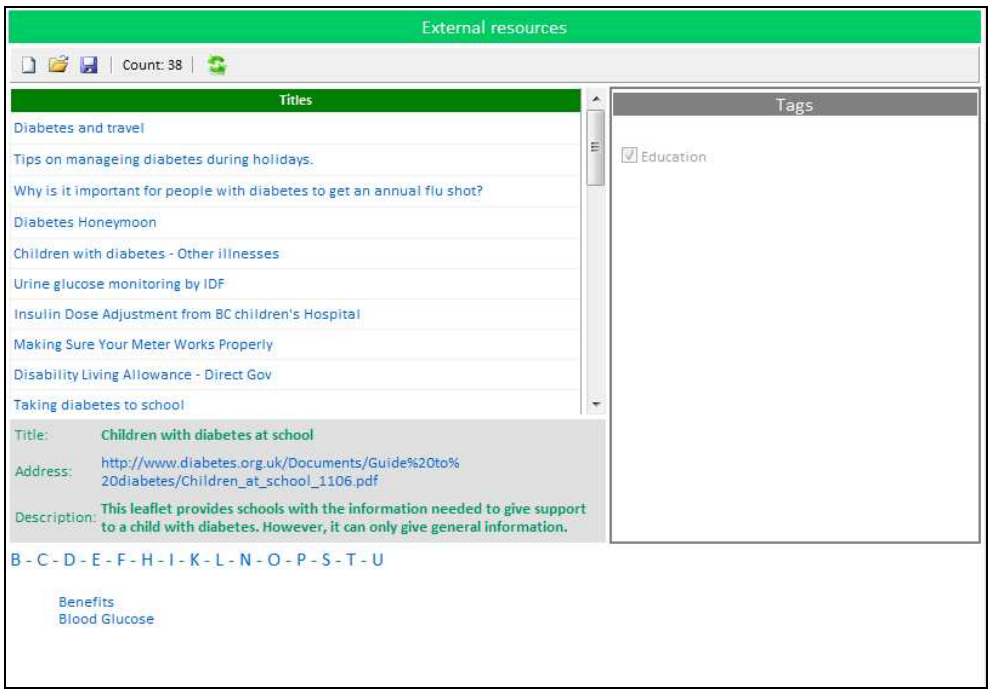

Figure 4.9: CareNet external resources

The process of contribution to external resources, as seen in Figure 4.10, starts with showing a list of external resources previously proposed by the user. The user has the option to add new resources to this list and tag them using diabetes-related tags available in the system. The system administrator (principal investigator) will check the proposed resources. If they are relevant and useful, they will be approved by the system administrator. This approval will authorize that link to appear in the education section.

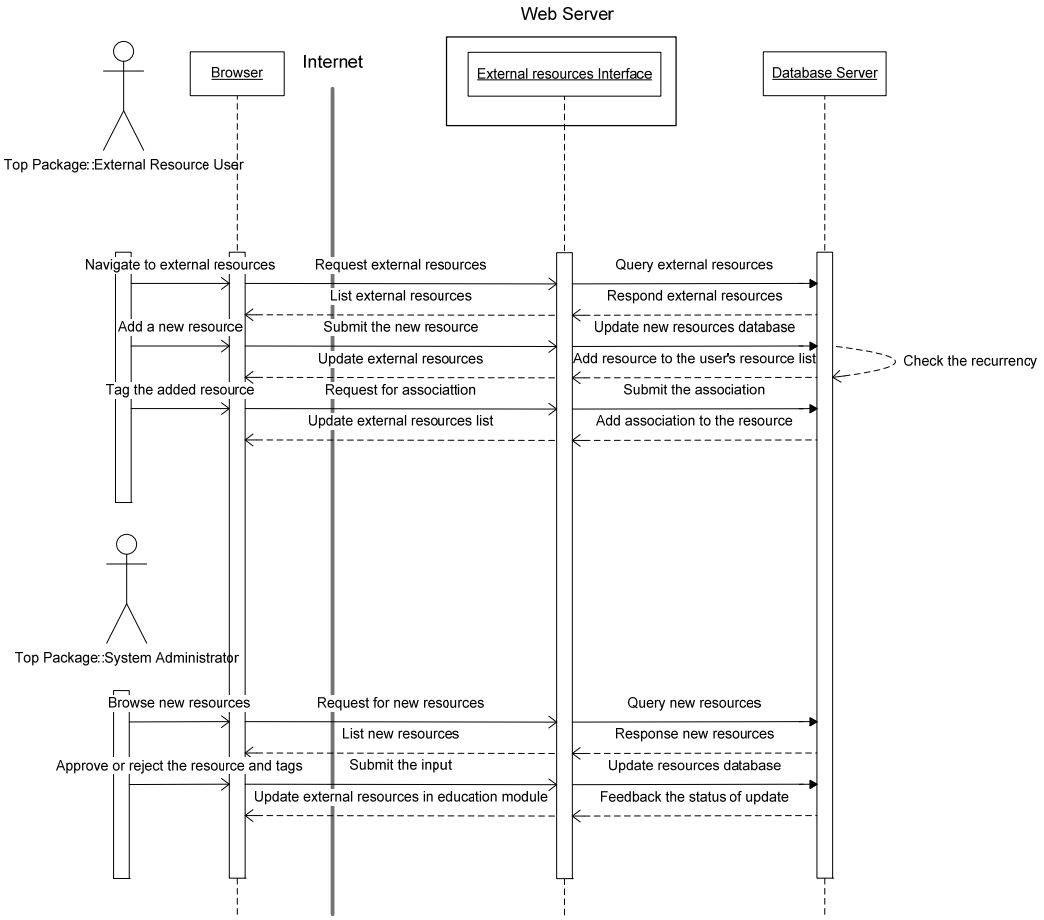

Figure 4.10: Sequence diagram for using external resources section of CareNet

4.6.6- Food quiz

Deciding the ingredients and amount of food for each meal is an important requirement to control the calorie intake for both types of diabetes. The food database in this section is populated from a National Nutrient Database for Standard Reference provided by the United States Department of Agriculture (USDA) (130). This database included the name and nutritional information (including carbohydrate content) of 6210 nutrients. An Extract, Transform and Load (ETL) package was developed by the principal investigator to integrate the data from this database, shown in Figure 4.11, into the CareNet database.

Figure 4.11: CareNet food database

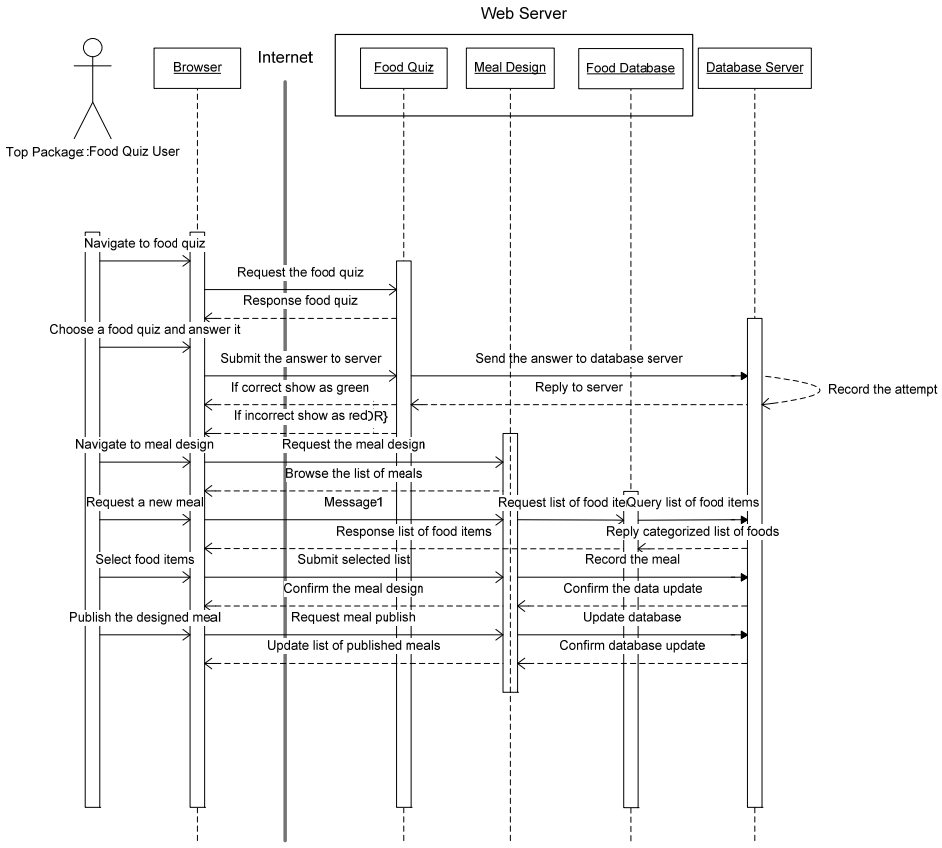

Figure 4.12: Sequence diagram for using the food section of CareNet

Participants have the option to design meal quizzes using these nutrients and share it with others. Other users can calculate the amount of carbohydrate content of these meals. The system shows the result of these calculations using a colour-coded feedback which tells them whether their answer as correct or incorrect. In case of incorrect answer the system will tell them whether their answer was below or above the correct answer. A schema for using the food section of the CareNet is depicted in Figure 4.12.

4.6.7- Clinical Data

This section has links to pages for different clinical parameters related to diabetes control, as shown in Figure 4.13.

- *Blood glucose:* People with type 1 DM normally measure their blood glucose several times a day. The frequency is lower in type two diabetics but it is very important for them as well. Using this section, participants can record their measurements and view them in a graphical representation which shows them the extent of their compliance with the acceptable range.
- *HbA1C:* This is a clinical measure which shows the level of blood glucose control over the past four months. In this part, users can record and see the chart presenting their measurement on this test (see Figure 4.14).
- *BMI:* Body Mass Index (BMI) is a measure to determine the level of obesity in people. BMI is calculated using the following formula:

$$BMI = \frac{Weight\ (kg)}{Height\ (m)^2}$$

  In this part users can record their height and weight and the system will automatically calculate their BMI.
- *Insulin Injection:* Injecting insulin is the main part of treatment for all type 1 diabetics and some type 2 patients. The amount of insulin injection is dependent on the calorie intake, level of physical activity and sensitivity to insulin. It should be fine tuned to prevent hypo or hyperglycaemic episodes (clinical manifestation of blood glucose going below or above the normal limit). In this section participants can record their insulin injections.

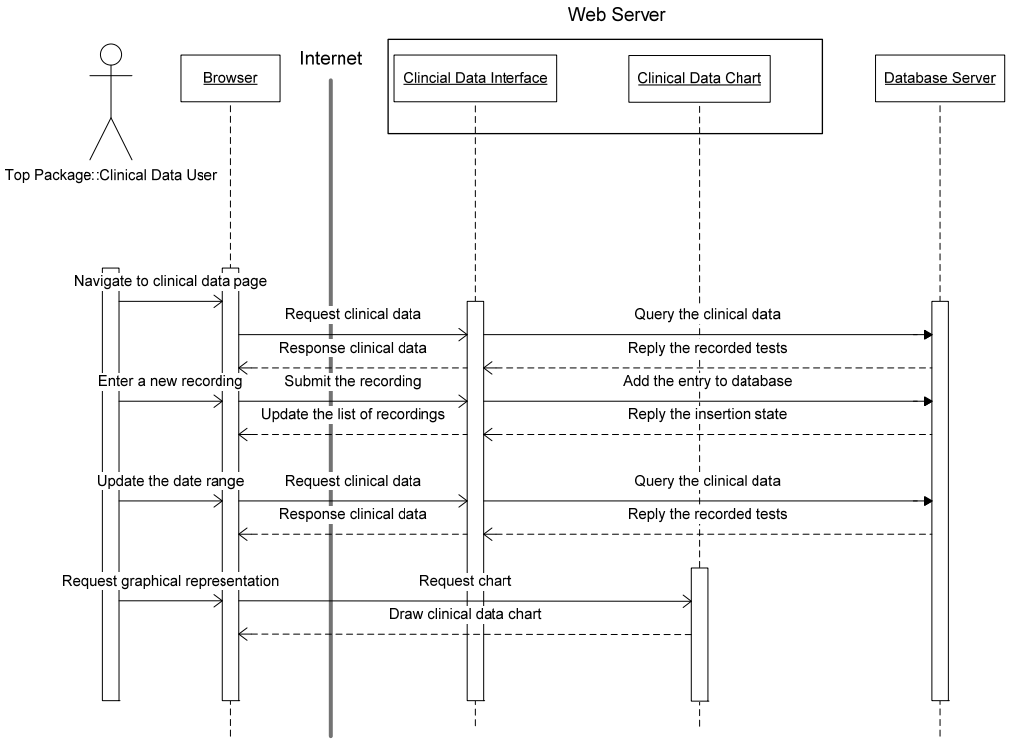

Figure 4.13: Sequence diagram for using the clinical data section of CareNet

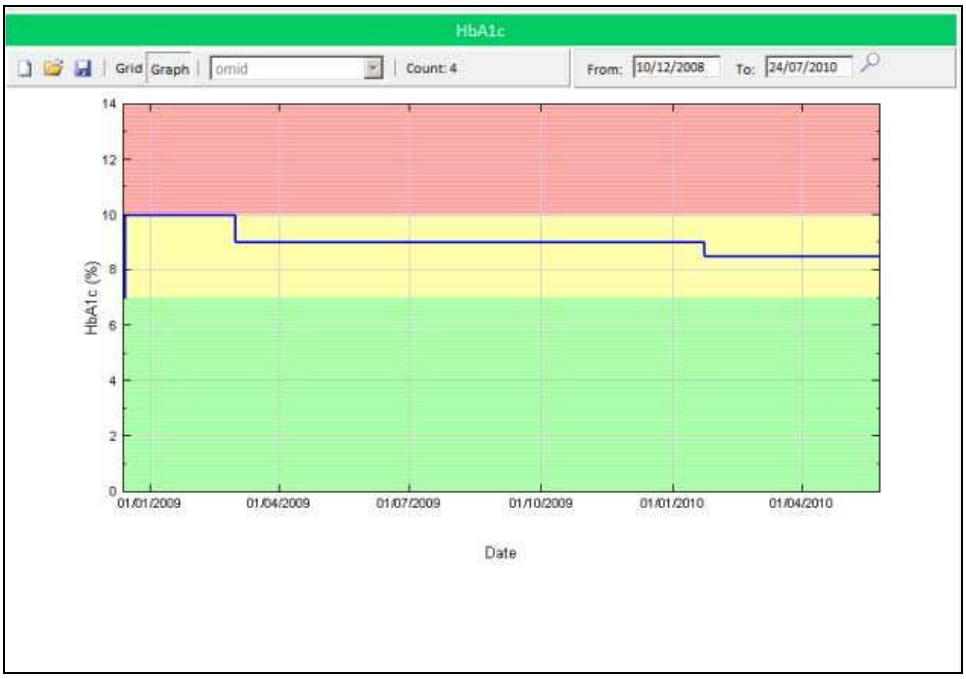

Figure 4.14: CareNet HbA1C chart

The system will provide them with a graphical representation of their clinical measurements. These graphs show them whether or not their test results are within the normal range. The time window for showing the data and graphs is

changeable to give them the opportunity to see their results in either a broad or narrow range of time.

Data validation procedures were developed for these modules. If the date of the measurement is outside the possible scope (six months before the recruitment date for HbA1C and current date for BG and BMI) or a date in the future, the system will not accept the entry and mark the incorrect fields in red. Also if the user enters a new value in these sections and tried to navigate away from that page before saving the data, the system will show a pop-up warning message asking the user to save their entry before they go to another page. People with type 1 diabetes normally have a diary to record each measurement of BG level and respective dose of injected insulin. To make the CareNet similar to that model and facilitate data entry, the dashboard page contains a section to record the same parameters in one place. The system will record each item in its related tables in the back-end database.

4.6.8- Evaluation

In this section participants have access to the surveys for second and fourth phases of the study. The survey tool is shown in Figure 4.15.

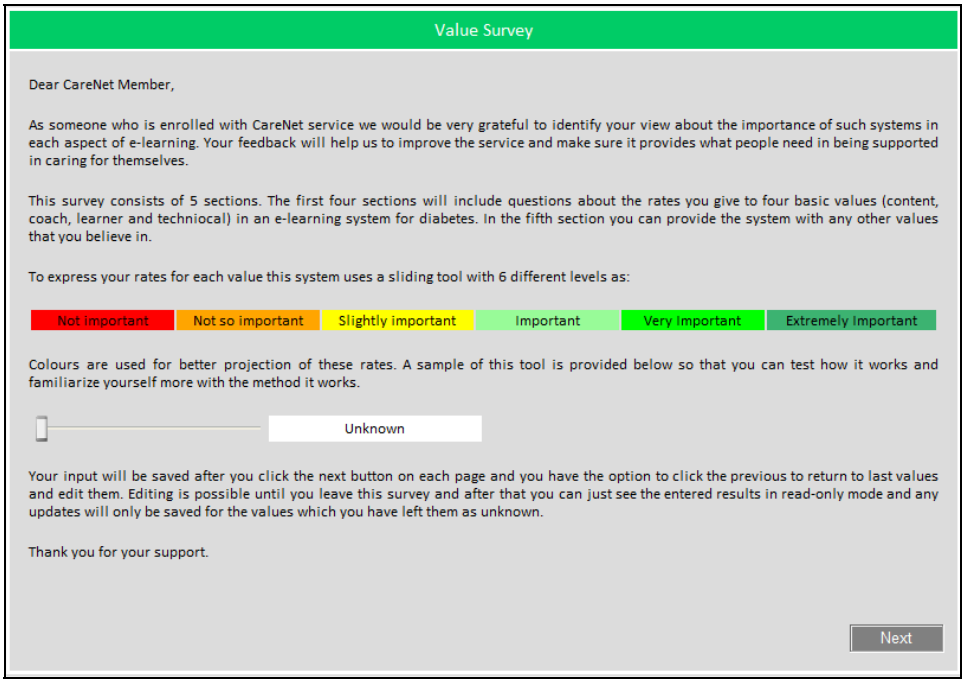

Figure 4.15: CareNet survey tool

In the survey for the second phase the users were asked about their expected values of each characteristic of a system for electronic diabetes education. The survey in relation to the fourth phase was developed to measure the user's satisfaction with each of those values.

The questions from the value survey are divided into multiple parts for faster loading and easier responding. After finishing each section the system automatically records the responses before going to next section. The sequence diagram for using the value survey in the CareNet is shown in Figure 4.16.

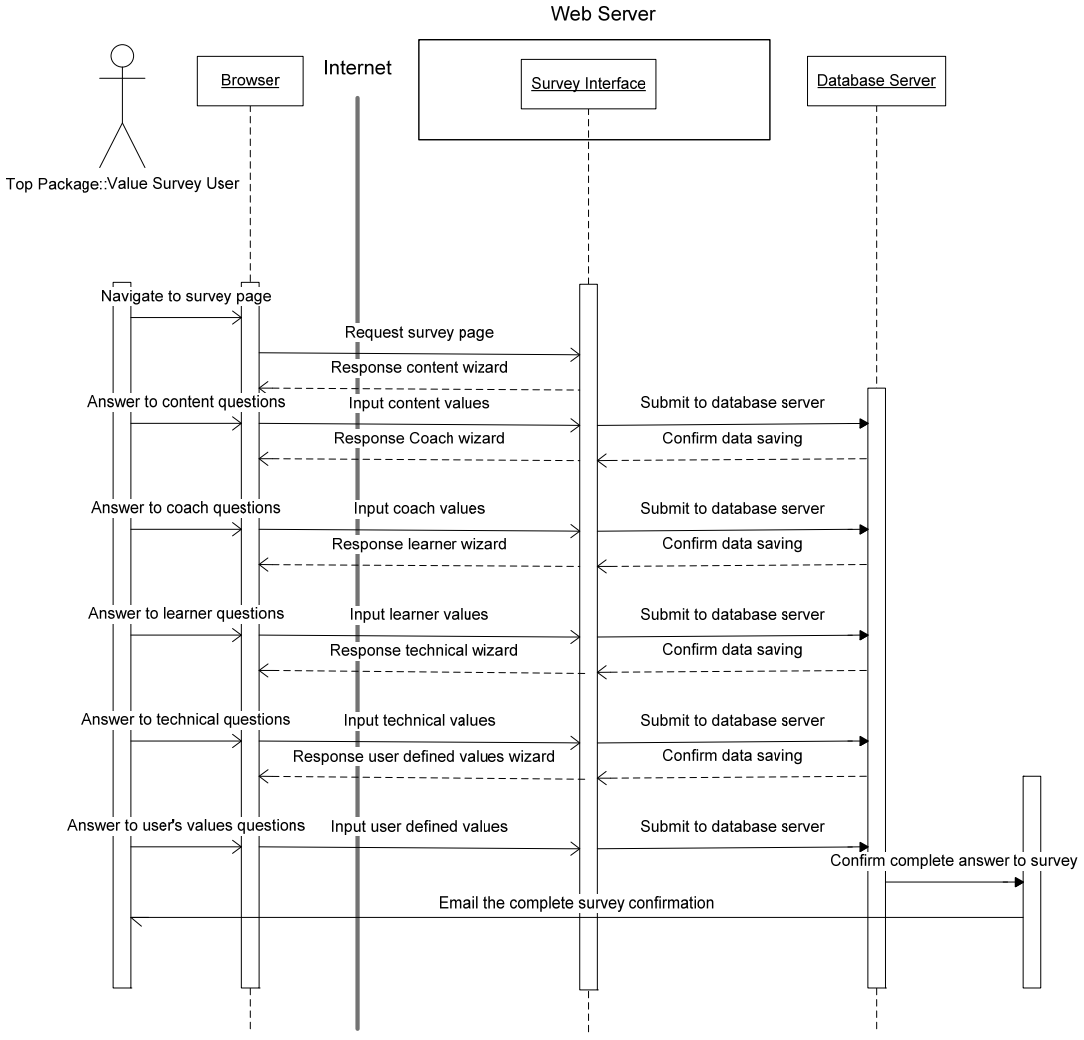

Figure 4.16: Sequence diagram for using the value survey in CareNet

To prevent the risk of leaving the answer to the default choice, the initial answer is marked as "Unknown". Users have the option to change their answer only in the

case where they had left it as unknown. Changing the previously answered items is disabled. The system is designed to inform the users about completion of the survey. AJAX technology with a traffic-light colour schema and labels is used for rapid response to the users about their selected level of importance. An ASP.Net user control was developed for this functionality. Users are presented with Likert-type options and they can simply answer each item by sliding the indicator to the level that they consider appropriate.

This questionnaire was designed as a semi-structured survey. Users have the option to add other items to it after they finished the predefined value items.

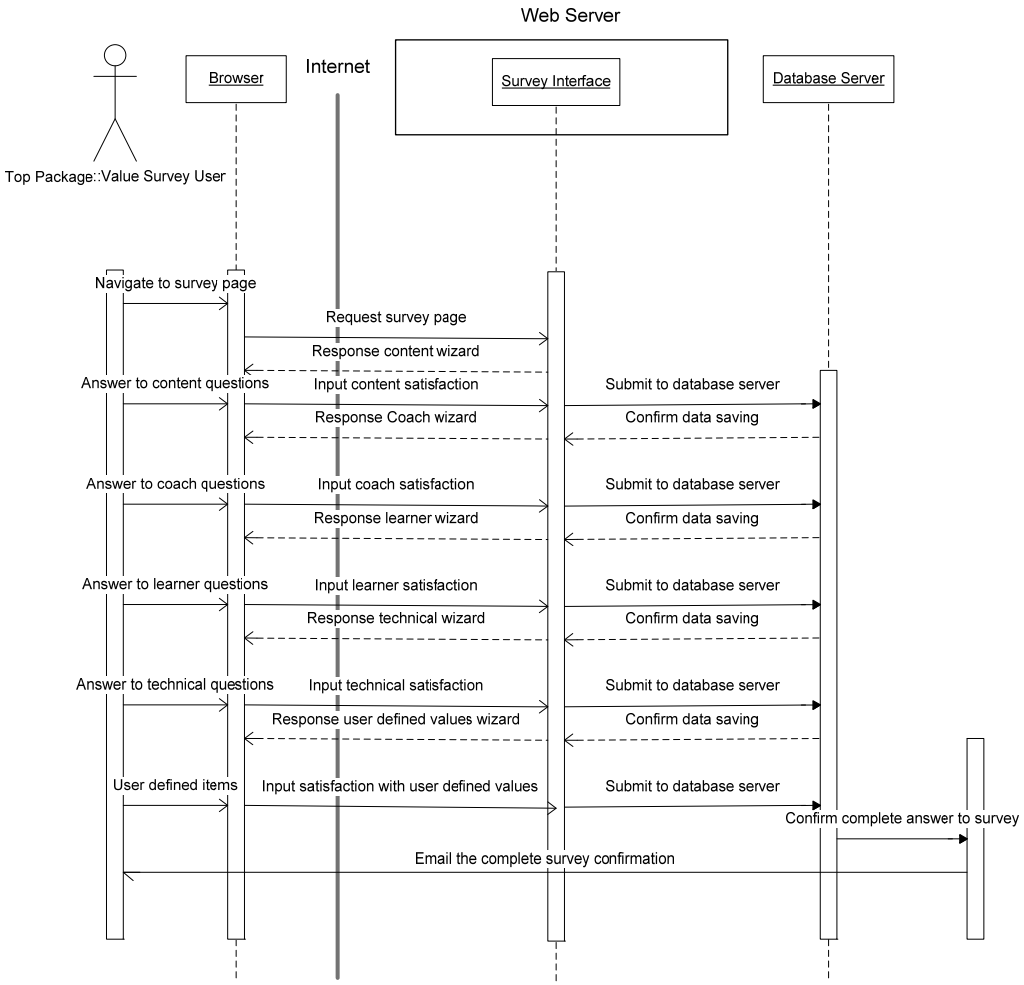

Figure 4.17: Sequence diagram for using the satisfaction survey in the CareNet

Answering to satisfaction questionnaire (see Figure 4.17) is similar to the value questionnaire. Similar user control was used in this section with labels appropriate to the satisfaction questionnaire.

4.6.9- System

In this section users have access to their profile, and the vocabularies used in tagging the external resources. These vocabularies are represented in a tree structure format showing their parent-child relativity.

In the profile page users can customize the appearance of the program interface. These changes will be stored in the system and next time the user connects to the system, the selected appearance will be used.

Each user can see a list of delegated permissions given or received from other users to see each other's clinical data and can modify or rate these delegations. Also a utility to change the password was provided in this section (see Figure 4.18).

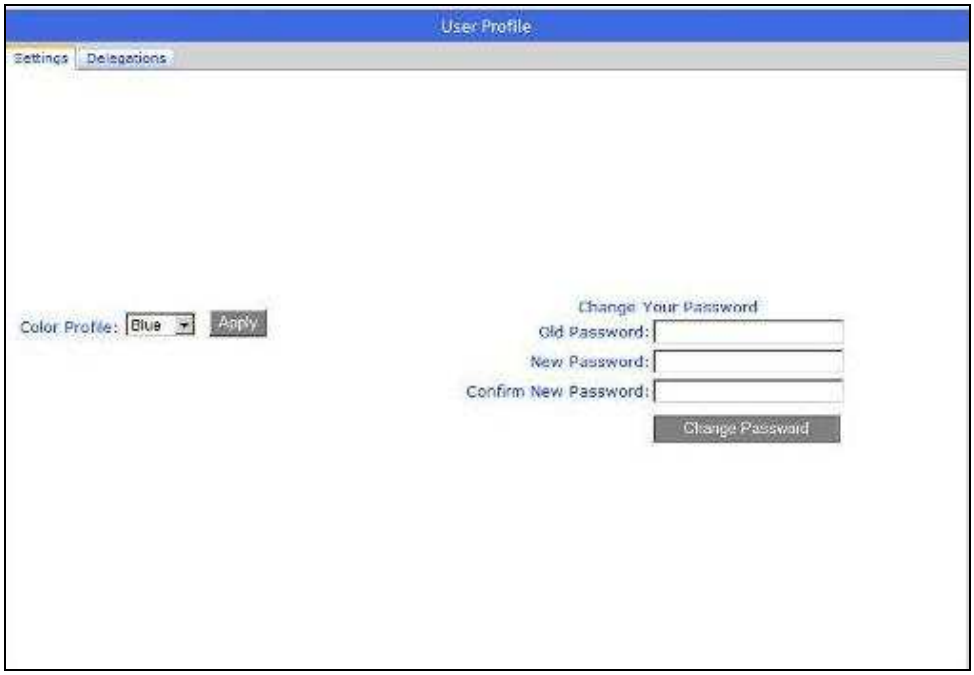

Figure 4.18: CareNet profile page

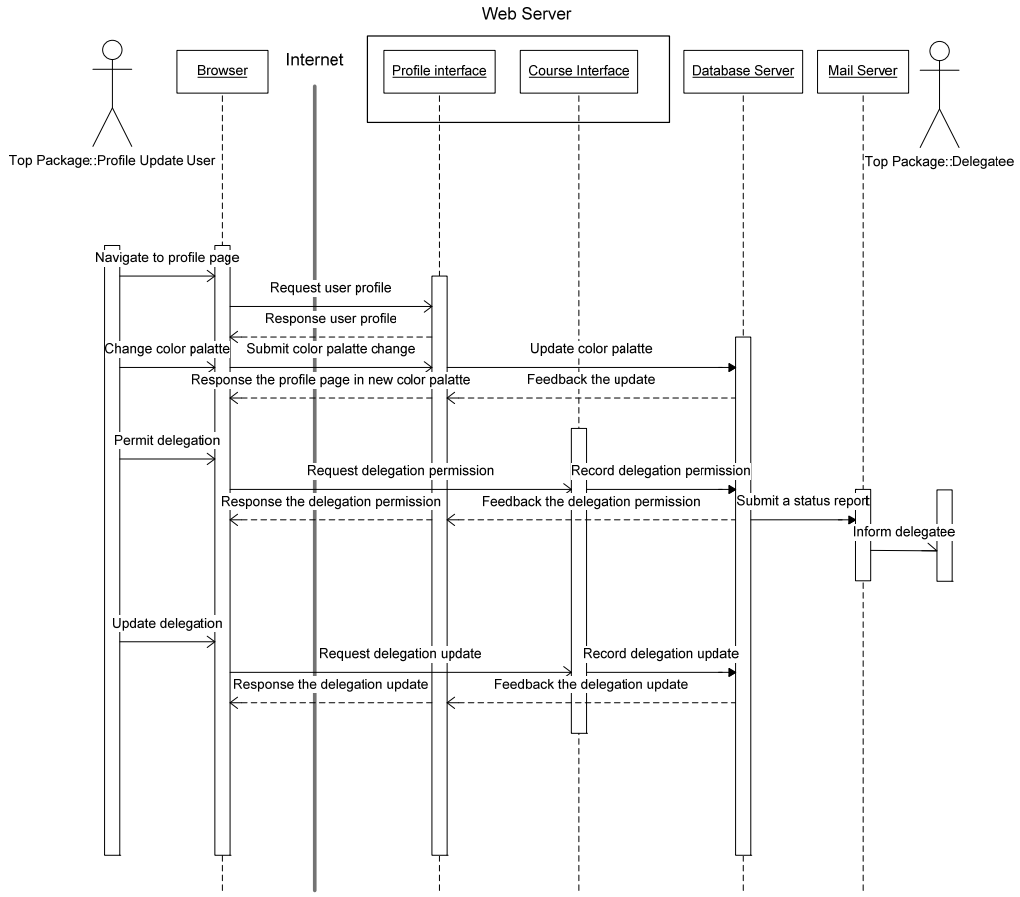

Figure 4.19: Sequence diagram for personalization and access delegation in the CareNet

4. 7 - Usability Testing

To ensure the correct functionality of the developed website, a two-stage usability test was carried out. In the first stage a temporary username and password were given to six MSc and PhD students in Health Informatics and they were asked to provide feedback to the principal investigator. Their feedback was used to improve the website.

In the next step, eight first-year students from non-computing courses were recruited to do a task-based usability testing in the human-computer interaction laboratory in the School of Informatics of City University. The system testers received the same user guide which was prepared for participants of the final evaluation three days before the usability test. The assigned task in this test was as follows:

1. Login to the system with the username and password provided.
2. Enter personal information: After logging in, you will be redirected to your personal information page. On this page you should enter your year of birth, gender and ethnicity. For age of diagnosis enter 0. Save the data you have entered by clicking on save button.
3. After saving the information on this page you will be redirected to the value survey. Rate the “Amount of material in the course” as “Important” in the first page of value survey. Click next until you reach the user values section in the survey.
4. Add a user value named “Test” with the rate of “Extremely Important” and insert it to the values.
5. Go to the “Education Topic” section. Choose “Specific Issues” in education headlines. Then choose “Other illnesses” from education topics. Click on Pre-test hyperlink to go to the pre-test page. Select each question, choose the correct answer and save your choices. After answering all of questions you will be redirected to the course material page.
6. Follow the link to “Diabetes honeymoon” and open the related link. Then close the link and rate it using the six-star rating provided. Save your rating.
7. From the same page give “Omid” read-only access to you clinical data.
8. Go to “My External Resources” in the education section. Add http://www.diabetes.org as a new link and tag it as “Diabetes”
9. From the clinical data section, choose “HbA1C”. Insert a new measurement as with the value of 8. Check the measurement against the chart and tell me the colour category of this value.
10. From the “User Profile” link in system section, change the colour profile to “Blue”. Apply the change and log off from the website.

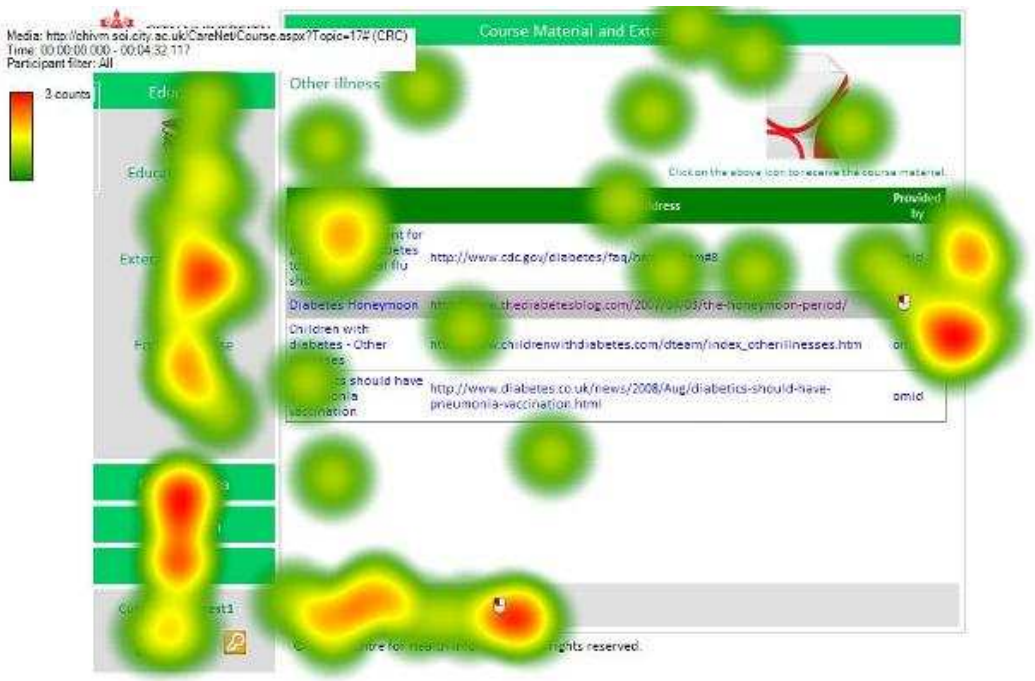

Figure 4.20: Sample heat map of gaze points and clicks in the CareNet usability test

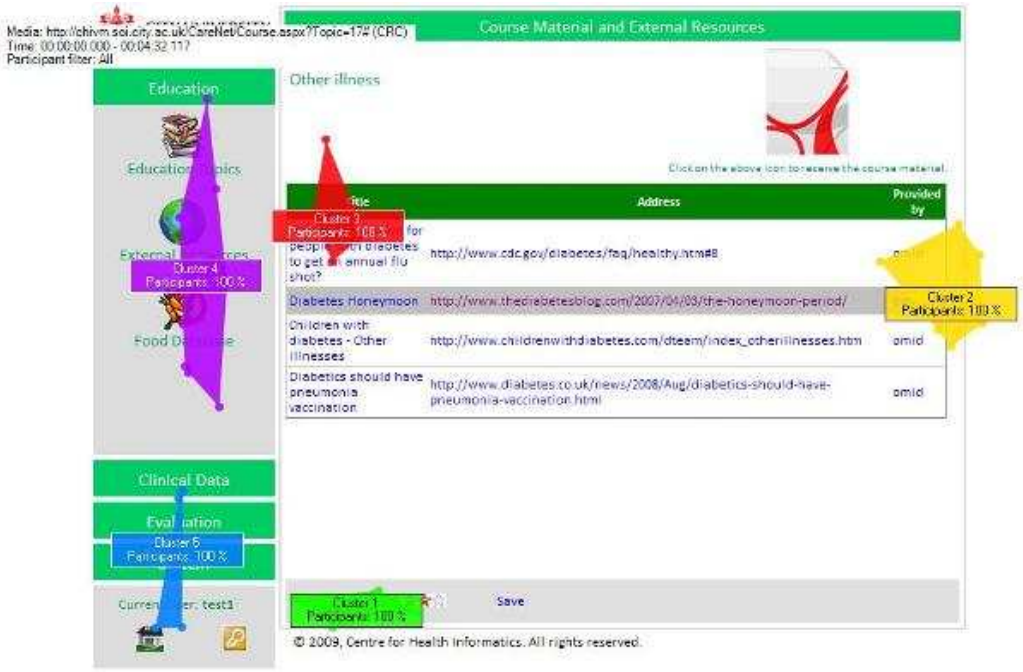

Figure 4.21: Sample cluster map of focus areas in the CareNet usability test

All of the system testers successfully completed their tasks in a timely fashion (Mean ± SD = 25:18 ± 3:21). The hardware facilities in the Interaction Lab provided the facilities to control and record the point of glaze on the computer screen using an infra-red camera by Tobii Technology. These recordings showed that the hottest spots on the web pages were navigation panel and action buttons (see Figure 4.20). These hot points were identified easily by the system testers. A sample cluster map of focus areas in the CareNet usability test is shown in Figure 4.21.

The data produced during the test phase were removed from the back-end database to have a clean dataset for the final analysis

4. 8 - Ethical approval

The online ethics application system in the Integrated Research Application System (IRAS) at https://www.myresearchproject.org.uk/ was used to prepare the required documents.

The ethics application was discussed and approved at the Outer North London Research Ethics Committee on 23/12/2009 (Application reference number: 09/H0724/42). The approval letter is included in Appendix 2.

4. 9 - R&D approval

After obtaining the ethics approval, the application for the R&D approval was sent separately to the R&D or clinical governance committee of each collaborating hospital. The approval letters are also available in Appendix 7.

4. 10 - Summary

The CareNet website was initially designed in UML 2.0 and then developed in Microsoft Visual Studio 2005 development platform. Usability testing in a controlled environment proved the expected functionality of this website.

Chapter 5 Results

In this chapter, the demographic data of the recruited participants are compared with the people who were not interested in this mode of education. After that, the results of the value survey and initial HbA1C data of the participants are presented.

Then the result of HbA1C measurements after intervention is compared with the initial test result of each participant in the form of a pre-test / post-test comparison. Finally, the information about a satisfaction survey in the fourth phase of the evaluation is presented.

5. 1 - Recruitment

After obtaining ethical approval from City University, invitation messages were posted on UK-based diabetes-related discussion groups, online forums and social networking websites.

Also diabetes-related societies and foundations were contacted, asking them to inform their members about this study. The organisations contacted and the outcome of these communications were as follows:

1. Diabetes UK: They responded that because of the current policy of the organisation against the high interest of the pharmaceutical companies, they do not advertise any research project.
2. Juvenile Diabetes Research Foundation (JDRF): They informed their members about this study in their newsletter.
3. Diabetes Research and Wellness Foundation (DRWF): They posted an Ad on their website about this research (A copy of the message is included in Appendix 4)
4. A message was posted on Diabetes Support Forum UK: No response was received from young people, but some of the older members responded and asked questions about the reason for specifically looking for young people in this study. The explanation about the rationale behind this research protocol was posted on the forum.

   Also some comments were posted about the limitations of the current diabetes service offered by the NHS which affects the perception of people about these researches and their participation in it.

Overall, the number of recruitments from these advertisements was five participants.

Diabetes care in NHS hospitals is provided as a team-based process. At least one consultant, a Diabetes Specialist Nurse (DSN) and a dietician are involved in the process of care. A brief description about the study was sent to the diabetes-care team in collaborating hospitals. Then a group meeting was held in each hospital about the study. In these meetings, they were informed as to the target group being

sought and the inclusion criteria for this research. Also the process of this research was explained and the website developed for this study was demonstrated to the diabetes-care team. The feedback from the diabetes-care team was recorded by the principal investigator. This feedback was used to improve some features of the website.

Initially, the availability of patient information to identify the potential candidates for this study was investigated. Some of the hospitals participating in this study have a diabetes registry system. In others, these data were recorded in the Patient Administration System (PAS). The search in these resources provided the list of potential candidates. Usually the patients have quarterly appointments with their diabetes consultant in each year. At the early stages of the recruitment a low attendance rate at the appointments was noticed.

The PAS systems and diabetes registries in the participating hospitals did not have the email address of the patients. To increase the chance of recruiting the participants, invitation letters were sent out to the patients who were in the age range of the inclusion criteria. A sample of this letter is included in the Appendix 4. The other method used for advertising was putting up a poster about the study in the collaborating clinics and in the healthcare centre at City University. A copy of the poster is also available in Appendix 4.

The response rate to these invitations was low. So the principal investigator (PhD student) attended the clinics and spoke to the potential participants. A better response was achieved as a result of these conversations. The result of the recruitment from the hospitals is presented in the Table 5.1.

Hospital Name	**Participants**	**Non-participants**
Barnet and Chase Farm	21	111
Mayday	13	172
Total	34	283

Table 5.1: Frequency of potential patients in the participating hospitals

The anonymised information of the potential participants in the hospitals was profiled and recorded in the database of this study. The data items that were available in the diabetes registries or PAS systems to be included in this profile were:

- Type of diabetes
- Gender
- Year of birth
- Age at diagnosis with diabetes
- Ethnicity
- Latest HbA1C test result
- Previous HbA1C test result

The statistical analysis presented in this study was performed with SPSS Statistics v. 17 unless otherwise specified. The descriptive statistics about the participants and non-participants are as follows:

1. *Type of diabetes*

   Diabetes type 1 normally starts earlier than type 2; so we had more type 1 cases in the potential participants (see Table 5.2).

Type of Diabetes	Participants	Non-participants	Total
Type 1	34	263	297
Type 2	0	16	16
Unknown	0	4	4
Total	34	283	317

Table 5.2: Frequency of type of diabetes among the participants and non-participants in the NHS

Diabetes type 1 requires more rigorous care including routine blood glucose measurement and insulin injections several times a day. This care process obliges them to more clinic attendance. Young people living with type 2 usually do not have significant complications. They normally develop these problems a few decades later.

2. Gender

There was no significant difference in frequency of gender between participants and non-participants (κ^2 (1, n = 317) = 0.01 and p = 0.92). Both groups were interested in online diabetes education at relatively the same level (see Table 5.3).

Gender	Participants	Non-participants	Total
Male	17	139	156
Female	17	144	161
Total	34	283	317

Table 5.3: Frequency of gender among the participants and non-participants in the NHS

3. Ethnicity

For the purpose of simplification, the ethnic origins are classified into five main groups (see Table 5.4).

Ethnicity	Participants	Non-participants	Total
White	23	160	183
Black	4	34	38
Asian	2	22	24
Other	5	17	22
Not stated	0	50	50

Table 5.4: Frequency of ethnicity among the participants and non-participants in the NHS

Because of violation of the assumption about minimum expected frequencies, direct use of Pearson Chi-square test was not possible for comparing these two groups. Fisher's exact or Yate's correction was not applicable because they are more suitable for 2×2 tables. So the low value cells in the bottom groups were combined as "other" and the test was re-calculated. This discretisation resulted in Pearson κ^2 (2, n = 317) = 7.177 and p= 0.028. According to this test, there is a considerable difference between the two groups with more white people participating in the study.

4. Age

To check the normality for distribution of the age, a Shapiro-Wilk test was used. This test is more suitable for small samples, compared to the Kolmogorov-Smirnov test which is used for large samples. The test showed a non-normal distribution with $p < 0.00$ (see Table 5.5), skewness to the right (0.71) and platykurtic distribution (- 0.48).

Age	Participants	Non-Participants
Mean	16.5	18.2
SD	5.29	5.56

Table 5.5: Distribution of age among the participants and non-participants in the NHS

To test the difference between the two groups on the basis of age, a Mann-Whitney Test was used which showed that the participants were younger but that the difference was not statistically significant ($Z = -1.77$, $p = 0.077$).

5. Duration of living with diabetes

Another important factor for comparing between the participants and non-participants is the duration of living with diabetes. This comparison is mostly under-reported in other studies. This attribute was found not to be normally distributed using a Shapiro-Wilk test ($p < 0.00$) with skewness to the right (1.25) and leptokurtic distribution (1.70) (see Table 5.6)

Living with diabetes	Participants	Non-Participants
Mean	6.29	7.04
SD	5.02	5.45

Table 5.6: Duration of living with diabetes among the participants and non-participants in the NHS

The Mann-Whitney test showed no significant difference between the two groups, comparing the duration of living with diabetes ($Z = - 0.71$, $p = 0.48$).

6. Latest HbA1C test result

The other important factor for comparison between the participants and non-participants is the level of HbA1C. This parameter was measured based on the Diabetes Control and Complication Trial/ National Glycohaemoglobin Standardisation Program (DCCT/NGSP) in the UK, presented as a percentage (%). For compatibility with other countries, it was decided to use the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) unit (mmol/mol) alongside the old model from June 2009. Both units will be reported for two years and after that the IFCC unit will be the only unit of measurement. The participants in the CareNet study are as yet more familiar with the percentage unit so it was used in the interface of the application. The measurements were converted to the IFCC unit for the report. The conversion formula used for this transformation was:

$$HbA1C_{mmol/mol} = Round(10.929 \times (HbA1C_{\%} - 2.15), 0)$$

The HbA1C levels did not have a normal distribution ($p < 0.00$, Shapiro-Wilk test), so non-parametric tests were used to compare them. The mean of the HbA1C level in the participating group was lower than for the non-participants (see Table 5.7), but the difference was not statistically significant using the Mann-Whitney test ($p = 0.15$).

HbA1C	Participants	Non-Participants
Mean	73.66	79.52
SD	17.96	22.91

Table 5.7: Distribution of HbA1C among the participants and non-participants in the NHS

The HbA1C measurement shows the numerical value of the test, but in medical practice these measurements should be converted to something with clinical value. To achieve this goal a "Quality and Outcome Framework" (QOF) model was used to discretise these measurements. QOF is a group of indicators for measuring the level of achievement in patient care. It has been used to control

the quality of care since 2004. In the NHS, the National Institute of Clinical Excellence (NICE) is responsible for the development of QOF indicators in partnership with other organisations (131).

Until 2010 the QOF method discretised the HbA1C measures to three buckets. The dividing values for these buckets were 7 and 10. Since 2010, the British Medical Association (BMA) announced that achieving the level of 7 as the upper limit of the target is very difficult and they changed the dividing values to 8 and 9 for a one year trial period (132). This change was discussed with the consultants collaborating in this study. They mentioned that the new model is considered for all the people living with diabetes. However, for younger people, they prefer to use the old model for tighter control and preventing future complications. So the old model was used in this study.

The comparison of HbA1C QOF using Pearson Chi Square with Fisher exact showed no significant difference between participants and non-participants κ^2 (2, n = 317) = 1.281 and P=0.734. The number of participants in each group is presented in Table 5.8.

HbA1C QOF	Participants	Non-Participants
Normal (<7)	3	34
Borderline (between 7 and 10)	19	153
High (> 10)	7	86
Unknown	0	15

Table 5.8: Frequency of HbA1C groups based on QOF model among the participants and non-participants in the NHS

7. Trend in HbA1C test

The trend in HbA1C did not have a normal distribution ($p < 0.00$, Shapiro-Wilk test), so non-parametric tests were used to compare them. The trend in the HbA1C level before recruitment shows a very wide range (see Table 5.9).

HbA1C Trend	Participants	Non-Participants
Mean	-0.21	-0.09
SD	8.16	15.91

Table 5.9: Distribution of change in HbA1C among the participants and non-participants in the NHS

The mean of the HbA1C trends in the participating group was lower than for the non-participants but the difference was not statistically significant using the Mann-Whitney test ($p = 0.78$).

The comparison of change in HbA1C QOF using Pearson Chi Square with Fisher exact showed no significant difference between participants and non-participants κ^2 (2, n = 241) = 1.647 and P=0.439. The number of participants in each QOF group is presented in Table 5.10.

HbA1C	Participants	Non-Participants
Worsened	0	27
Not changed	17	168
Improved	2	27

Table 5.10: Frequency of change in HbA1C using QOF model among the participants and non-participants in the NHS

5. 2 - Data preparation

Before the final analysis of the data obtained in this study, a process of data preparation was followed to ensure the validity and reliability of the analysis in this research.

5.2.1- Missing value analysis

The missing values in this study can be classified into the following groups:

- Missing data in the potential participants included the not-stated ethnicity and incomplete data about HbA1C. If the potential participant was recently diagnosed or had no HbA1C measurement in the six months before the data

collection date, they were considered as missing values for the HbA1C trend analysis. The missing data were neglected pairwise in that analysis.

- The data for the value survey had no missing items.
- Twenty-nine participants completed the satisfaction survey.
- Thirteen participants did not attend the follow-up clinic appointments and were excluded from the clinical outcome analysis. The group who attended the follow-up clinic had lower HbA1C at the time of recruitment, but the difference between this group and the rest of the participants was not statistically significant using the Student T-test ($p = 0.526$).

5.2.2- Validity

The validity of the questionnaires used in this study can be examined in the following manner:

- *Content validity*

  Validation of content refers to ensuring that the items in the questionnaire are covering all aspects of the subject under investigation. The questionnaire in this study was developed using previously validated models. Also it was developed as a semi-structured questionnaire so that participants could add other items that they want. No additional item was identified in the database extract.

- *Construct validity*

  For this validation, the correlation between the characteristic items and the overall level of importance of their group was measured. A minimum correlation of $r = 0.3$ was considered as the acceptable level (133). All characteristic items passed this minimum level.

5.2.3- Multicollinearity

Highly correlated items pointing to a similar concept will increase the size of the questionnaire without considerable benefit. Also this condition can falsely increase the reliability of the questionnaire. So it is very important to check the level of

correlation between the items in a questionnaire tool. If two or more items are considerably correlated ($r > 0.7$) and they are pointing at a similar concept, they should be merged together in one question. Any independent variables with such high correlation should be carefully inspected for multicollinearity.

Although the questionnaire used in this study was previously validated in the field of information science, this check was performed to ensure that there are no redundant items for applying it to the online diabetes education.

Testing on the data obtained from the value survey for this issue showed high correlations between some characteristics shown in Table 5.11.

System characteristics	Interesting subject matter	Reduced system errors	System operation time	Accessibility of the content
Enjoyment from the education	0.782			
Comfort with online learning and technology	0.754			
Quick answer from technical support by e-mail		0.771		
High system availability and low Internet traffic			0.843	
Access of all courses from one area (Dashboard)				0.755

Table 5.11: Correlation matrix presenting highly correlated characteristics in value questionnaire

Interesting subject matter is highly correlated with enjoyment from the education and comfort with online learning, but they are from different aspects of the system values (content and learner) so they were kept in the questionnaire.

A quick answer from technical support and reduced system errors are also

correlated, but they are looking at different concepts in the system and they were kept for the final analysis.

High system availability and system operation time are the other two related characteristics of the system. They look at responsiveness of the system in terms of speed and availability at any time of the day so both of them are kept in the final analysis.

A dashboard page is one of the methods of making the concept available, but because this method is one of the main interfaces in Web 2.0 systems it was kept for the final analysis.

This high level of correlation between the items that are conceptually near each other shows that the participants have filled in the questionnaire with close attention and the risk of a random response is very low.

5.2.4- Outlier control

An important procedure in the questionnaire-based studies is control for the outliers. An outlier response can expose the results of the research to a significant bias. Outliers can be extreme responders or serial responders. In this study three methods were used to identify multivariate outliers in the values and satisfaction surveys:

- Residual Statistics measures the difference between the observed value of the dependent variable and its predicted value. Any case that has the residual statistics value of above 3.3 or below -3.3 should be considered as an outlier and dropped from the final analysis (Figure 5.1). No outlier was identified with this method.
- Mahalanobis distance which measures the distance between a case and the centroid for overall characteristics. The cut-off point for this test is determined by the critical chi-square with degree of freedom equal to the number of independent variables. In this study there are 37 independent variables so the critical value for the alpha level of 0.001 was 69.35.

- Cook's Distance measures the level of violation from homoscedasticity or homogeneity of variance. Cases with Cook's value of larger than one are considered as outliers.

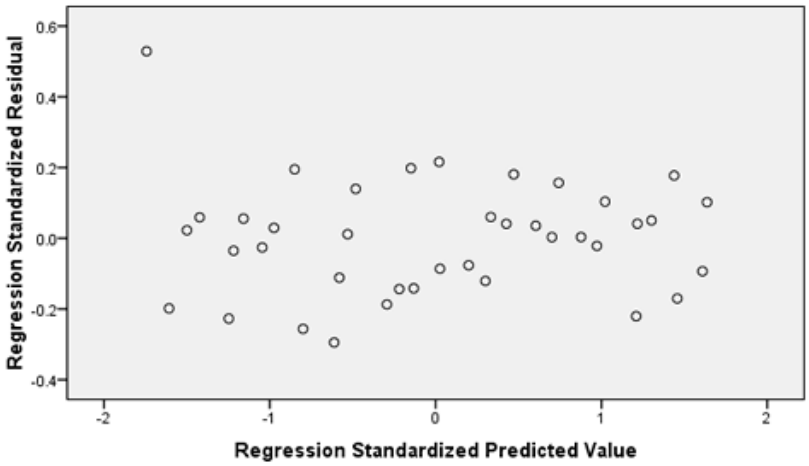

Figure 5.1: Scatterplot for checking the outliers in value survey

The last two methods identified five outliers in responses to the value questionnaire among the patients and no outliers among the healthcare professionals. An exploratory data check was performed on those outlier responses and they were identified as serial responders. These outliers were excluded from value analysis. The satisfaction questionnaire had no outlier responses.

5.2.5- Reliability

Using a survey tool such as the method used in the value or satisfaction survey, a summative scale is produced to calculate the score associated with the purpose of the survey. It is essential to measure the reliability of those tools for being able to use their items as predicting factors. Cronbach's Alpha test was used to measure the reliability of the tools. This coefficient ranges in value from zero to one. The acceptable level for a questionnaire to be considered as reliable is 0.7. however, if the questionnaire is designed for psychometric or clinical measurements, it should have a reliability of more than 0.9 (134). The result of the reliability test for the value survey was 0.942 in the responses from people living with diabetes and 0.925 in healthcare professionals. Both these values showed a very acceptable level of

reliability of the value questionnaire used in this study.

5.2.6- Normality

After dropping the outlier responses, the pattern of distribution of the characteristics should be measured. This test is especially important considering the normality of the distributions as it will indicate whether parametric or non-parametric tests should be used for further analysis of the results. Using the Shapiro-Wilk test showed that none of the characteristics has a normal distribution; so non-parametric tests were used for further comparison of these characteristics with any other data item.

5. 3 - Analysis of values

The value questionnaire was completed by both patients and healthcare professionals. The respondents from the healthcare professional group were selected from all the different professions responsible in the care of people living with diabetes. The frequency of these respondents is presented in Table 5.12.

Healthcare Professions	Frequency
Doctors	6 (46%)
Nurses	5 (38%)
Dietitians	2 (16%)

Table 5.12: Frequency of the healthcare professionals participating in the value survey

As explained before, the values of online diabetes education characteristics were classified into four groups including content of the system, coaching by the healthcare professionals, learner and “technical specifications and support”. For the purpose of simplicity the healthcare professionals will be addressed as professionals through the rest of this chapter. These results show that patients have given the highest values to technical issues and system support and then learners, content and the coaching (see Table 5.13). A detailed discussion about the comparison between the people living with diabetes and the healthcare professionals will be presented in Section 6.4.

Aspects of the e-learning system for diabetes	Patients		Professionals	
	Mean	SD	Mean	SD
Technical issues and the system support	4.71	0.87	4.62	1.12
Learner of the system	4.50	0.79	4.69	0.75
Content of system	ˆ.44	0.79	4.54	1.13
Coaching in the system	4.41	0.78	3.77	1.09

Table 5.13: Comparison between the levels of importance of different aspects diabetes e-learning

Colours in the following figures are coded according to this diagram:

The following figures only represent the responses from the patients, but the mean and standard deviation of the responses from both patients and healthcare professionals are presented in tables after each figure.

5.3.1- System content

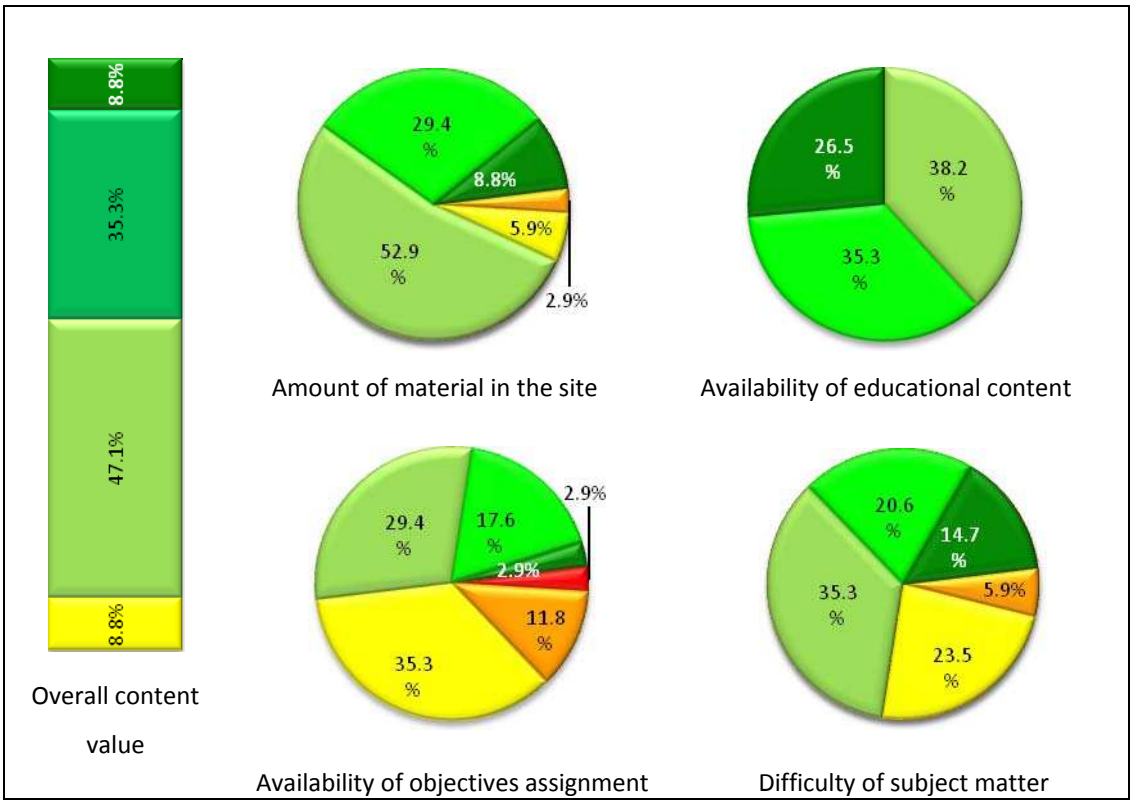

Figure 5.2: Relative frequency of the overall level of importance of "content of system" and its characteristics

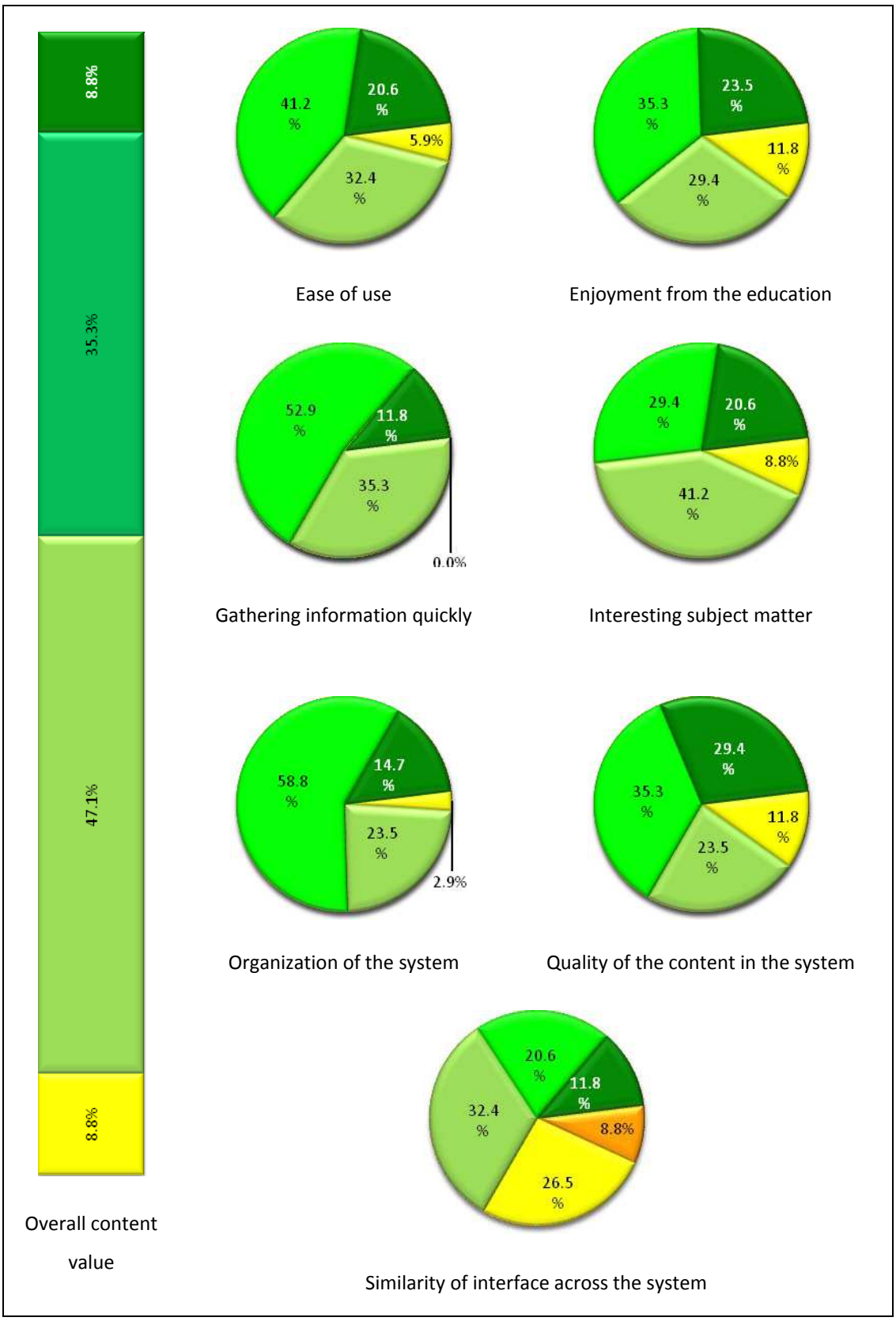

Figure 5.2: Relative frequency of the overall level of importance of "content of system" and its characteristics (continued)

The relative frequency of the overall value for this group and the relative frequency of the individual characteristics are depicted in Figure 5.2.

Kahle and Kennedy (135) proposed to use a zero to positive rating model for this value survey. This model was used to convert the ratings in the value survey to numeric equivalents. The average and standard deviation of each content characteristic measured in patients and professionals are listed in the Table 5.14.

System content	Patients		Professionals	
	Mean	SD	Mean	SD
Availability of educational content	4.88	0.81	4.54	0.78
Organisation of the system	4.85	0.70	4.92	0.95
Quality of the content in the system	4.82	1.00	5.31	0.75
Gathering information quickly	4.76	0.65	4.54	0.97
Ease of use	4.76	0.85	5.08	0.86
Enjoyment from the education	4.71	0.97	5.08	0.86
Interesting subject matter	4.62	0.92	4.92	0.76
Amount of material in the site	4.35	0.85	4.23	0.83
Difficulty of subject matter	4.15	1.13	3.77	1.42
Similarity of interface across the system	4.00	1.15	3.92	1.32
Availability of other content - objectives assignment	3.56	1.11	3.31	1.03

Table 5.14: Comparison between the levels of importance of different characteristics of the system content

The top three characteristics of the system content from the patients' point of view were availability, organisation and quality of the information in the system.

5.3.2- Learning coach

The relative frequency of the overall value for learning coach and the relative frequency of the individual characteristics are provided in Figure 5.3. The average and standard deviation of each characteristic measured in patients and professionals are listed in Table 5.15.

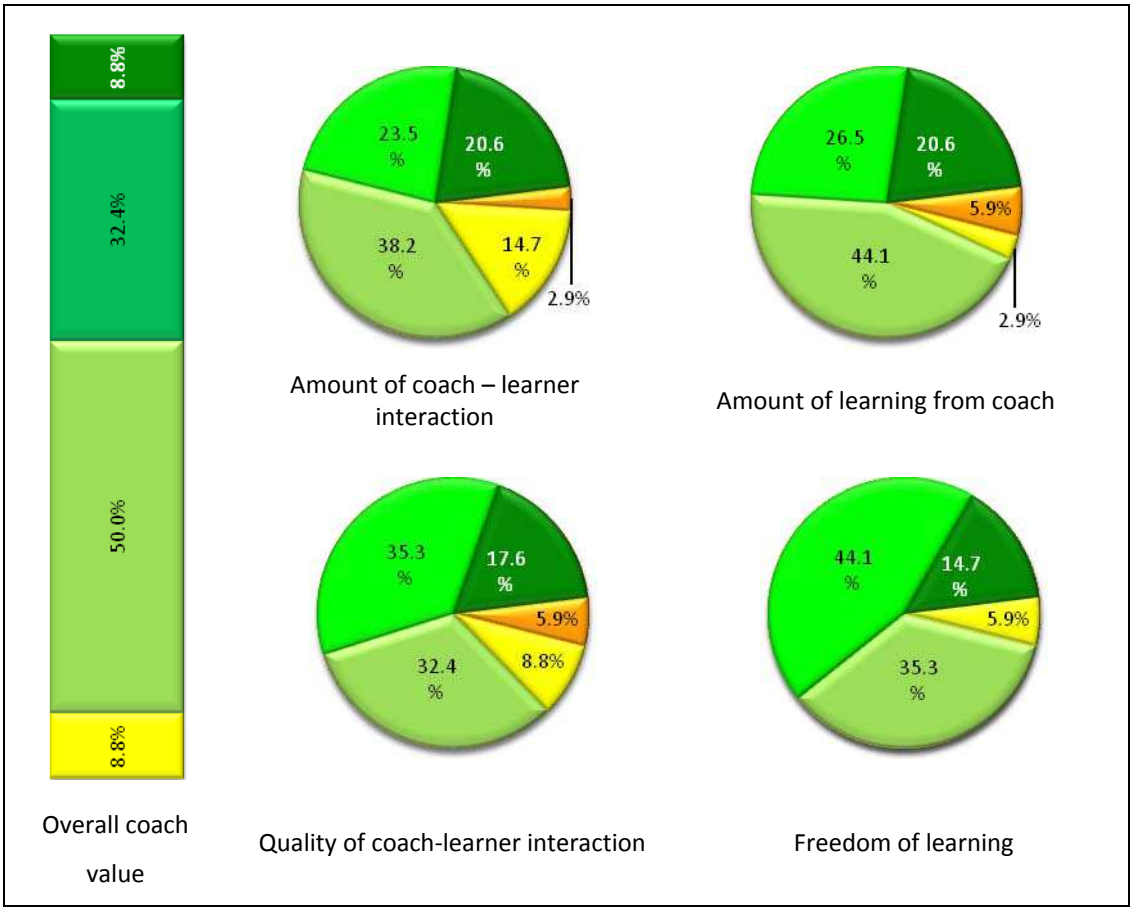

Figure 5.3: Relative frequency of the overall level of importance of "Coach of system" and its characteristics

Among the coaching characteristics both patients and professionals are more concerned about the freedom of learning. At the second step patients and professionals consider direct learning from the coach.

Learning coach	Patients		Professionals	
	Mean	SD	Mean	SD
Freedom of learning	4.68	0.81	4.77	0.93
Amount of learning from coach	4.53	1.05	4.62	1.19
Quality of coach-learner interaction	4.50	1.08	4.62	1.12
Amount of coach – learner interaction	4.44	1.08	3.92	1.04

Table 5.15: Comparison between the levels of importance of different characteristics of the coaching

5.3.3- Learner

The values regarding system characteristics that belong to the learner group are provided in Table 5.16. The relative frequency of the ratings given to this group is available in Figure 5.4

Learner	Patients		Professionals	
	Mean	SD	Mean	SD
Amount of learning from this system	4.76	0.89	4.69	1.32
Comfort with online learning and technology	4.62	0.99	4.08	1.32
Self-discipline and time management	4.53	0.79	3.92	1.66
Family support	4.53	1.28	4.69	1.25
Reduced travel cost and time cost	4.26	1.42	4.69	0.95
Internet and computer skills	4.00	1.33	4.23	1.24
Amount of interaction with other learners	3.91	1.29	4.38	1.45

Table 5.16: Comparison between the levels of importance of different characteristics of the learner

Regarding the learners characteristics, patients are more concerned with the amount of material, comfort with technology and self time-management whereas professionals consider reduced travel cost, family support and amount of the learning from the system.

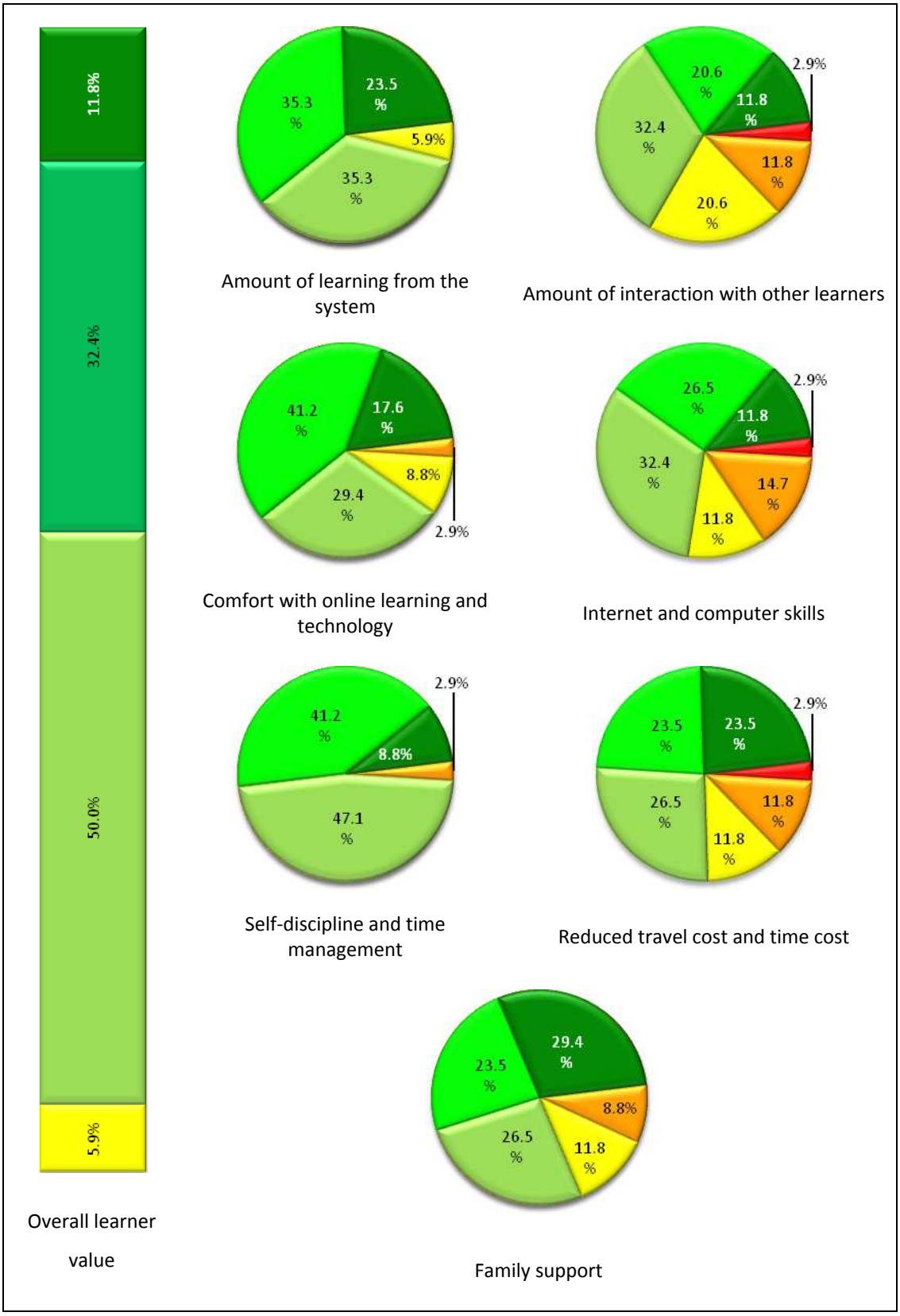

Figure 5.4: Relative frequency of the overall level of importance of "Learner of system" and its characteristics

5.3.4- Technical and support

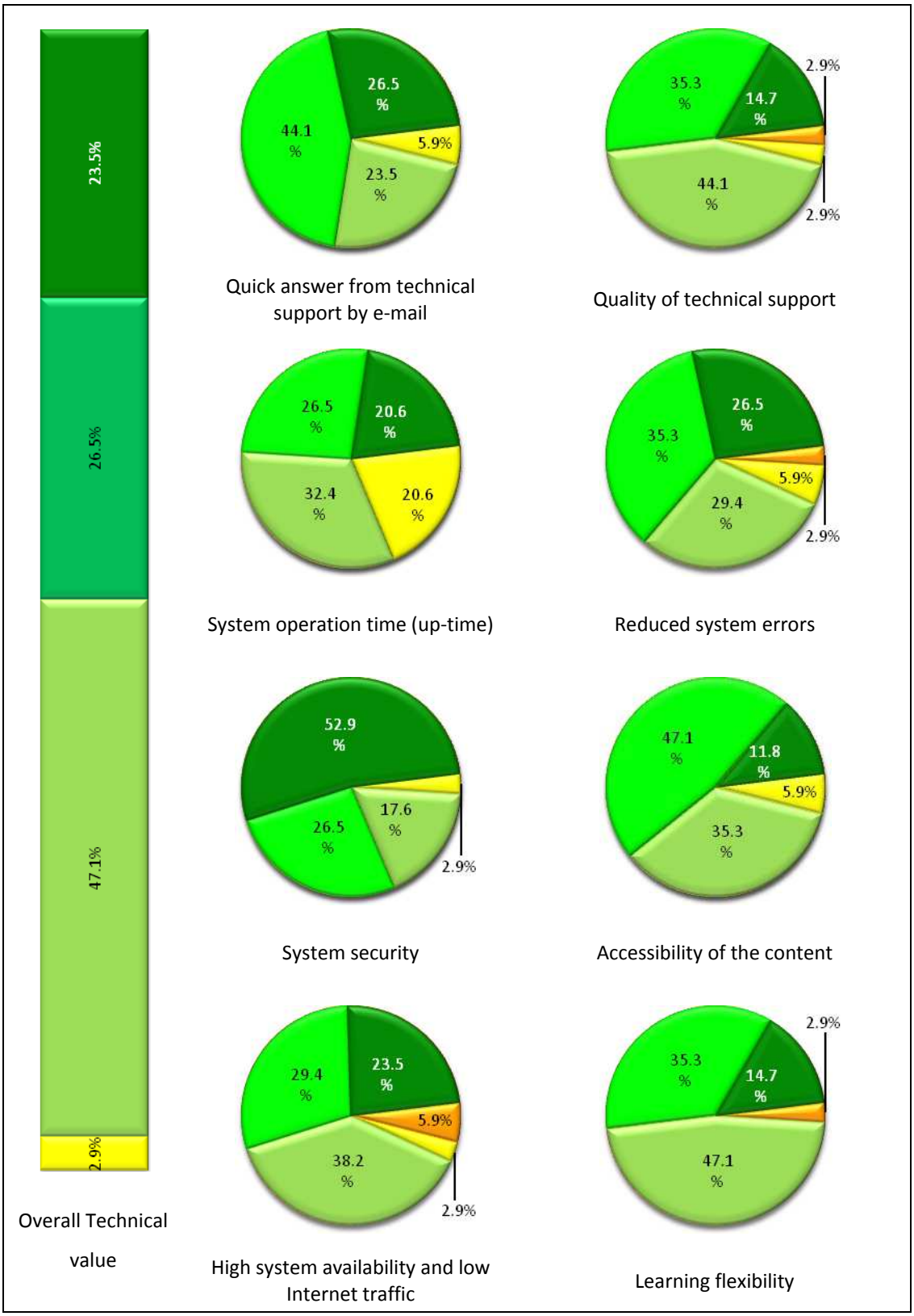

Figure 5.5: Relative frequency of the overall level of importance of "Technical issues and support of system" and its characteristics

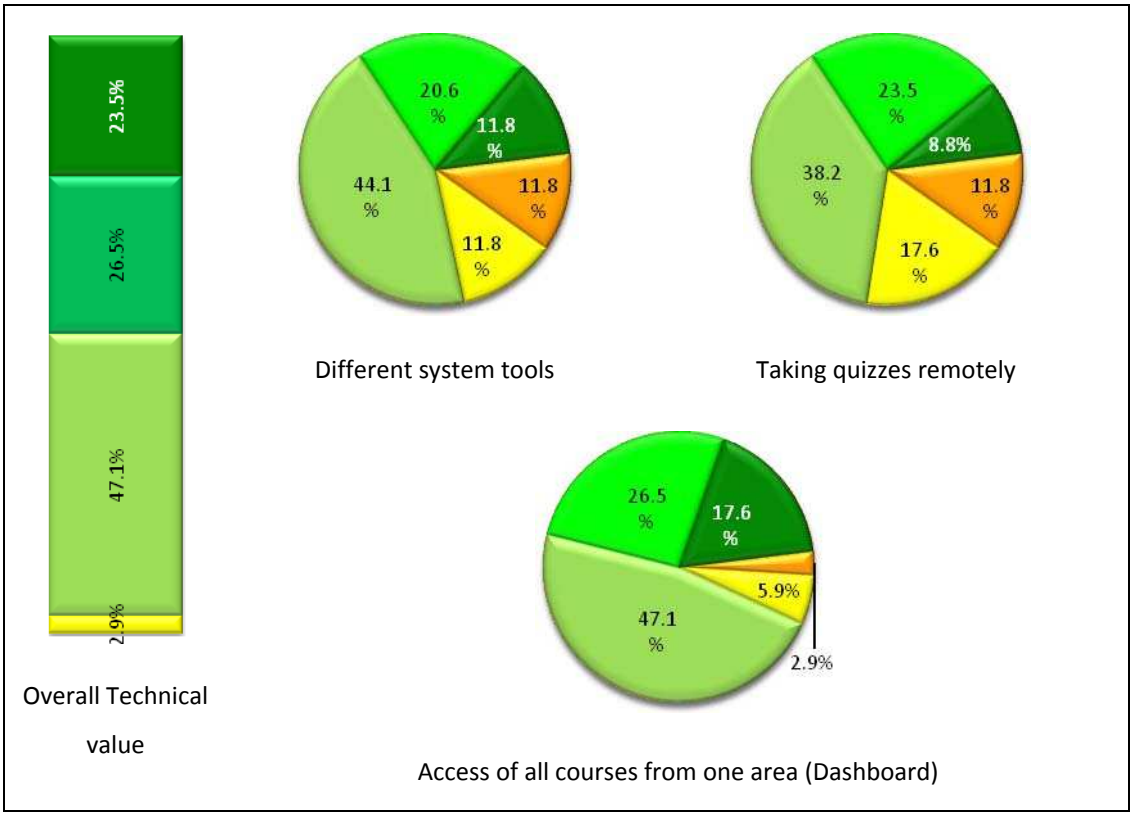

Figure 5.5: Relative frequency of the overall level of importance of "Technical issues and support of system" and its characteristics (Continued)

The relative frequencies of the ratings given to the importance level of technical and support-related characteristics are depicted in Figure 5.5. The average and standard deviation of these ratings are listed in Table 5.17.

Considering the technical characteristics of the online diabetes education, patients believe that system security, responsiveness of the technical support and reduction of the system error are the most important items whereas the professionals rank the responsiveness of the support, different system tools and system operation time as the most important characteristics of the system.

Technical issues and support	Patients		Professionals	
	Mean	SD	Mean	SD
System security	5.29	0.87	4.46	1.27
Quick answer from technical support by e-mail	4.91	0.87	4.92	0.86
Reduced system errors	4.76	1.02	4.38	0.87
Accessibility of the content	4.65	0.77	4.15	1.28
High system availability and low Internet traffic	4.62	1.07	4.31	1.25
Learning flexibility	4.59	0.86	3.92	1.12
Quality of technical support	4.56	0.89	4.69	1.49
Access of all courses from one area (Dashboard)	4.50	0.96	4.54	1.05
System operation time (up-time)	4.47	1.05	4.69	0.95
Different system tools	4.09	1.14	4.92	0.86
Taking quizzes remotely	4.00	1.13	4.54	0.97

Table 5.17: Comparison between the levels of importance of different characteristics of the technical issues and support

These results are the answers to the third question of this study about the importance level of different characteristics of web-based diabetes education.

5. 4 - System Usage

One of the greatest benefits of the web-based systems for diabetes education is the high availability of these systems. The users can access the education materials at any time and in any place that they can access the Internet. The usage monitoring module developed in the CareNet study enabled us to measure different parameters about activities of the participants. In previous studies only the users' logging-in was analysed in a few cases (27, 29, 30, 32, 34, 36, 41). These data cannot be a good representation of system usage, because they cannot rule out the possibility of logging-in and leaving the system without usage. Also, no information about the mostly used modules can be extracted from that log file.

The extracted data from the CareNet log file were used to measure different factors. As a result of using AJAX technology and partial post-back commands in the CareNet, refreshing the pages such as inserting new records in clinical data and answering to the questions in education tests or surveys was not logged multiple times. This feature increases the accuracy of the logged data.

5.4.1- Comparison of system usage at different hours of the day

CareNet pages were browsed 6399 times during this evaluation. The frequency of the browsing the CareNet pages at different hours of the day is presented in Figure 5.6.

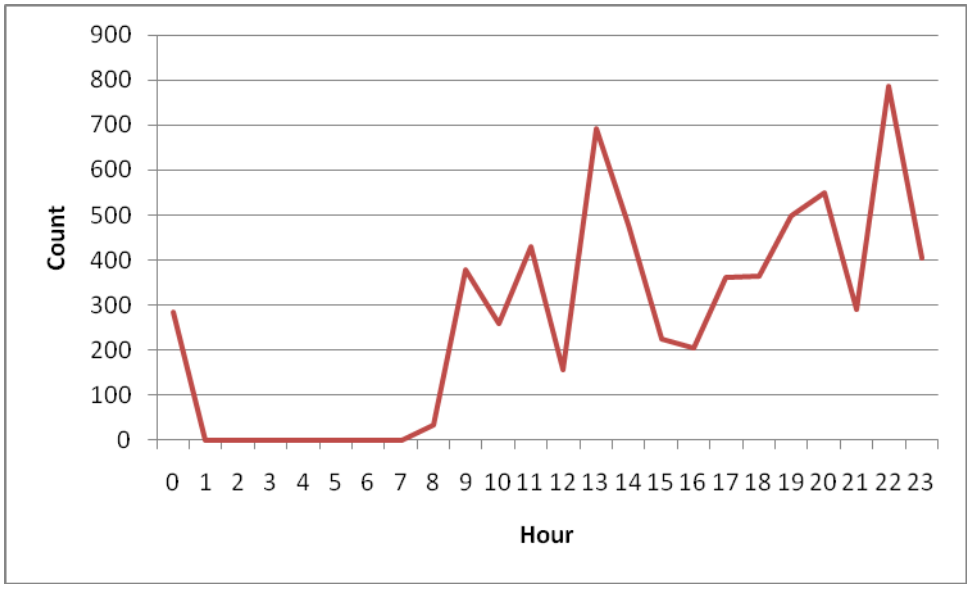

Figure 5.6: Frequency of browsing pages at different hours of the day

The two main peaks of usage are at 1:00 PM and 10:00 PM.

5.4.2- Comparison of system usage between working hours and non-working hours

Face-to-face courses for diabetes are mostly held during working hours. The benefit of web-based diabetes education is that it can extend this service to outside the working hours. For this comparison the working hours are considered as Monday to Friday 9:00 AM to 4:00 PM. The hours of day outside this limit and weekends are considered as Non-working hours.

Figure 5.7 shows that the usage of the CareNet website was higher during non-working hours. The amount of usage was considerably more in non-working hours.

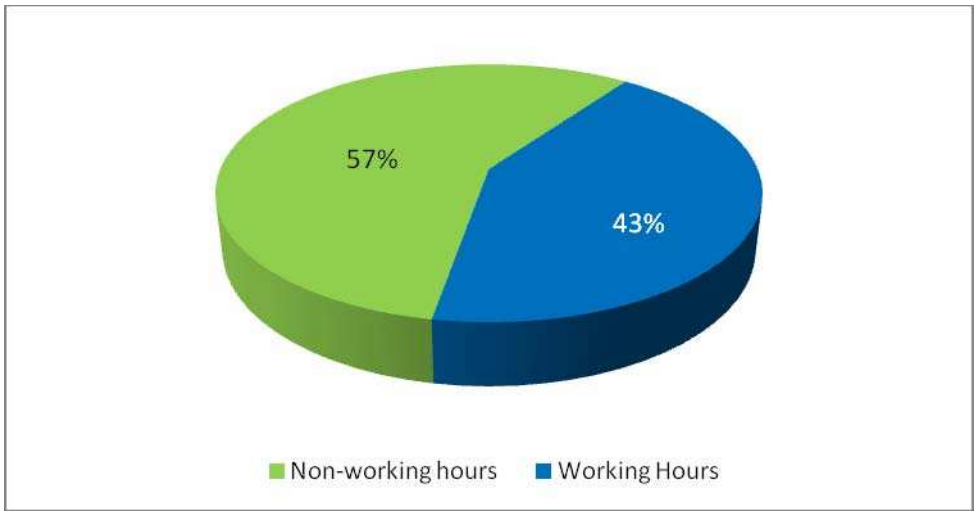

Figure 5.7: Relative frequency of system usage in working and non-working hours

5.4.3- Monthly usage of the CareNet website

The chart in Figure 5.8 provides the information about website usage in the evaluation of CareNet. The peak usage was in the middle of evaluation in April.

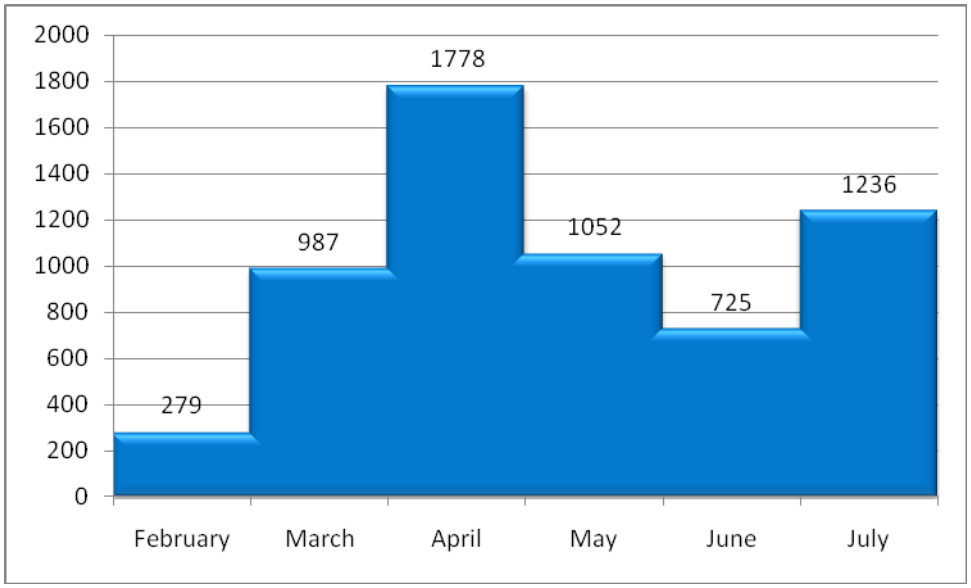

Figure 5.8: Frequency of browsing pages per month

5.4.4- Most commonly used modules

The usage-log data showed that the most frequently used modules in the CareNet website were those relating to education. Additional features such as system, food and external resources were used less than others. The detailed numbers and frequencies of usage are presented in Table 5.18.

Module	Frequency
Education	3021 (47.21%)
Survey	2047 (31.99%)
Clinical Data	704 (11.00%)
System	460 (7.19%)
Food	138 (2.16%)
External Resources	29 (0.45%)

Table 5.18: Most commonly used modules of CareNet

The mostly visited education topics are listed in Table 5.19. The impact of diabetes and information about life style are those subjects most frequently visited.

Topic	Visits
Significance and implications of a diagnosis of diabetes; the impact of diabetes	30
Relationship between blood glucose levels, dietary intake and physical activity	15
Importance of a healthy lifestyle, especially physical activity, a balanced diet and not smoking	14
Short- and long-term consequences of poorly controlled diabetes	13
Aims and different types of treatment	12
Importance of carrying personal identification	11
Importance of continuing to take insulin or tablets	10
Holidays	10

Topic	Visits
Hypoglycaemia (for those on insulin or hypoglycaemic agents)	9
Importance of annual surveillance for complications.	9

Table 5.19: Top visited education topics

5.4.5- Personalizing their profile

Eight users personalized the gadgets on the dashboard page and four users changed the appearance of their web environment using the facilities provided in the system. Overall usage of these features was less than expected.

5. 5 - Learning Achievements

The participants in the CareNet study were asked to answer a few questions related to each education module, before and after accessing that module. The rate of correct answers to these questions is used as a measure for the amount of learning in this study. The overall number of answers recorded in the system was 516.

Table 5.20 provides a summary of the data about this parameter.

Stage	Incorrect Answers	Correct Answers
Pre-Test	38.25%	61.75%
Post-Test	24.91%	75.09%

Table 5.20: Relative frequency of correct answers to learning measurement tests

A Chi square test showed a significant improvement in the correct answers with $p\ (1, n = 516) = 0.0012$.

5. 6 - Analysis of Clinical Improvements

The HbA1C test was used as a measure of clinical performance in the CareNet study. If available, three measurements of this test were used for analysis. The first measurement was the level of this test before being recruited into this study. Some of the participants were newly diagnosed and did not have an HbA1C measurement

before recruitment. The second measurement was at the time of being recruited and the third was after six months of being in this study.

The HbA1C levels were normally distributed using the Shapiro-Wilk test with p = 0.088 for HbA1C at recruitment and p=0.215 for the HbA1C after intervention. So a Student paired-sample t-test was used for comparing these two measurements. The average value of the HbA1C decreased after the intervention; for baseline HbA1C the mean ± SD was 71.67 ± 16.70 and for post-intervention HbA1C, the mean ± SD was 70.67 ± 14.03. The difference between these two measurements was not statistically significant p (20, n = 21) = 0.441.

The first trend in HbA1c was calculated by subtracting the level of HbA1C measured up to 6 months before recruitment from the HbA1C result at the time of recruitment. The second trend was calculated by subtracting the result of this test at the time of recruitment from the final measurement after 6 months of using the system. The average trend of the HbA1C was improved after the intervention; for baseline HbA1C trend, the mean ± SD was –0.85 ± 6.69; and for post-intervention HbA1C the mean ± SD was -1.69 ± 4.35. Comparison of these two trends using a Student paired-sample t-test showed a non-significant improvement of this trend p (12, n=13) = 0.725. The HbA1C QOF levels of the participants did not change after intervention.

Although a separate module was provided in the system to record blood glucose measurements, only six participants used this module. This issue was investigated during the follow-ups. Most of the participants expected a more automatic technology to transfer their measurements from their glucose-meter to the system. The data structure in glucose-meters is proprietary to the companies that manufacture them. There is no standard open-source protocol to extract the data from these systems. So this user requirement was not feasible at this stage of the CareNet study.

5. 7 - Analysis of End-users' Contribution

The participants in this study had several options to contribute to the system.

5.7.1- Rating the external resources in education section

The top 10 sites according to this rating are listed in Table 5.21. Overall 75 ratings were recorded in the system using a star-based rating model ranging from one to six. The Mean ± SD of the overall rating was 3.09 ± 0.9.

Web page	Rate
Driving & Diabetes - Diabetes UK	6
Influenza and Pneumococcal vaccinations	6
What is type 1 diabetes?	5
Check-ups for diabetes	5
Having a hypo	4
Keeping active	4
Diabetes Control	4
Complications of diabetes	4
Insulin injection techniques	4
Children with diabetes at school	4

Table 5.21: Top highly rated diabetes web pages

5.7.2- Proposing new external resources to the system

Although the procedure for proposing external resources was clearly explained in the user guide, no external resource was proposed by the participants to the system. The users were not confident enough to contribute to the system. The principal investigator initially provided the external resources for some of the modules to give the participants the opportunity to propose resources for the rest of the modules. Because of the lack of contribution, the remainder of the modules were populated by the principal investigator.

5.7.3- Delegating access to their clinical information

This tool was only used between two brothers participating in the system. This result shows that participants in this study were not keen to share their clinical information with the people whom they only know virtually.

5. 8 - Analysis of Satisfaction Survey

The results from the satisfaction survey had an acceptable level of reliability with Cronbach's Alpha test equal to 0.822. Among the overall levels of satisfaction with different aspects of the CareNet, technical characteristics received the highest level of satisfaction, learner characteristics were second, content was third and the coaching-related characteristics had the lowest level of satisfaction. The ratings for levels of satisfaction were converted to numerical values adopting the same method used in the value survey. The detailed information about the averages and standard deviations of this survey is presented in Table 5.22

Aspects of the e-learning system for diabetes	Patients	
	Mean	SD
Technical issues and the system support	4.52	0.87
Learner of the system	4.03	1.15
Content of system	3.97	1.09
Coaching in the system	3.24	1.18

Table 5.22: Overall satisfaction levels with different aspects diabetes e-learning

Colours in the following figures are coded according to this diagram:

Detailed information about the relative frequency of the ratings for the levels of satisfaction with each group and their characteristics is presented in the following sections.

5.8.1- System content

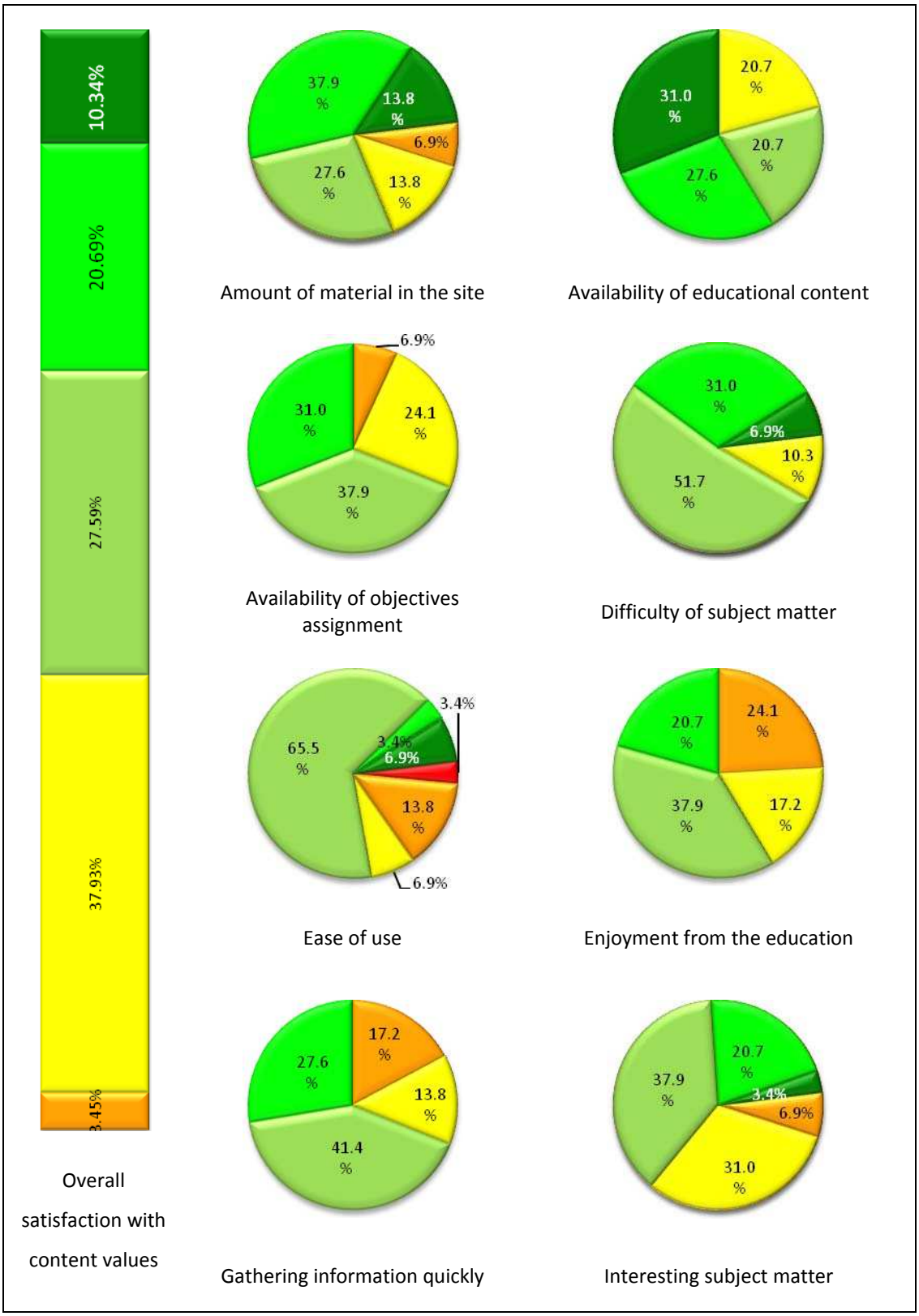

Figure 5.9: Relative frequency of the overall level of satisfaction with "content of system" and its characteristics

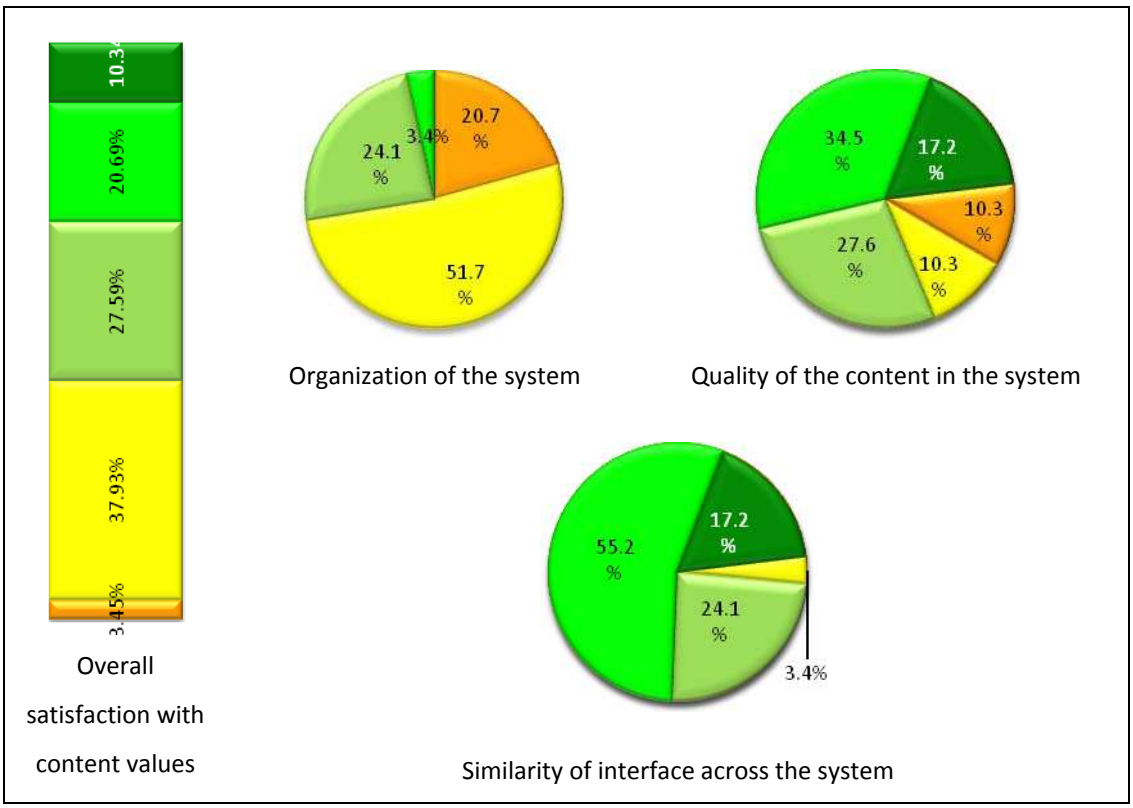

Figure 5.9: Relative frequency of the overall level of satisfaction with "content of system" and its characteristics (continued)

The relative frequencies of the ratings about satisfaction with content-related characteristics are depicted in Figure 5.9.

System content	Patients	
	Mean	SD
Similarity of interface across the system	4.86	0.74
Availability of educational content	4.69	1.14
Amount of material in the site	4.38	1.12
Quality of the content in the system	4.38	1.21
Difficulty of subject matter	4.34	0.77
Availability of other content - objectives assignment	3.93	0.94
Interesting subject matter	3.83	0.95
Gathering information quickly	3.79	1.05
Ease of use with system	3.72	1.10
Enjoyment from the education	3.55	1.09
Organization of the system	3.10	0.77

Table 5.23: Satisfaction level with different characteristics of the system content

The highest level of satisfaction in this group was with the consistency of the interface. The participants considered the quantity of material and especially the educational content as the next highest satisfactory characteristics. The disease related information was not perceived to be very interesting, as was apparent in the satisfaction levels given to this item. The participants found that the CareNet is not very easy to use although the user guide explained the how-to do things in detail. No measurable evidence was available regarding the usage of the user guide. The organization of information in the site was not as good as they expected. For further detail about the average and standard deviation of the satisfaction with each characteristic, please check the information presented in Table 5.23.

5.8.2- Learning coach

Detailed information about this group is presented in Figure 5.10

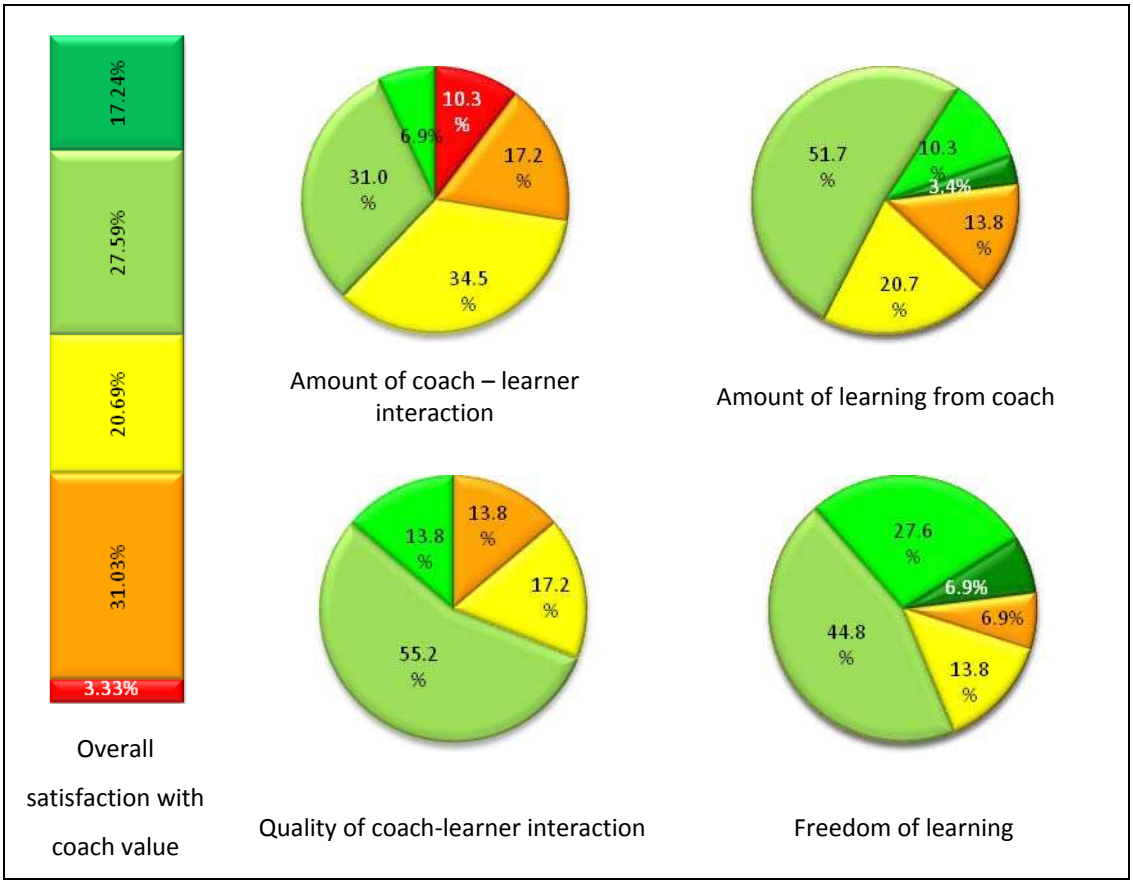

Figure 5.10: Relative frequency of the overall level of satisfaction with "Coach of system" and its characteristics

Freedom of learning received the highest level of satisfaction among coach-related characteristics in the CareNet study (see Table 5.24). The other three characteristics had considerably lower satisfaction. The lowest satisfaction was with the amount of coach - learner interaction.

Learning coach	Patients	
	Mean	SD
Freedom of learning	4.14	0.99
Quality of coach-learner interaction	3.69	0.89
Amount of learning from coach	3.69	0.97
Amount of coach – learner interaction	3.07	1.10

Table 5.24: Satisfaction level with different characteristics of the coaching

5.8.3- Learner

The relative frequencies of the satisfaction with the characteristics in this group are presented in Figure 5.11. The highest satisfaction in learner-related characteristics was given to reduced travel cost and time cost. The second highest satisfaction level was with the amount of learning in CareNet. The lowest rating was given to the amount of interaction with other users. Self-discipline and time management had the second lowest level of satisfaction (see Table 5.25).

Learner	Patients	
	Mean	SD
Reduced travel cost and time cost	4.62	0.82
Amount of learning in this system	4.31	1.14
Internet and computer skills	4.00	0.96
Comfort with online learning and technology	3.76	0.87
Family support	3.72	1.13
Self-discipline and time management	3.62	0.86
Amount of interaction with other learners	3.00	1.13

Table 5.25: Satisfaction level with different characteristics of the learner

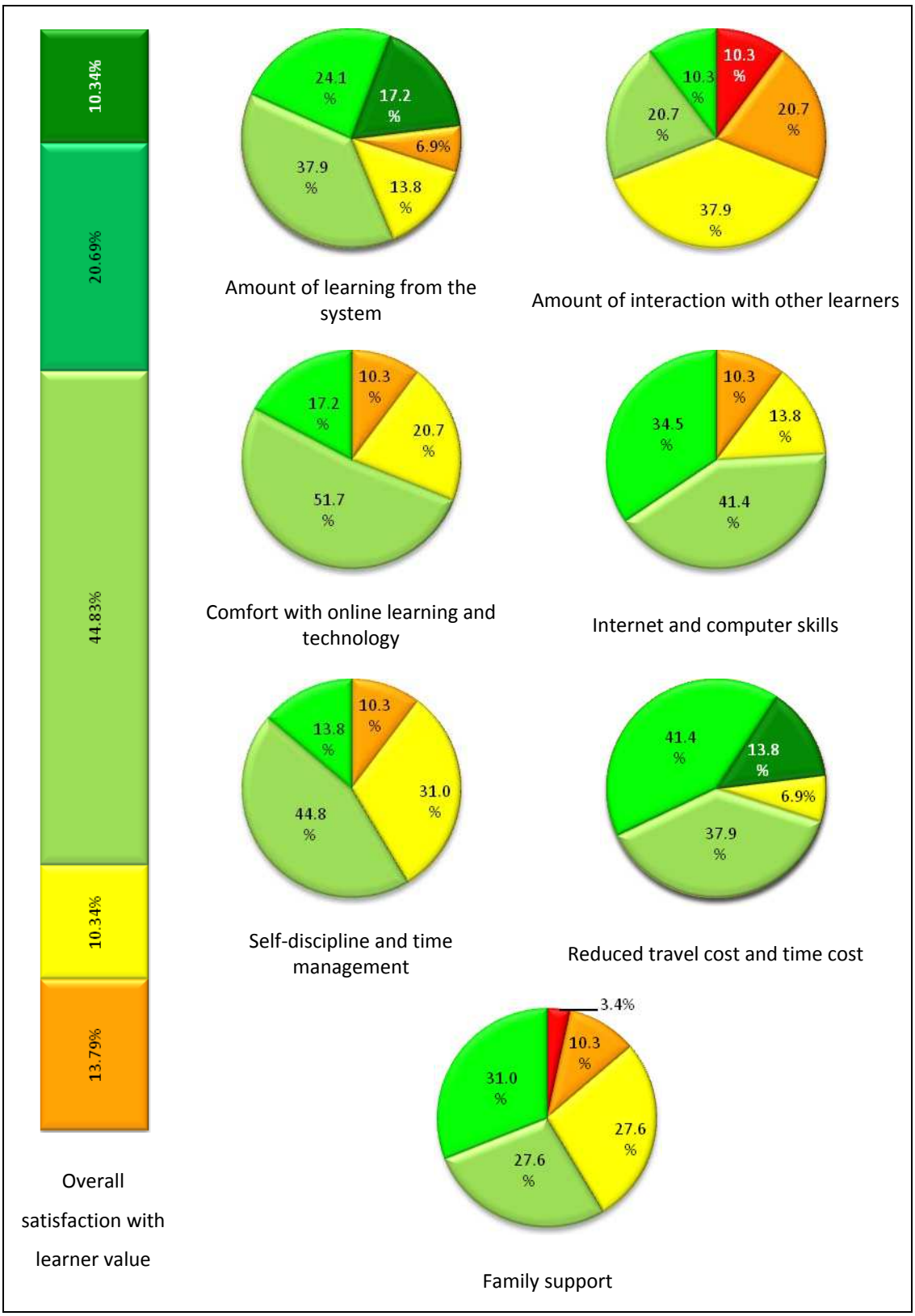

Figure 5.11: Relative frequency of the overall level of satisfaction with "Learner of system" and its characteristics

5.8.4- Technical and support

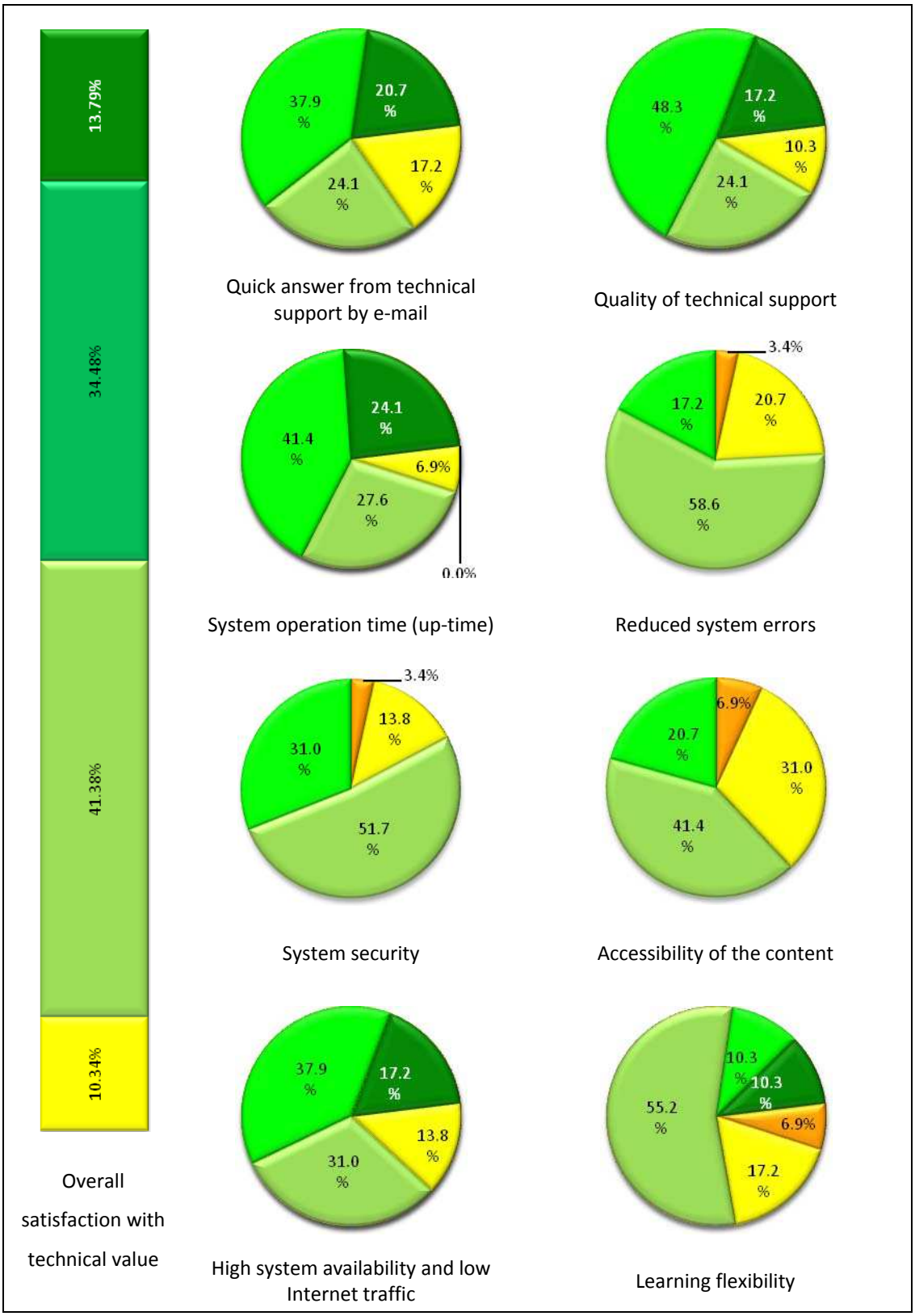

Figure 5.12: Relative frequency of the overall level of satisfaction with "Technical issues and support of system" and its characteristics

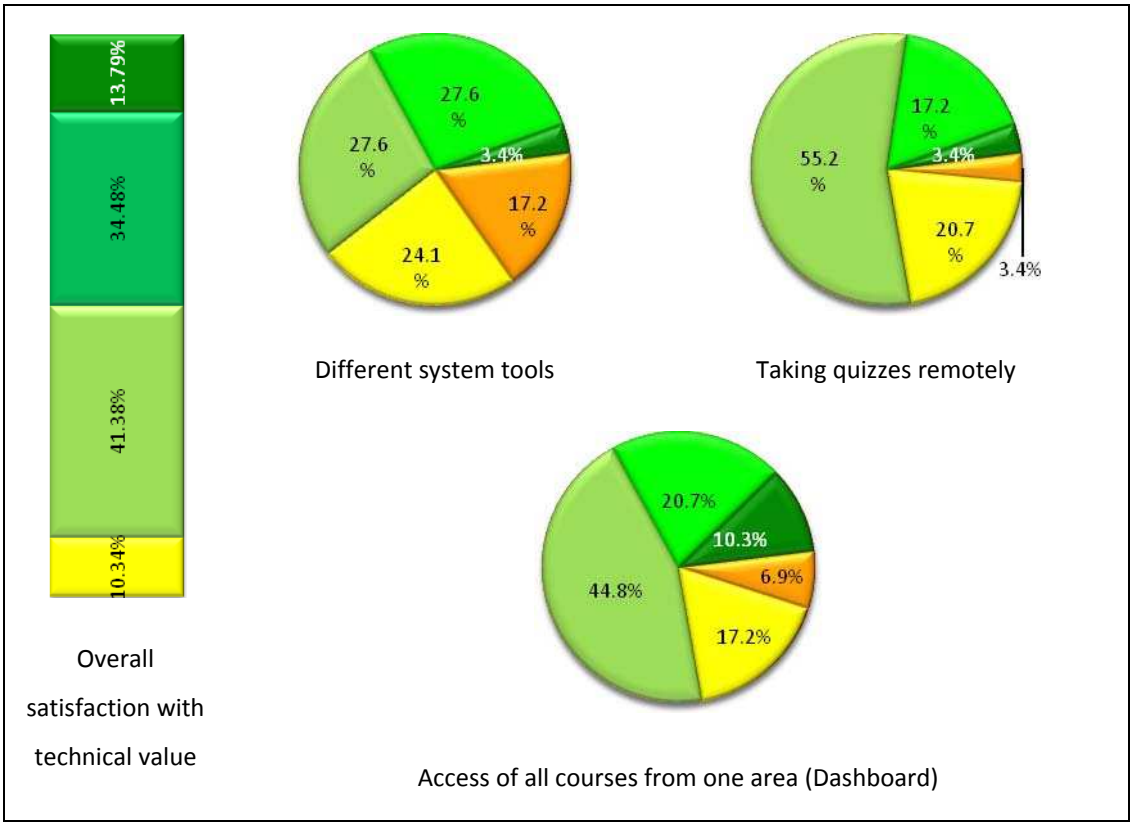

Figure 5.12: Relative frequency of the overall level of satisfaction with "Technical issues and support of system" and its characteristics (Continued)

Technical issues and support	Patients	
	Mean	SD
System operation time (up-time)	4.83	0.89
Quality of technical support	4.72	0.88
Quick answer from technical support by e-mail	4.62	1.01
High system availability and low Internet traffic	4.59	0.95
System security	4.10	0.77
Taking quizzes remotely	4.10	1.05
Learning flexibility	4.00	1.00
Access of all courses from one area (Dashboard)	3.97	0.82
Reduced system errors	3.90	0.72
Accessibility of the content	3.76	0.87
Different system tools	3.76	1.15

Table 5.26: Satisfaction level with different characteristics of the technical issues and support

The relative frequencies of the levels of satisfaction with technical-related characteristics are depicted in Figure 5.12. The highest level of satisfaction in technical and support-related characteristics was achieved in system operation time. The CareNet website had only six hours of down-time during the evaluation. This down-time was because of a single instance of server failure which was rectified by the IT support team at the School of Informatics. The quality of technical support was the second best characteristics in this survey. Among these characteristics, different system tools and accessibility of content had the lowest satisfaction as can be seen in Table 5.26.

The results of the satisfaction survey are the answers to the fourth question of this study. These results are lower than the ratings about the level of importance in most of the system characteristics. This shows the need for further development and extended collaboration with the healthcare professionals in these systems.

5. 9 - Summary

The results of the CareNet study show the high level of ratings given to the importance of different system characteristics. The clinical outcome showed a not statistically significant improvement of HbA1C in the participants. The amount of usage and the contribution to the system was less than expected. The level of satisfaction was lower than the ratings for their importance in most of the system characteristics.

Chapter 6 Discussion

In this chapter, a comparison between the perceived levels of importance among patients and healthcare professionals for web-based diabetes e-learning is presented. This comparison is used for developing a framework for improvement of existing websites for diabetes education. Then the effect of different parameters about system usage on outcome of the evaluation is presented. Finally a model for measuring the effect of different characteristics of the current prototype on its effectiveness is presented.

6. 1 - Comparison of Web-based versus face-to-face diabetes education

The results from the review of the literature showed a promising prospect about implementation of web-based diabetes education. In this section a prospective model is developed using a system dynamics model to compare the potential effect of web-based versus traditional diabetes education. This part was published as a paper about ROI from web-based education of people living with diabetes (136). The data published after that paper showed that the current prevalence of diabetes is higher than the level that was initially expected. The model presented in this section is updated according to these changes.

Considering its lifelong duration, the high rate of diabetes will result in a very high cost of care for people living with diabetes. Also the complications of diabetes significantly increase the cost of diabetes care for healthcare providers. One of the best methods to prevent these complications is increasing the patient's responsibility for self-care via education and better self-control of blood glucose.

Based on reports from Department of Health the cost of diabetes care in the UK is £9.6 million per day (137). From the research of Wagner et al. (138) in 2001, we can assume that diabetes cost reduction is 7.5% per each percent of reduction in HbA1C. Structured education has shown to be able to help achieve a 1.6% reduction in HbA1C (139, 140).

Ko et al (141) in a randomized clinical trial (RCT) in 2007 and also some previous researchers (142, 143) evaluated diabetes education in long-term follow-ups of the educated patients and demonstrated that the efficacy of education is not long lasting; the difference between HbA1C level of the educated patients and the control group will not remain significant after one year. There are suggestions that continuous reinforcement may prevent this relapse (144).

Education capacity for diabetes in the UK is limited. Reports from Diabetes UK and the healthcare watchdog indicate that increase in coverage of structured education between 2005 and 2007 was 1.5% per year (145, 146). This capacity is unlikely to be efficient even for a single course of education: the 2007 report of the UK Healthcare

watchdog indicated that 11% of people living with diabetes received structured education (146). If we assume the level of diabetes patients waiting for education as an oven level (first in, first served) in the traditional diabetes education model, it takes approximately 60 years for a recently diagnosed person with diabetes to receive structured education. In most cases this timing is not compatible with their life expectancy. This reinforces the requirement for an alternative method for patient education.

E-Learning via the Internet has been used for many years in different courses as a wide spread and efficient method of education. This system has proven to be useful for diabetes education by many researchers, as is discussed in the literature review. A report from the Office of National Statistics (ONS) shows that 61% of UK households have access to the broadband Internet (147). There is no evidence that shows diabetes is limited to specific regions in the UK, so this method can cover a high percentage of people living with diabetes.

Literacy could be considered as a barrier for self-education via the web. In this research education in form of coaching by parents is not included because there is no quantitative evidence to substantiate it. Based on this assumption, the 12.5% of the UK population who are below 10 years old are not considered suitable for this method of education (148). Also there are some people who do not like to use high-tech systems for any reason. This group is considered as a technology-refusing group. Based on reports from similar web-based education, the percentage of flow toward this level is considered equal to 18.72% (149). Another limiting factor for people living with diabetes is mortality rate. Based on a Diabetes UK report (150) this rate in diabetes is 5 times more than the mortality rate of the general population which equals 4.1% in the UK (151).

Most of the previous similar studies were retrospective and did not give prospective financial information. This section aims to build a prospective model to examine the effect of diabetes education.

There are many interrelated factors affecting diabetes education and its cost reduction that makes it a complicated model. In this part of the study system dynamics modelling is used to predict the flow of patients in the education system and calculate the cost of care comparing between traditional (see Figure 6.1) and web-based educational systems (see Figure 6.2).

PowerSim version 2005 was used for drawing diagrams and simulation of the models. Separate models were developed for each educational method and variables affecting the system were included in those models. For a long-term prospect the models were simulated until 2020 with one year intervals. In both models the total cost of diabetes care was considered as a system level which showed the cumulative value of diabetes care in all people living with diabetes.

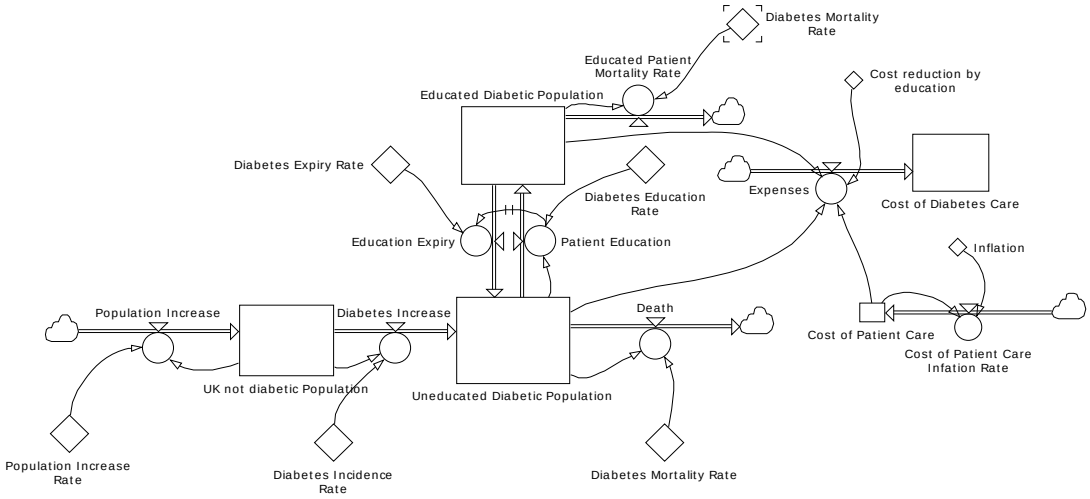

Figure 6.1: System dynamics model for traditional diabetes education

Based on the diabetes incidence rate as an increasing factor and diabetes mortality rate as a restricting factor in each cycle, the population of people living with diabetes was updated. The population of educated people living with diabetes was calculated based on the educational capacity and age limits in each method. In the traditional method, the people who received education were moved back to the uneducated population level next year based on the evidence mentioned earlier.

In web-based model the patients who are considered as technology-refusing cases

were moved to another level to separate them from the group that have the possibility to receive online education.

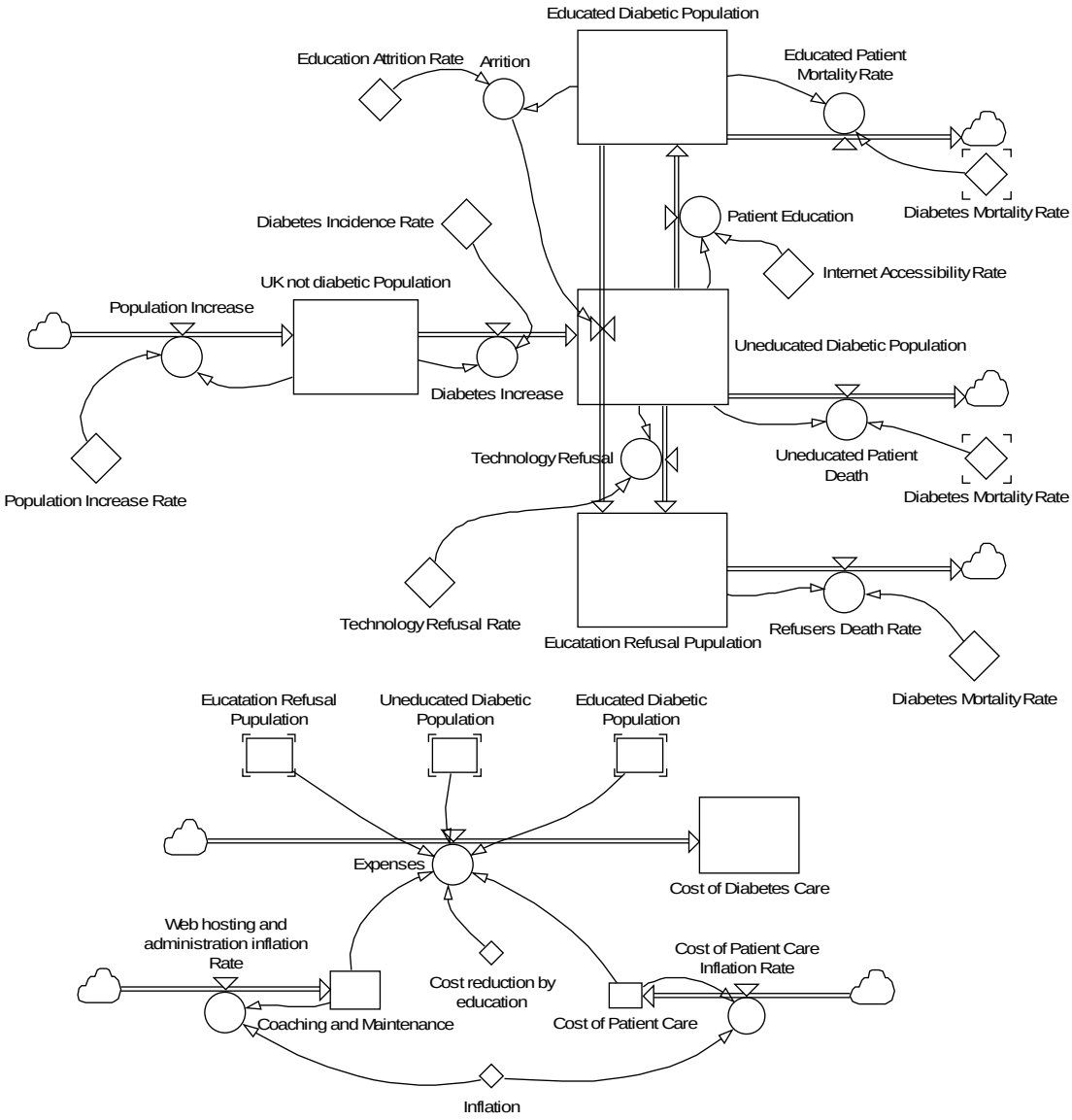

Figure 6.2: System dynamics model for web-based diabetes education

The cost of diabetes care was calculated based on the NHS report, per number of patients, considering the difference of cost between uneducated and educated patients. In the web-based model £50 million was estimated as the setup cost for the first year and £30 million for the cost of coaching, system maintenance and upgrading for each consecutive year (1000 band 5 nurses, IT infrastructure, administration and maintenance).

Because of the long duration of the model simulation (12 years) an inflation rate of 3% was added as a constant value affecting cost of diabetes care and cost of web-based diabetes education.

The population of the UK in 2008 was 61.1 million and was increasing at a rate of 0.9% in our model. As a result the UK population would be 66 million in 2020; which gives similar results to those used in the ONS model (148).

Based on the data obtained from prevalence and incidence of diabetes and its mortality rate, the population of people living with diabetes in the UK will be increased dramatically in this model leading to 3.3 million patients in 2020. According to these models, the web-based system will have 86.75% more educated people at the end of 2020 (see Figure 6.3).

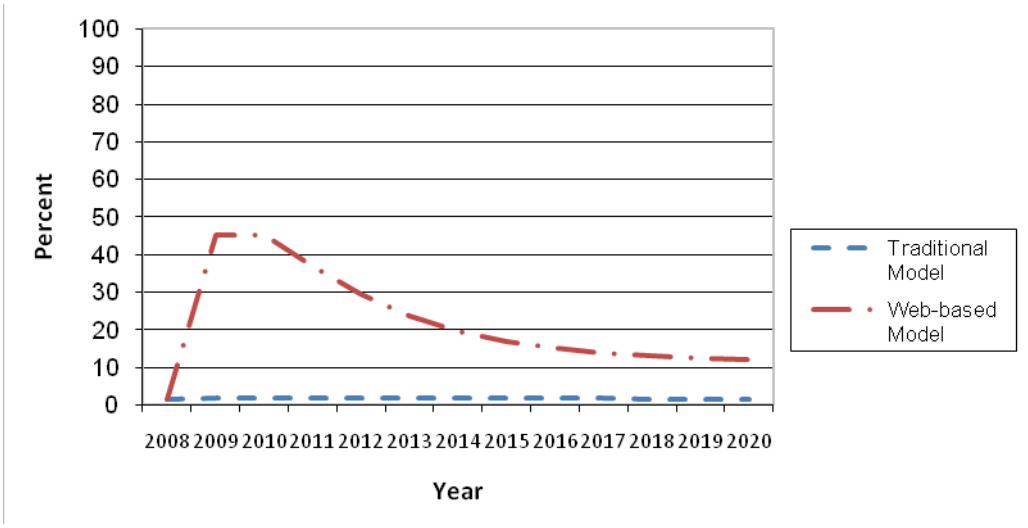

Figure 6.3: Forecast of diabetes education coverage in web-based vs. traditional education model

The annual cost of diabetes care in the traditional model will increase to £6.18 billion in 2020 whereas the web-based model will keep this cost to £6.16 billion.

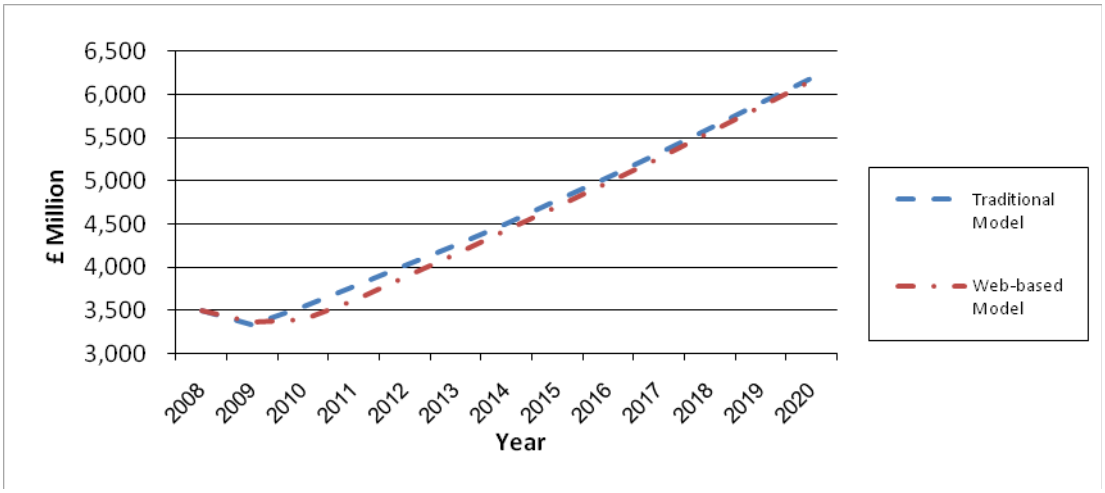

Figure 6.4: Forecast of diabetes education cost in web-based and traditional education model

Because of initial setup price and the low percentage of the educated people living with diabetes, the cost of the web-based system is higher in the first two years, but comparing with the traditional model, it will start to reduce significantly from the third year resulting in a final difference of cumulative cost to near £4 billion in 2020 (see Figure 6.4).

Year	Cumulative Cost of Traditional Model (£ Millions)	Cumulative Cost of Web-based model (£ Millions)
2008	3,500	3,500
2009	6,829	6,859
2010	10,380	10,255
2011	14,160	13,870
2012	18,178	17,750
2013	22,441	21,905
2014	26,955	26,335
2015	31,729	31,043
2016	36,772	36,030
2017	42,091	41,301
2018	47,696	46,863
2019	53,596	52,722
2020	59,779	58,886

Table 6.1: Cumulative cost of diabetes care in web-based and traditional diabetes education

Education in diabetes is a very simple and effective method. However, because of the limitations in requirements for establishing the educational system such as lack

of educators and conflict of programme scheduling with patients' other programmes, it could not be implemented on the required scale. The proposed web-based solution would be under development in the first year and will not increase the education rate. Although there is a large investment for the initial setup of this system, it will cover all the investments in the third year.

Return on Investment (RoI) is calculated using the following formula:

$$\frac{Benefit - Cost}{Cost} \times 100 = \frac{892{,}902{,}00\ 0 - 518{,}534{,}000}{518{,}534{,}000} \times 100 = 72\%$$

The average annual cost of diabetes care in the period of study is £3.5 billion and considering the results from this model it can be assumed that implementation of web-based education will be equal to one season free diabetes care for the UK.

There is a limiting factor in the outcome of this model which relates to attrition rate. As presented in the review of literature, the attrition rate in the previous studies was very variable. The maximum reported attrition rate (30%) was considered in this model. The introduction of Web 2.0 and online collaborative technologies is expected to decrease this phenomenon but there is no existing evidence regarding this.

Investment in web-based diabetes education is not a matter of benefit but a requirement to reduce the cost of diabetes on the NHS. The web-based system can be more compatible with the life style of the younger generation. Also this system can be attractive for expert patients, which is a major point of interest in recent policies of Department of Health (152), and can be implemented to expand the educational capacity of the system. This is the answer to the first question in this study about the potential impact of web-based diabetes education.

6. 2 - Specifications of candidates for online diabetes education

Comparison of demographic data between participants and non-participants showed that the only significant difference between the two groups was ethnicity with a greater proportion of white people participating in the study. The data for

this comparison were extracted from the PAS system and diabetes registries in participating hospitals. There could be other confounding factors causing the difference in their interest, but it was outside the scope of the data that were available. This is the answer to the second question of this study about the difference between the participants and non-participants.

6. 3 - Online Diabetes Education values

The participants in this part of the study gave the highest rating to technical issues and system support (Mean ± SD = 4.71 ± 0.87), and the lowest ratings to the coaching of the system (Mean ± SD = 4.41 ± 0.78). This rating shows that although this generation is considered as being computer-native, they are not fully confident on using this system and they expect proper support in order to be able to use this e-learning environment. Another result from this survey is that they consider such systems as a medium for extended communication with their healthcare providers. This conclusion is supported by the lower ratings for the content of the system. Also there is some other evidence for this theory that will be discussed in other aspects given to the value questionnaire. The higher importance of the technical support in comparison with the coaching in the system is evidence for the interest of the end-users in independence and self-discipline.

Among the values related to the content of the system, the highest rating was given to the availability of the content (Mean ± SD = 4.88 ± 0.81). The reliability of medical information on the Internet has always been a concern (153). This high rating shows that the patients are looking for a source of information that they can rely upon. The second highest rating was given to the availability of the educational content. This high rating is evidence for the usefulness of Internet-based education as it can be accessed at anytime and from anywhere with Internet access.

“Ease of use”, “organisation of the content” and “gathering information quickly” are all system characteristics related to usability. These characteristics were ranked after the availability characteristics discussed before. The participants believed that their disease and anything related to it is not a pleasant matter and they gave lower ratings to the “enjoyment from education” and “interesting subject matter”.

“Amount of material in the site”, “similarity of the interface” and “difficulty of the subject” had received a relatively low rating. This is further evidence that patients see this system as a communication channel to extend their connection with their healthcare team.

The next set of values relates to the learning coach. The highest rating in this group was given to “freedom of learning”. The high rating for this characteristic can be correlated with the low rating for “objective assignment” in the content values.

In this group the quality of interaction with the coach had relatively higher rating than its quantity. This difference can be explained by the experience of the patients with the very busy environment of the healthcare system.

The amount of learning from the coach has a relatively high rating which is further evidence for the interest of patients in direct connection with their healthcare team.

The other dimension of the system is about learners. In this group the highest rating was given to the amount of learning, which demonstrates their interest in learning. The second highest rating was given to self-discipline and time-management. This is in compliance with the high rating given to freedom of learning in the coach dimension. The other interesting result is between the “comfort with online learning” and “Internet and computer skills”. The higher rating in the being comfortable with the system and lowest rating given to computer skills show that the participants believed that they should not require high computer skills for being able to use the system.

“Family support” was ranked in the middle of this group (Mean ± SD = 4.53 ± 1.28). The high standard deviation in this characteristic shows the diversity of the idea about the role of the family in this learning process.

An unexpected result was obtained about the level of importance of interaction with other users. This characteristic received a lower rating which was even lower than the value given to the amount of interaction with the coach. This result shows

that the patients expect more communication with the healthcare team than socializing with others.

The last group of values are about the technical issues and system support. The highest rating in this group was given to system security (Mean ± SD = 5.29 ± 0.87). This was the highest rating among all characteristics of the e-learning system and it shows the great concern of the patients about exposing their clinical information on the Internet. For a successful integrated e-learning system for diabetes on the Internet, this is a key factor that should be addressed properly in order to obtain positive support from the users.

Also there was a high demand for a rapid response from the technical support team (Mean ± SD = 4.91 ± 0.87). This high rating can be discussed from two different points of view. From the users' perspective, it shows their interest in having a system which they could rely on and if they had any problems there would be someone available to help them. From the providers' point, it shows that such collaborative networks are not like general social networks which mostly work on a fire and forget model. The high expectation of the users for support in these systems limits their availability because enough human resources should be foreseen to support them. Considering this limiting requirement, it would be a wise choice to identify the people who are most likely to benefit from them and proactively invite them to join the system. The participants have given a higher rating to the speed of support. This shows the high demand for a system that can quickly help them resolve their real-time problems with health issues and with the usage of the system itself.

Accessibility of the content, dashboard interface and reduced system errors are all characteristics pointing to the design and development of the system and they received a relatively high rating. Although the ratings given to freedom of learning and objective assignment reflected the interest of the users to self-discipline, technical provision for flexibility of the learning obtained a lower rating compared to other technical and support characteristics. This outcome is consistent with the overall higher rating for technical issues and it is another piece of evidence for the

patients' view about these systems as a reliable communication channel with healthcare professionals, compared with a self-controlled learning environment. Both system speed and operation time have received relatively lower ratings.

The lowest ratings in this group were given to remote knowledge testing with quizzes and different system tools. This result shows that participants do not like to be tested and instead of a complete learning program, they are looking for a system fit for their specific needs.

Some of the participants made extensive use of the system tools later, when they had the chance to learn more about the capabilities of the system. For example, there was one participant whose parents were separated and had shared the responsibility of caring for the child. They used this system to communicate the blood sugar readings of their child for the intervals that the participant was with each of them and they said that it worked very well for them.

The participants were divided into adolescents and young people with the age cut-off point of sixteen. There was no significant difference on ratings given to the value of system characteristics among these two groups using a Mann-Whitney test. The level of significance was considered below 0.05.

6. 4 - Requirement engineering framework for improving websites developed for diabetes education

Although the previously mentioned diabetes education websites were designed for patients, the patients had not been involved in the design of the system from the beginning. There were some patient-centred studies, but they were mostly designed by computer experts according to the requirements provided by healthcare professionals. Bull et al studied the user friendliness, accessibility, interactivity and support level of the existing diabetes education websites and reported that the sites fell short of their potential to help consumers (154).

In this part of the discussion, the expectations of the patients as the end-users of the system and the healthcare professionals are compared using the value theory

applied to evaluation of the CareNet study. This comparison can highlight the difference between the opinions of those two groups and can be used as a requirement engineering model to change the currently developed systems to something more acceptable to its end-users.

There was no significant difference between the mean values of the main aspects of all the online diabetes education ingredients in these two groups (P=0.953) using a Mann-Whitney test, but comparison of the individual characteristics showed the significant differences listed in Table 6.2.

Characteristics significantly higher among the patients	P-Value
System security	0.03
Learning flexibility	0.043
Characteristic significantly higher among the professionals	**P-Value**
Different system tools	0.024

Table 6.2: Significant differences in values of online diabetes education between the patients and healthcare professionals

Although the two groups had no significant difference on the overall picture about this method of learning, their views demonstrated considerable differences about the detailed characteristics of it. The detailed comparison between these two groups is depicted in Figure 6.5.

Considering the system content, the patients gave more value to the difficulty of the subject matter and availability of the content. These are the items that need more investment in the current systems. On the other hand, enjoyment from the education and quality of the content had less importance comparing the patients with professionals, and increased investment in them will have less value.

Among the coaching-related characteristics only the amount of coach-learner interaction had a higher value voted by the patients and the others received less

relative value than the ratings from the professionals.

With regard to the learning characteristics, the patients were more concerned about self-discipline and comfort with online learning and their concern was less than that of the professionals regarding family support. This shows the evidence for their interest in independence. Also it emphasizes that organizers of these systems should ensure that their users have the required level of computer knowledge to utilize their service properly.

The other interesting piece of evidence in the learner-related characteristics is that patients gave much less value to the interaction with other users. It shows that the professionals are more interested in increasing the degree of collaboration among the patients, but patients consider these systems as a method to expand their direct channels of communication with their care team. High level of ratings for learning from the coach is further evidence for this result.

With regard to technical and support-related characteristics, the patients had the highest expectation on system security and learning flexibility. Their perceived level of importance was much lower than that of the professionals on taking quizzes remotely and different system tools. These ratings show that the patients see such systems more as a secure extension for their communication with their care team than a complete educational package.

6. 5 - Development of a rating tool for diabetes education websites

The very high reliability of the value questionnaire in this study resulted from Cronbach's Alpha test; this being an initiative for developing a rating tool for diabetes education websites. There are several existing tools for rating websites for consumers of health information. Eysenbach et al. (155) published a systematic review in 2002 about the application of some of these tools in assessing related websites.

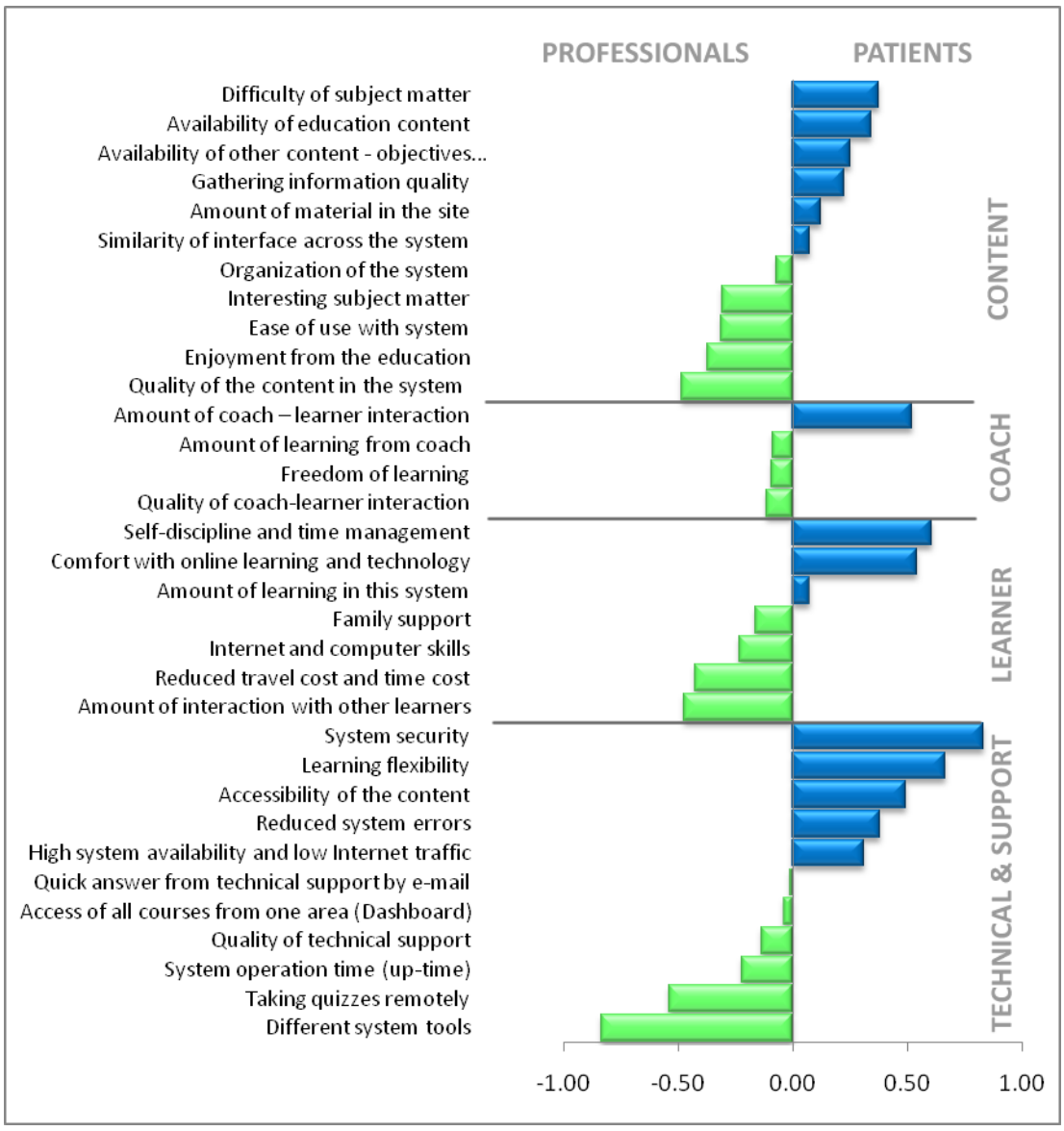

Figure 6.5: Comparison of levels of importance of diabetes e-learning characteristics expressed by patients and healthcare professionals

The factors that they used for this evaluation were:

- Accuracy
- Completeness
- Source
- Readability
- Technical
- Design

They identified two main scoring systems named DISCERN and SAM. They mentioned that these tools have not been validated in terms of showing that their higher score can reflect better health outcome.

The DISCERN instrument (156) was developed by the University of Oxford for NHS consumers helping them choose the best treatment. It has been used for both paper-based publications and electronic publications. It consists of 16 multiple-choice questions with ratings from one to five. The odd number of choices raises doubt about bias toward the mid-point in this instrument. The rating items are clearly tagged to help the users understand the meaning of each choice and a good scoring guide is provided for the users of this instrument to interpret the results.

Although this instrument was evaluated for rating the online information on the websites (157), it is completely focused on the content of the website and neither technical issues nor interaction between users are included in it.

The second instrument is Suitability Assessment of Materials (SAM) (158). This tool is used to rate the websites in six areas.

- Content
- Literacy demand
- Graphics
- Layout and type
- Learning stimulation and motivation
- Cultural appropriateness

It has 22 items. The rating model has only three levels which is very abstract and also raises the risk of central tendency. Similar to the previous instrument, the problem of neglecting the collaborative factors is also present in this tool.

Another review was published by Gagliardi and Jadad (159) in the same year. They identified 51 online accreditation instruments of which only five were functional and provided useful information. They also reported that their reliability had not been tested.

The other instrument which was used for the evaluation of diabetes related

websites by Thakurdesai et al. (153) in 2004 was the rating tool provided by the Health Summit Working Group (HSWG). The main criteria evaluated in this instrument are:

- Creditability
- Content
- Disclosure
- Links
- Design
- Interactivity
- Caveats

The added benefit in this tool is that of considering the interactivity between the users and system. However, yet again it does not include factors for measuring the collaboration between the users and it does not consider the difference between importance levels for different characteristics of the system

The last identified rating tool is the Information Quality Tool from Mitretek systems which changed its name to Noblis in 2007. This tool has 21 weighted questions. However, like with the other tools, the questions in this tool are only related to the content of the website.

This review of the existing instruments shows that there is a need for developing a new tool covering the educational and collaborative aspects of online diabetes education websites. Such a tool can be useful in the more accurate ranking of existing systems.

As explained before, the level of effectiveness in an information system depends on both the level of importance of its characteristics and the satisfaction of the end-users with them. King and Epstein (160) developed a linear model by using the two measures for accessing the value of information systems for importance of information system characteristics, the level of satisfaction produced by them and the overall value of the total system.

Their model was based on the following formula:

$$W=\sum V_i S_i$$

where "W" represents the overall satisfaction, V_i is relative measure of value for information system characteristic "i" and S_i is the level of satisfaction with that characteristic. Dividing the $V_i S_i$ by its maximum possible value (thirty-six) will result in a number between zero and one which is called the Learners' Value Index of Satisfaction (LeVIS) (122).

There are two methods to summarize the results of the value survey for each characteristic. The common method is using the arithmetic average of the responses to each characteristic. However, the geometric average has been suggested as the better choice for aggregation over individuals' judgement (161). The arithmetic mean uses addition to summarize data whereas geometric uses multiplication for this purpose and provides a lower score than the arithmetic mean. In this model the geometric mean was used for summarizing the characteristic values.

Characteristic Group	Characteristic Item	Coefficient
Content	Availability of educational content	0.54
	Amount of material in the site	0.48
	Interesting subject matter	0.51
	Difficulty of subject matter	0.45
	Availability of other content - objectives assignment	0.38
	Enjoyment from the education	0.52
	Quality of the content in the system	0.53
	Ease of use with system	0.53
	Similarity of interface across the system	0.43
	Gathering information quickly	0.53
	Organization of the system	0.54
Coach	Amount of coach – learner interaction	0.48
	Amount of learning from coach	0.49
	Quality of coach-learner interaction	0.49
	Freedom of learning	0.52

Characteristic Group	Characteristic Item	Coefficient
Learner	Amount of learning from the system	0.54
	Amount of interaction with other learners	0.42
	Comfort with online learning and technology	0.51
	Internet and computer skills	0.43
	Self-discipline and time management	0.51
	Reduced travel cost and time cost	0.45
	Family support	0.49
Technical & Support	Quick answer from technical support by e-mail	0.58
	Quality of technical support	0.53
	System operation time (up-time)	0.52
	Reduced system errors	0.55
	System security	0.62
	Accessibility of the content	0.55
	High system availability and low Internet traffic	0.53
	Learning flexibility	0.54
	Different system tools	0.47
	Access of all courses from one area (Dashboard)	0.52
	Taking quizzes remotely	0.46

Table 6.3: Value coefficients for diabetes website scoring model

In the next step the resultant mean values were multiplied by the mean dimension value to add the dimension weight to each characteristic. In the final step, all the mean characteristic values were divided by 38.74 so that the maximum possible score for “W” becomes one hundred. The final coefficients are listed in Table 6.3. A sample of the proposed questionnaire is included in the Appendix 8.

6. 6 - Clinical outcome

Analysis of the change in HbA1C showed a non-significant improvement in the participants. The trend of change in HbA1C was improved. The average before recruitment was -0.85 and the trend after recruitment was -1.69, but the difference was not statistically significant ($p = 0.725$)

Further analysis was performed to investigate this result based on different parameters. The young participants showed a greater improvement, but applying an Independent Sample Student t-test no significant difference was identified between these two groups $p (19, n = 21) = 0.829$.

The second analysis was performed to compare the results based on the amount of

system usage, the mean rating given to the resources, number of ratings and the improvement in the pre-test and post-test quizzes.

The number of browsed pages was weakly correlated with clinical improvement. The improvement in educational tests was moderately correlated with clinical improvement. The number and average of ratings given to external resources were negatively correlated to clinical improvement (see Table 6.4). This shows that the people who made greater use of the system needed it. There is a possibility that in a longer follow-up study an improvement in this group might be seen.

Parameter	Correlation (r)
Number of pages browsed	0.043
Number of ratings given to education resources	- 0.416
Average rating given to education resources	- 0.339
Improvement in education tests	0.371

Table 6.4: Correlation between amount of clinical improvement (HbA1C) and other parameters

These results are the answers to the fifth question of this study. The effect of other demographic parameters on clinical improvement was also investigated. There was no significant difference between the boys and girls, p (19, n = 21) = 0.343 using an Independent Sample Student t-test. An ANOVA test showed no significant difference between the ethnicity groups p (3, n = 21) = 0.274.

6. 7 - System Effectiveness Grid

Comparison between the satisfaction and the level of importance given to each characteristic of the developed website can help to highlight the future tasks needed to improve the effectiveness of this system. Initially a 2×2 grid model was designed which has the values on the Y axis and the satisfaction on the X axis. In this model each quadrant will represent a certain class for the characteristics (see Figure 6.6).

The first quadrant (Q1) is the upper right section which shows high importance and

high satisfaction. This quadrant encompasses the effective characteristics of the system. These are the points of strength in the system and are very good candidates for any advertisement for the system.

The second quadrant (Q2) will include the characteristics which have been highly valued but achieved a low satisfaction. The characteristics that fall into this class are the most important candidate for future investment. Proper improvement in relation to this group is the main factor in seeking to reduce user attrition.

The third quadrant (Q3) is the lower left section which represents the items with lower value and lower satisfaction. The characteristics that are shown in this section are less effective. They are generally at the stage of *status quo* and they can be disregarded. However a closer investigation may result in a plan to increase the value of these items by better introduction of them to the end-users.

The last quadrant (Q4) is the lower right section which has high satisfaction and low value. They are not very important to the users. The resources used for the characteristics falling in this section should be critically reviewed and if possible any investment in them transferred to other characteristics.

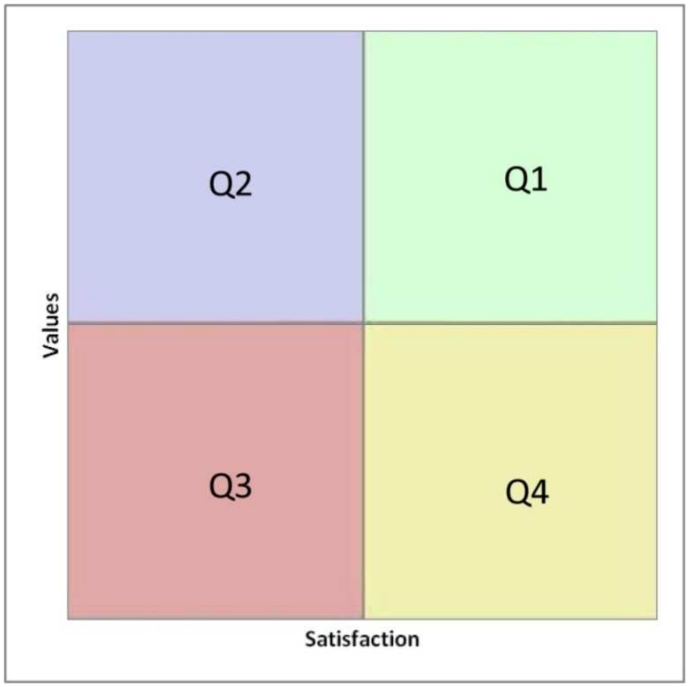

Figure 6.6: Effectiveness grid model

As was previously explained, the overall effectiveness of a system is the function of both values and satisfactions. In order to be able to evaluate the system in greater detail, hyperbolic curves are added to the above grid to present the LeVIS index and value-satisfaction grid in one diagram (see Figure 6.7). This extended grid can be labelled as follows (122):

- Q1a: High effectiveness
- Q1b: Moderate effectiveness
- Q2a: Easy Improvement effectiveness
- Q2b: Demanding improvement effectiveness
- Q3a: Low effectiveness
- Q3b: Least effectiveness
- Q4a: Misleading effectiveness
- Q4b: False effectiveness

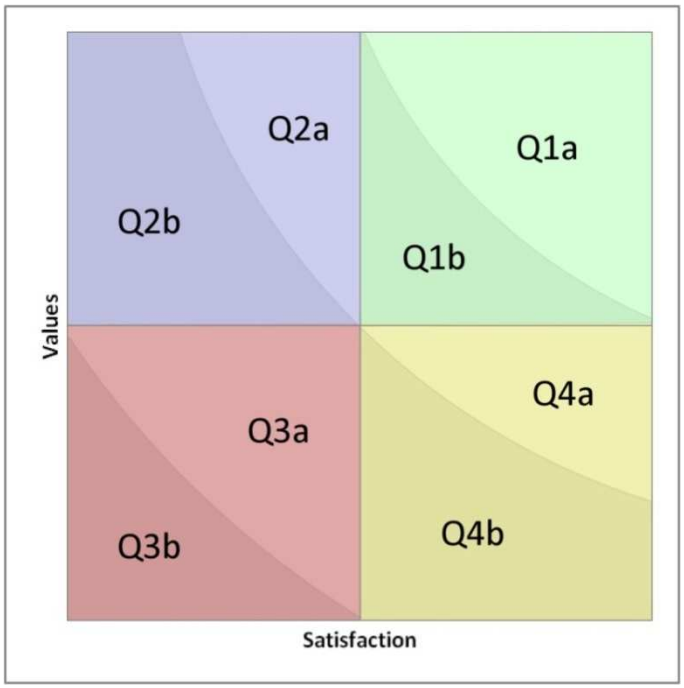

Figure 6.7: Effectiveness grid and LeVIS index model

Because there were no characteristics mapped in the lower left quadrant (value or satisfaction below 3), the grid was rescaled. The crossing point of the axes was moved to the value of 3 on both axes and the cut-off point was moved to 75% of

both axes which equals to 4.5.

6.7.1- Content grid

In this group the characteristics are loaded in the following areas (Figure 6.8):

- **Moderate effectiveness**
  - *C1 - Availability of educational content*

    The participants considered that the educational content is very important and they were satisfied with its availability in the system. The initial idea behind this system was to give them the opportunity to contribute to this content. However as previously explained, in the first month of the intervention they did not have any considerable activity until the principal investigator started to provide them with scheduled email and links to the information on the Internet. From that time on, usage increased considerably.

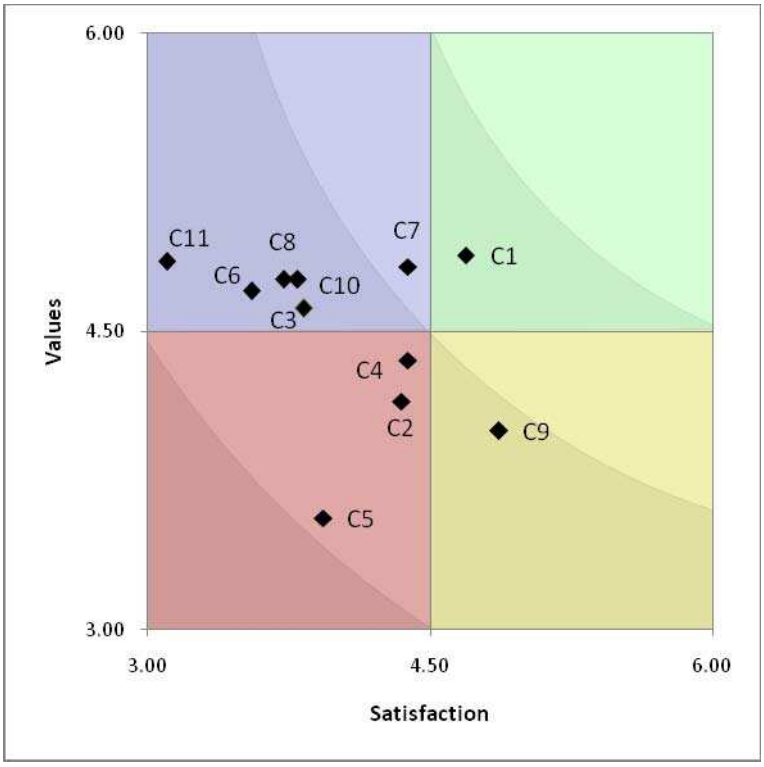

Figure 6.8: Effectiveness grid for content-related characteristics

- **Easy Improvement effectiveness**
  - *C7 - Quality of the content in the system*

    Although the quality of the content did not secure a very high importance rating, the participants were happy with it.

- **Demanding improvement effectiveness**
  - *C3 - Interesting subject matter*

    Disease-related information is not expected to be an interesting subject for the patients, especially when it comes to a disease such as diabetes with a wide range of complications. Participants had moderate satisfaction with it. It is noticeable that increasing the interest on the part of the subject is one of the key factors that can decrease the attrition rate and hence should be investigated for the future development in the CareNet.
  - *C6 - Enjoyment from the education*

    This characteristic has received a relatively low value and lower satisfaction. Enjoyment can be considered as one of the factors that can increase usage of the system. Increased quality of communication in the system can improve this enjoyment.
  - *C8 - Ease of use*

    This characteristic had relatively high value, but low satisfaction. Improved interface and human-computer interaction models should be implemented in the system to increase the satisfaction with this characteristic.
  - *C10 - Gathering information quickly*

    The education module of the CareNet study was designed for sequential learning. Moderate satisfaction with this characteristic highlights the requirement for a query-based model such as search engines for accessing the related resources quickly.
  - *C11 - Organization of the system*

This characteristic had the lowest satisfaction in this group. The reason behind this result is that the users were mostly looking for quick answers to their real-time questions and a complete set of educational topics was less appreciated.

- **Low effectiveness**
  - *C2 - Amount of material in the site*

    Although this characteristic was not very satisfactory for the participants, they did not contribute to it. More work should be done to increase the contribution of the users.
  - *C4 - Difficulty of subject matter*

    In studies such as CareNet, which are developed for lay people, it is very important to explain the subject in using easily understandable language. In general, the content-related items did not receive high value in the survey which could be evidence in favour of interest on the part of patients to communicate with their healthcare team rather than learning from the system itself. This characteristic received a moderate level of satisfaction.
  - *C5 - Availability of other content (objectives assignment)*

    This characteristic received the lowest value and relatively low satisfaction. Objective assignment is related to structured education but the participants were more interested in specific problem solving rather than a complete course.
- **False effectiveness**
  - *C9 - Similarity of interface across the system*

    Low value and high satisfaction with this characteristic shows that investment in it is sufficient and that in the future the development resources should be focused on other aspects of the system.

6.7.2- Coach grid

The characteristics in this group are categorized as shown in Figure 6.9 .

- **Demanding improvement effectiveness**
  - *H2 - Amount of learning from coach*

    The idea behind this study was providing a platform for group learning. This result shows that the patients are more interested in learning from a professional such as a member of their healthcare team.
  - *H4 - Freedom of learning*

    The low satisfaction with this characteristic is further evidence for their interest in being supported in relation to their specific problems. For the future studies, the healthcare team should focus on the individualized needs of the participants.
- **Low effectiveness**
  - *H3 - Quality of coach-learner interaction*

    This characteristic had relatively higher satisfaction, but like other characteristics it needs more improvement.

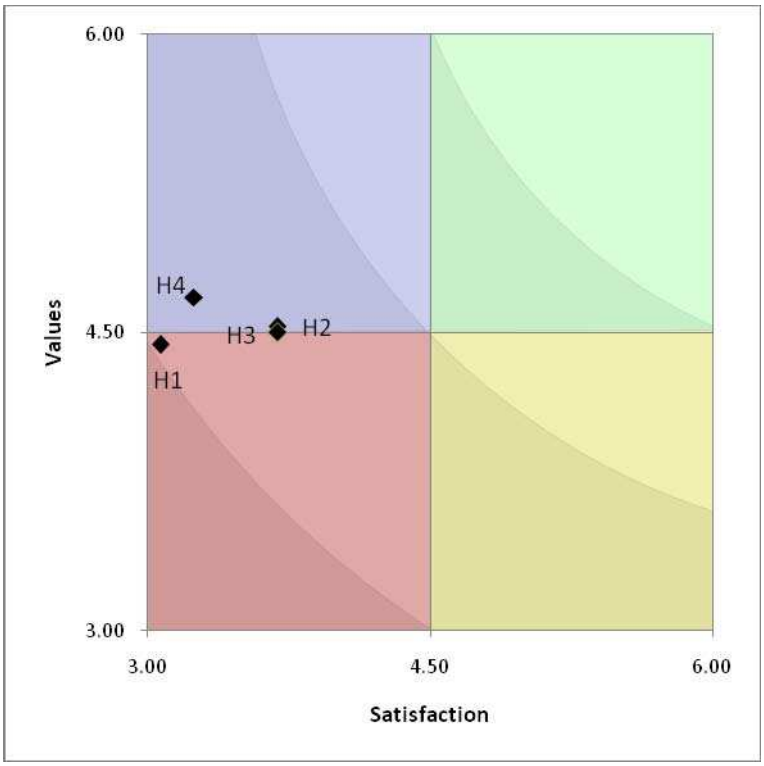

Figure 6.9: Effectiveness grid for coach-related characteristics

- *H1: Amount of coach–learner interaction*

  This characteristic had the lowest satisfaction in this group. In the first month of the evaluation the participants were given their accounts without any follow-up. The intention behind this method was to check how much they were going to use the system on their own. As presented in the results section, the amount of usage in that month was the least. In the following months, the interaction between the principal investigator and the participants was changed by sending emails with the links to the educational subjects two times a month. This intervention considerably increased the amount of usage. The result from the satisfaction survey shows an even higher expectation.

Low satisfaction in all characteristics related to this group provides evidence of the interest in being supported by the healthcare team responsible for the diabetes care of the participants.

6.7.3- Learner grid

For the learner characteristics the categorization is as follows (Figure 6.10):

- **Easy Improvement effectiveness**
  - *L1 - Amount of learning from the system*

    This characteristic was close to the effectiveness area. Adding a search capability to the system can move it to the effective level.
- **Demanding improvement effectiveness**
  - *L3 - Comfort with online learning and technology*

    The result from this characteristic highlights the requirement for more training on this topic.
  - *L5 - Self-discipline and time management*

    The level of satisfaction with this characteristic is less than its value. Although the participants expressed their interest in freedom for

learning, it seems that a general framework is required for them. This requirement is supported by the evidence of their increased usage of system once the reading plan was sent to them via email.

- *L7 - Family support*

  Family support was not satisfactory. Although the participants are of an age at which they are gaining independence, more support from their family is required to help them go through this process.

- **Low effectiveness**
  - *L4 - Internet and computer skills*

    Overall computer skill was more satisfactory than e-learning. So the above mentioned training should be more specific towards e-learning.

- **Least effectiveness**
  - *L2 - Amount of interaction with other learners*

    This was the least satisfactory characteristic. It was a limitation that was recognised from the beginning of the study. Because of the requirement from the participating hospitals about preventing the risk of wrong advice, it was not possible to provide free-text service such as blogs or chat-rooms to extend this communication.

- **False effectiveness**
  - *L6 - Reduced travel cost and time cost*

    This characteristic was not a very important point for the participants, but they were happy with the system from this point of view. The information about the amount of usage in different hours of the day is good evidence that they managed to use it at any time of the day.

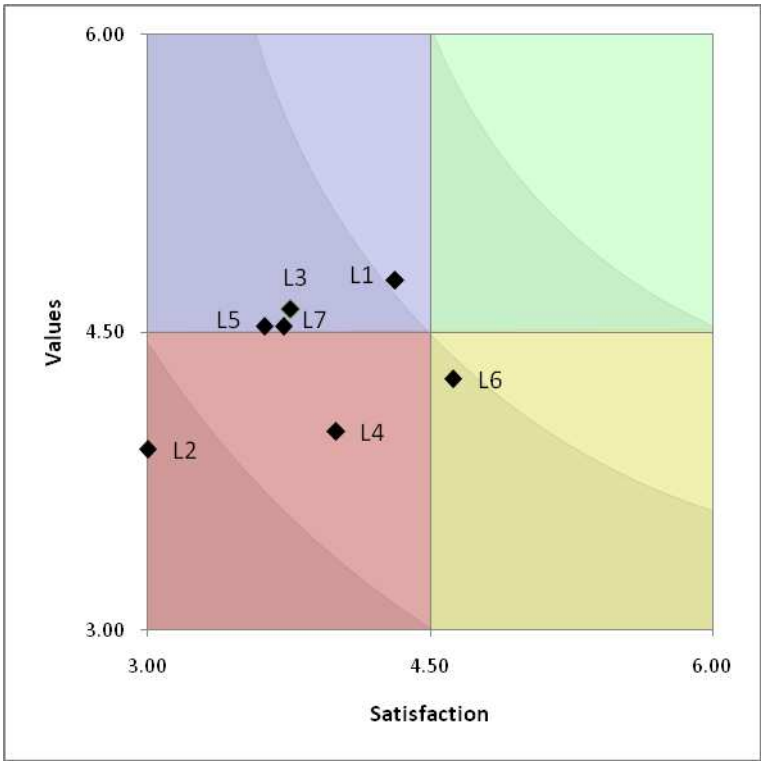

Figure 6.10: Effectiveness grid for learner-related characteristics

6.7.4- Technical and support grid

Technical and support related items appear in the following areas (Figure 6.11):

- **Moderate effectiveness**
  - *T1 - Quick answer from technical support by e-mail*

    This characteristic was important for the participants and the system managed to satisfy their need. For more improvement in the future, online support such as net-meeting service is suggested.
  - *T2 - Quality of technical support*
  - *T7 - High network ability and low Internet traffic*

    In relation to these characteristics, satisfaction was a near their perceived value. The important issue about this result is that CareNet was not utilized as much as had been expected. Providing features such as automatic uploading of blood glucose measurements and communication with the care team could increase this usage and shift the level of satisfaction with these characteristics.

- **Easy Improvement effectiveness**
  - *T5 - System security*

    This characteristic should be improved in the future. In the current trial, no evidence regarding unauthorized data access was recorded or reported, but it should be recognised that this characteristic was the most important one in the value survey.

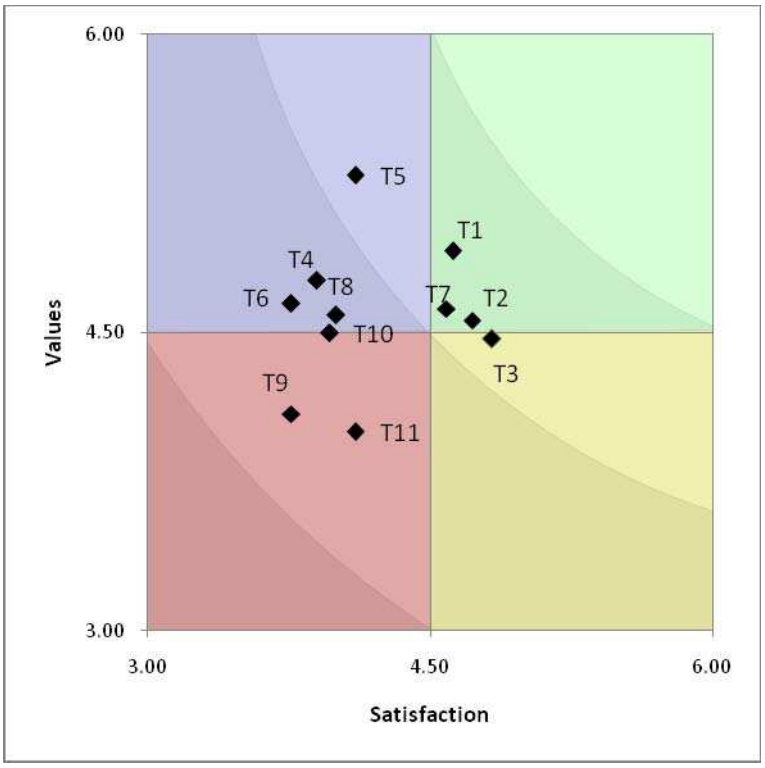

Figure 6.11: Effectiveness grid for technical and support-related characteristics

- **Demanding improvement effectiveness**
  - *T4 - Reduced system errors*

    This characteristic had a moderate level of satisfaction. The ability to directly upload blood glucose data was suggested by the users. However, this was not possible as explained previously. Also further improvement to the interface should be considered.
  - *T6 - Accessibility of the content*

    The content relating to the user-guide was provided in a separate pdf file which was available on the site. It was also attached to the welcome email sent to the participants. A separate help file for each

section enriched with multimedia is suggested to improve the satisfaction with this characteristic.

- *T8 - Learning flexibility*

  Problem-based education is a key concept in seeking to improve this characteristic. Because of a lack of access to blood glucose measurements, this concept could not be implemented in the current system. An ability to easily upload blood glucose measurements would be a means to improve this characteristic.

- *T10 - Access of all courses from one area (Dashboard)*

  This characteristic had moderate value and satisfaction. It can be made more useful if the idea about competition between the users is emphasized more by their healthcare team. The dashboard page had a gadget item to show the ranking of the user among all participants.

- **Low effectiveness**

  T9 - Different system tools

  Although this characteristic falls into the low effectiveness category, automated procedures to enrich the utilization of these tools, such as proposing meals based on the blood glucose levels at different times of the day can increase the value and satisfaction with regarding to this characteristic.

- *T11 - Taking quizzes remotely*

  The satisfaction with this characteristic was higher than its value. Higher acceptance regarding competition, such as providing an award for the best participant, can boost this characteristic.

- **Misleading effectiveness**

- *T3 - System operation time (up-time)*

  Although the satisfaction with this service was higher than its value, it should be emphasized that the sustainability of a service is a very important factor. In this evaluation there were no problems in this characteristic. However, increased system failure could easily reverse

the balance between value and satisfaction of this characteristic.

Considering the age grouping described before as adolescents and young participants, only one characteristic revealed significant difference between those two groups. The satisfaction with the amount of learning in the system was significantly higher in young participants using the Mann-Whitney test ($p = 0.01$).

In general the satisfaction survey shows that there should be more development in the CareNet study to increase its effectiveness. Also the contribution of the healthcare professionals in the development of this system should be increased.

6. 8 - Contribution to the knowledge

In the first year of this study, a system dynamics model was built to highlight the importance of web-based diabetes education. The result of this model motivated the researcher to study the effectiveness of collaborative web-based diabetes education system. A prototype system was built for this study and a model, based on theories in "information science", was adapted to evaluate the developed prototype.

Using this model, the level of importance of different aspects of online diabetes education was measured. The data collected for measuring these importance levels were used to build a rating tool for diabetes education websites.

The prototype website built for this study was used to evaluate the effect of different system parameters such as the most frequently used education topics and the level of satisfaction with the system. This measurement can be used as a baseline for further upgrades in the system in order to achieve greater effectiveness in future versions of CareNet. The effectiveness model used in this section provided the answer to the sixth question of this study.

The model developed for the evaluation of the CareNet can be applied to the evaluation of other websites for health education. It should be noted that the importance level of system characteristics can be different among people with other health problems. They should be measured in the first phase of those studies

before exposing the participants to the system.

6. 9 - Summary

The system dynamics model presented in this chapter showed the potentials of web-based diabetes education. The comparison between the people interested in diabetes education and the rest of candidates showed that other than ethnicity there was no significant difference between the two groups. The website rating model proposed in this chapter can be used for comparison between the existing systems and the comparison of the results from the value survey provided a framework for improving the existing systems.

The system effectiveness grid based on the results from the value and the satisfaction survey showed that most of the system characteristics in the developed prototype can be improved.

Chapter 7 Conclusion

In this chapter the outcome of the CareNet evaluation is summarized.

The CareNet study was developed as a prototype platform for the application of Web 2.0 technologies in diabetes education. The online survey tools integrated with this website allowed measurement to be made of the perceived levels of importance for different characteristics of collaborative e-learning for diabetes education. This value survey was conducted before using the CareNet website and its results can be extended to other websites for diabetes education.

One of the important findings in the value survey is the high level of importance given to the health coach. Many of the previous studies emphasized that patients lose proper control of their blood glucose a few months after receiving diabetes education and they concluded that re-enforcement of their education is required. However, no study has proved that the participants have lost the knowledge acquired in the intervention to relate it to the need for re-education. The result of this study emphasizes the user identification of need for extended coaching and support that they received during the intervention. Considering this assumption, it can be explained that after finishing those studies and going back to normal care, patients will not perform as well as they did during the study. Also it is potentially explained that a repeated educational process, which normally is combined with further follow-up and extended support, can bring them back to a state in which their disease is well managed.

A website rating tool was built using the data in value survey. Although this rating tool should be further evaluated to identify the threshold level for clinical effectiveness, it can be used as an instrument to boost the competition among diabetes education websites. This competition can result in improvement of those websites toward the requirements of their end-users.

A six-month follow-up of participants in this study showed improvement in HbA1C as an indicator of blood glucose control. The improvement had moderate correlation with the amount of learning from the system.

There is scope for further improvement of this platform to enable it to become more effective. Evidence for this has been provided by the results from the

satisfaction survey carried out at the end of this intervention, the effectiveness model developed using these results and the results from the value survey at the beginning of the evaluation.

The main outcomes of these surveys are the evidence for two requirements. The first requirement is that the education systems for diabetes should be oriented toward resolving the specific needs of the patients. To achieve this goal these systems should be integrated with the clinical data of the patients using an automated process that does not require the patients to type in their data. The second requirement is the direct involvement of the healthcare professionals, who have the authority to modify the treatment of the patients, in these systems. These professionals are expected to work as e-coaches in the system.

Following studies are recommended based on the findings in this study:

- Improve the characteristics with low perceived effectiveness and measure the educational and clinical outcome of the website after those changes.
- A long-term follow-up of the diabetes education with the developed system for at least two years.
- Validation of the ranking tool for diabetes education websites by applying it to several existing systems and comparing the outcome of the ranking with the educational and clinical effectiveness of those websites
- Applying the similar model for development of ranking tools for websites developed for other chronic diseases.

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Appendices

Appendix 1. Database Directory

CareNet database is developed using Microsoft SQL Server 2005. The collation selected for this database was Latin General and Case Insensitive for compatibility with Unicode in case of future Globalization of system for other languages.

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1. Table CareNet.dbo.aspnet_Applications

#	Column Name	Data type	Comment
1	ApplicationName	nvarchar(256)	Name of ASP.Net application
2	LoweredApplicationName	nvarchar(256)	Application name for case sensitive lookups
3	ApplicationId	uniqueidentifier	Identifier of the applications table
4	Description	nvarchar(256)	Description of the application

2. Table CareNet.dbo.aspnet_Membership

#	Column Name	Data type	Comment
1	ApplicationId	uniqueidentifier	Reference to applications table
2	UserId	uniqueidentifier	Reference to the users table
3	Password	nvarchar(128)	Stores the password for the user in the format configured on SqlMemershipProvider
4	PasswordFormat	int	Used internally by system when decoding the value in the Password and PasswordAnswer columns.
5	PasswordSalt	nvarchar(128)	The system will automatically hashes passwords and password answers using a string that consists of the text and the random salt values.
6	Email	nvarchar(256)	Users' Email Address
7	LoweredEmail	nvarchar(256)	Users' Email Address for case sensitive lookups
8	PasswordQuestion	nvarchar(256)	Text of the password question for password recovery
9	PasswordAnswer	nvarchar(128)	The user's secret answer to a password question
10	IsApproved	bit	Stores the approval state of registered users
11	IsLockedOut	bit	Stores information for checking locked users because of several incorrect login attempts
12	CreateDate	datetime	Date of account creation

#	Column Name	Data type	Comment
13	LastLoginDate	datetime	Last date of successful login
14	LastPasswordChangedDate	datetime	Last password change date
15	LastLockoutDate	datetime	Last account lockout date
16	FailedPasswordAttemptCount	int	Number of failed login attempts
17	FailedPasswordAttemptWindowStart	datetime	Number of password change requests
18	FailedPasswordAnswerAttemptCount	int	Number of failed password change attempts
19	FailedPasswordAnswerAttemptWindowStart	datetime	Time of failed password change attempts
20	Comment	ntext	Administrator note about the user

3. Table CareNet.dbo.aspnet_Paths

#	Column Name	Data type	Comment
1	ApplicationId	uniqueidentifier	Reference to applications table
2	PathId	uniqueidentifier	Identifier of this table
3	Path	nvarchar(256)	Path to the application in IIS Server
4	LoweredPath	nvarchar(256)	Path for lower case lookups

4. Table CareNet.dbo.aspnet_PersonalizationAllUsers

#	Column Name	Data type	Comment
1	PathId	uniqueidentifier	Reference to paths table
2	PageSettings	image	General settings for this path
3	LastUpdatedDate	datetime	Last update date for this setting

5. Table CareNet.dbo.aspnet_PersonalizationPerUser

#	Column Name	Data type	Comment
1	Id	uniqueidentifier	Identifier for this table

#	Column Name	Data type	Comment
2	PathId	uniqueidentifier	Reference to path table
3	UserId	uniqueidentifier	Reference to users table
4	PageSettings	image	User specific settings
5	LastUpdatedDate	datetime	Last update date for this setting

6. Table CareNet.dbo.aspnet_Profile

#	Column Name	Data type	Comment
1	UserId	uniqueidentifier	Reference to Users table
2	PropertyNames	ntext	Name of property
3	PropertyValuesString	ntext	Value of the property
4	PropertyValuesBinary	image	Binary code for the value
5	LastUpdatedDate	datetime	Last update date for this property

7. Table CareNet.dbo.aspnet_Roles

#	Column Name	Data type	Comment
1	ApplicationId	uniqueidentifier	Reference to applications table
2	RoleId	uniqueidentifier	Identifier of roles table
3	RoleName	nvarchar(256)	Role name
4	LoweredRoleName	nvarchar(256)	Lower case name for case sensitive lookups
5	Description	nvarchar(256)	Description of the role

8. Table CareNet.dbo.aspnet_Users

#	Coumn Name	Data type	Comment
1	ApplicationId	uniqueidentifier	Reference to applications table
2	UserId	uniqueidentifier	Identifier of users table
3	UserName	nvarchar(256)	User name
4	LoweredUserName	nvarchar(256)	Lower case user name for case sensitive lookups
5	MobileAlias	nvarchar(16)	Mobile alias user name

6	IsAnonymous	bit	The anonymous flag
7	LastActivityDate	datetime	Last activity date for this user

9. Table CareNet.dbo.aspnet_UsersInRoles

#	Column Name	Data type	Comment
1	UserId	uniqueidentifier	Reference to users table
2	RoleId	uniqueidentifier	Reference to roles table

10. Table CareNet.dbo.aspnet_WebEvent_Events

#	Column Name	Data type	Comment
1	EventId	char(32)	Identifier of events table
2	EventTimeUtc	datetime	Time of the event in Coordinated Universal Time format
3	EventTime	datetime	Time of the event in simple format
4	EventType	nvarchar(256)	Type of the event
5	EventSequence	decimal(19,0)	Hierarcy for this event
6	EventOccurrence	decimal(19,0)	Order of the event
7	EventCode	int	Event error code
8	EventDetailCode	int	Event detailed code based on .Net framework
9	Message	nvarchar(1024)	Message played back to user
10	ApplicationPath	nvarchar(256)	Local path of the application raising the event
11	ApplicationVirtualPath	nvarchar(256)	Virtual path of the application raising the event
12	MachineName	nvarchar(256)	Name of the machine running the application
13	RequestUrl	nvarchar(1024)	Requested Url related to this event
14	ExceptionType	nvarchar(256)	Type of exception raised
15	Details	ntext	Detail of the error

11. Table CareNet.dbo.ClinicalDataItem

#	Column Name	Data type	Comment
1	ClinicalDataItemID	numeric(18,0)	Identifier of clinical data item
2	ClinicalDataItemName	nvarchar(100)	Name of the clinical data item

3	ClinicalDataValueType	smallint	Data type of the clinical data item
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

12. Table CareNet.dbo.ClinicalDataValueType

#	Column Name	Data type	Comment
1	TestValueTypeID	smallint	Identifier of clinical data type
2	TestValueTypeName	nvarchar(50)	Type of clinical data (ordinal, scale etc)
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

13. Table CareNet.dbo.Concepts

#	Column Name	Data type	Comment
1	ConceptID	numeric(18,0)	Identifier of the concepts table
2	ConceptName	varchar(255)	Name of the concept of ontology
3	SCTID	numeric(18,0)	Reference to SNOMED-CT table
4	ParentConcept	numeric(18,0)	Parent of this concept
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

14. Table CareNet.dbo.ConceptTopic

#	Column Name	Data type	Comment
1	ConceptTopicID	numeric(18,0)	Identifier of ConceptTopic table
2	Concept	numeric(18,0)	Reference to concepts table
3	EducationTopic	numeric(18,0)	Reference to education topics table
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

15. Table CareNet.dbo.Delegation

#	Column Name	Data type	Comment

#	Column Name	Data type	Comment
1	DelegationID	numeric(18,0)	Identifier of the delegations table
2	Proposer	uniqueidentifier	Proposer of delegation
3	Pair	uniqueidentifier	Accepter of delegation
4	Withdrawer	uniqueidentifier	Person withdrawing the delegation
5	InitialLevel	tinyint	Initial level of delegation
6	Demographic	tinyint	Delegation of access to demographic data (Not used in this phase of research)
7	Educational	tinyint	Delegation of access to educational data (Not used in this phase of research)
8	Clinical	tinyint	Delegation of access to clinical data
9	PropositionTime	datetime	Date and time of proposal
10	AcceptanceTime	datetime	Date and time of acceptance
11	WithdrawalTime	datetime	Date and time of withdrawal
12	ProposerRating	tinyint	Rating from the proposer
13	PairRating	tinyint	Rating from the accepter
14	Editor	uniqueidentifier	User that recorded this item
15	Edition	datetime	Date and time of recording

16. Table CareNet.dbo.DelegationLevel

#	Column Name	Data type	Comment
1	DelegationLevelID	tinyint	Identifier of the delegation Level table
2	DelegationLevelName	nvarchar(50)	Name of delegation level
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

17. Table CareNet.dbo.DelegationTrack

#	Column Name	Data type	Comment
1	DelegationTrackID	numeric(18,0)	Identifier of the delegations track table
2	Proposer	uniqueidentifier	Proposer of delegation
3	Acceptor	uniqueidentifier	Accepter of delegation
4	Withdrawer	uniqueidentifier	Person withdrawing the delegation
5	InitialLevel	tinyint	Initial level of delegation
6	Demographic	tinyint	Delegation of access to demographic data (Not used in this phase of research)
7	Educational	tinyint	Delegation of access to educational data (Not used in this phase of research)
8	Clinical	tinyint	Delegation of access to clinical data
9	PropositionTime	datetime	Date and time of proposal
10	AcceptionTime	datetime	Date and time of acceptance
11	WithdrawalTime	datetime	Date and time of withdrawal
12	ProposerRating	tinyint	Rating from the proposer
13	PairRating	tinyint	Rating from the accepter
14	Editor	uniqueidentifier	User that recorded this item
15	Edition	datetime	Date and time of recording

18. Table CareNet.dbo.EducationHeadline

#	Column Name	Data type	Comment
1	EducationHeadlineID	numeric(18,0)	Identifier of education headlines
2	EducationHeadlineName	nvarchar(200)	Name of education headline
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

19. Table CareNet.dbo.EducationSatisfactionRate

#	Column Name	Data type	Comment
1	EducationSatisfactionRateID	numeric(18,0)	Identifier of education satisfaction table
2	EducationValue	int	Reference to education values table
3	EducationSatisfactionRate	smallint	Satisfaction rate
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

20. Table CareNet.dbo.EducationTopicOrder

#	Column Name	Data type	Comment
1	EducationTopicOrderID	numeric(18,0)	Identifier of education topics order table
2	EducationTopic	numeric(18,0)	Reference to education topics table
3	EducationTopicOrder	numeric(18,0)	Oder of education topic in education headlines
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

21. Table CareNet.dbo.EducationTopics

#	Column Name	Data type	Comment
1	EducationTopicID	numeric(18,0)	Identifier of education topics table
2	EducationTopicName	nvarchar(200)	Name of education topic based on NICE recommendation
3	EducationTopicShortName	nvarchar(100)	Short name of education topic
4	EducationHeadline	numeric(18,0)	Corresponding education headline
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

22. Table CareNet.dbo.EducationValueGroups

#	Column Name	Data type	Comment
1	EducationValueGroupID	int	Identifier of education value group table
2	EducationValueGroupN-ameEn	nvarchar(50)	Name of education value group
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

23. Table CareNet.dbo.EducationValueRate

#	Column Name	Data type	Comment
1	EducationValueRateID	numeric(18,0)	Identifier of education value rate table
2	EducationValue	int	Reference to education value table
3	EducationValueRate	smallint	Ratings for that value
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

24. Table CareNet.dbo.EducationValues

#	Column Name	Data type	Comment
1	EducationValueID	int	Identifier of education values table
2	EducationValueNameEn	nvarchar(100)	Name of the education value
3	EducationValueType	smallint	Reference to education value type table
4	EducationValueGroup	int	Reference to education value groups table
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

25. Table CareNet.dbo.ExternalResourceConcept

#	Column Name	Data type	Comment
1	ExternalResourceConce-ptID	numeric(18,0)	Identifier of external resource concept table
2	ExternalResource	numeric(18,0)	Reference to external resources table
3	Concept	numeric(18,0)	Reference to concepts table
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording
6	Approver	uniqueidentifier	User that approved this item
7	Approval	datetime	Approval time

26. Table CareNet.dbo.EducationValueTypes

#	Column Name	Data type	Comment
1	EducationValueTypeID	smallint	Identifier of education value type table
2	EducationValueName	nvarchar(50)	Name of education value
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

27. Table CareNet.dbo.ExternalResources

#	Column Name	Data type	Comment
1	ExternalResourceID	numeric(18,0)	Identifier of external resources table
2	ExternalResourceName	nvarchar(200)	Name of external resource
3	ExternalResourceURL	nvarchar(200)	URL address of the resource
4	ExternalResourceDescri-ption	nvarchar(400)	Description of the resource
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

28. Table CareNet.dbo.ExternalResourceTopicRate

#	Column Name	Data type	Comment
1	ExternalResourceTopic-RateID	numeric(18,0)	Identifier of external resource topic rate table

#	Column Name	Data type	Comment
2	EducationTopic	numeric(18,0)	Reference to education topic table
3	ExternalResource	numeric(18,0)	Reference to external resource table
4	Rate	tinyint	Rating provided by user
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

29. Table CareNet.dbo.Food

#	Column Name	Data type	Comment
1	NDBNo	numeric(18,0)	Reference Number for food table
2	FDGP_CD	numeric(18,0)	Code of food group
3	DESC	nvarchar(200)	Description of the food item
4	SCINAME	nvarchar(60)	Scientific Name
5	N_FACTOR	float	Factor for converting nitrogen to protein
6	PRO_FACTOR	float	Factor for calculating calories from protein
7	FAT_FACTOR	float	Factor for calculating calories from fat
8	CHO_FACTOR	float	Factor for calculating calories from carbohydrate
9	Water	real	Water content of the food item
10	Energy	real	Energy content of the food item
11	Protein	real	Protein content of the food item
12	Lipid	real	Lipid content of the food item
13	Carbohydrate	real	Carbohydrate content of the food item
14	TDF	real	Total Dietary Fiber
15	Ash	real	Ash content of the food item
16	Calcium	real	Calcium content (mg/100 g)
17	Phosphorus	real	Phosphorus content (mg/100 g)
18	Iron	real	Iron content (mg/100 g)
19	Sodium	real	Sodium content (mg/100 g)
20	Potassium	real	Potassium content (mg/100 g)

#	Column Name	Data type	Comment
21	Magnesium	real	Magnesium content (mg/100 g)
22	Zinc	real	Zinc content (mg/100 g)
23	Copper	real	Copper content (mg/100 g)
24	Manganese	real	Manganese content (mg/100 g)
25	Selenium	real	Selenium content (mcg/100 g)
26	Vitamin A	real	Vitamin A content (IU/100 g)
27	Vitamin E	real	Vitamin E content (mg /100 g)
28	Thiamin	real	Vitamin B1 content (mg/100 g)
29	Riboflavin	real	Vitamin B2 content (mg/100 g)
30	Niacin	real	Vitamin B3 content (mg/100 g)
31	Pantothenic Acid	real	Vitamin B5 content (mg/100 g)
32	Vitamin B6	real	Vitamin B6 content (mg/100 g)
33	Folate	real	Vitamin B9 content (mg/100 g)
34	Vitamin B12	real	Vitamin B12 content (mg/100 g)
35	Vitamin C	real	Vitamin C content (mg/100 g)
36	Sat FA	real	Saturated fatty acid (g/100 g)
37	Mono FA	real	Monounsaturated fatty acid (g/100 g)
38	Poly FA	real	Polyunsaturated fatty acid (g/100 g)
39	Cholesterol	real	Cholesterol (g/100 g)
40	GmWt1	real	Weight of Unit 1 /gr
41	GmWt_Desc	nvarchar(255)	Name of measurement unit 1
42	GmWt2	real	Weight of unit 2 /gr
43	GmWt2_Desc	nvarchar(255)	Name of Measurement unit 2

30. Table CareNet.dbo.FoodFootNote

#	Column Name	Data type	Comment
1	NDB_No	nvarchar(5)	Reference to Food Identifier
2	Footnt_No	nvarchar(4)	Food Note table Identifier

#	Column Name	Data type	Comment
3	Footnt_Typ	nvarchar(15)	The type of footnote: D=indicates a footnote adding information to the description N=indicates a footnote providing additional information on a nutrient value. If the Footnt_typ = N, the Nutr_Nowill also be filled in.
4	Nutr_No	nvarchar(3)	Identifier of food nutrient
5	Footnt_Txt	nvarchar(200)	Note text

31. Table CareNet.dbo.FoodGroup

#	Column Name	Data type	Comment
1	FDGP_CD	numeric(18,0)	Identifier of food group
2	FDGP_DESC	nvarchar(60)	Name of food group

32. Table CareNet.dbo.FoodMeasure

#	Column Name	Data type	Comment
1	MSRE_NO	numeric(18,0)	Identifier of measurement unit table
2	MSRE_DESC	nvarchar(120)	Name of measurement unit

33. Table CareNet.dbo.FoodNutdata

#	Column Name	Data type	Comment
1	NDBNo	numeric(18,0)	Identifier of food
2	NutrientNo	numeric(18,0)	Identifier of nutrient
3	Value	float	Measure of the nutrient in the food
4	N	int	Number of samples
5	SE	float	Standard error of mean
6	SrcCD	int	Identifier of food source table

34. Table CareNet.dbo.FoodNutrDef

#	Column Name	Data type	Comment
1	NUTR_NO	numeric(18,0)	Reference to nutrient table
2	UNITS	nvarchar(6)	Unit of measurement
3	TAGNAME	nvarchar(20)	Tag name for food
4	NUTRDESC	nvarchar(60)	Description of nutrient

35. Table CareNet.dbo.FoodQuiz

#	Column Name	Data type	Comment
1	FoodQuizID	numeric(18,0)	Identifier of food quiz table
2	Publish	bit	Flag for accessibility
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

36. Table CareNet.dbo.FoodQuizAnswer

#	Column Name	Data type	Comment
1	FoodQuizAnswerID	numeric(18,0)	Identifier of food quiz answer table
2	FoodQuiz	numeric(18,0)	Reference to food quiz table
3	FoodQuizAnswer	decimal(18,0)	Participants answer to quiz
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

37. Table CareNet.dbo.FoodQuizItem

#	Column Name	Data type	Comment
1	FoodQuizItemID	numeric(18,0)	Identifier of food quiz item
2	FoodQuiz	numeric(18,0)	Reference to food quiz
3	FoodQuizItem	numeric(18,0)	Reference too food item
4	FoodQuizMeasureUn-it	numeric(18,0)	Measurement unit for food item
5	FoodQuizMeasureA-mount	decimal(18,0)	Amount of food item
6	Editor	uniqueidentifier	User that recorded this item
7	Edition	datetime	Date and time of recording

38. Table CareNet.dbo.FoodSource

#	Column Name	Data type	Comment
1	SRC_CD	int	Identifier of source table
2	SRCCD_DESC	nvarchar(60)	Description of information source for food nutrients

39. Table CareNet.dbo.FoodWeight

#	Column Name	Data type	Comment
1	NDB_NO	numeric(18,0)	Reference to food identifier
2	MSRE_NO	numeric(18,0)	Reference to measurement unit
3	GM_WT	float	Weight in grams

40. Table CareNet.dbo.Gender

#	Column Name	Data type	Comment
1	GenderID	tinyint	Identifier of gender table
2	GenderName	char(10)	Name of gender
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

41. Table CareNet.dbo.HbA1C

#	Column Name	Data type	Comment
1	HbA1CID	tinyint	Identifier of HbA1C table
2	DCCT	decimal(3,1)	HbA1C based on DCCT Unit
3	IFCC	decimal(3,0)	HbA1C based on IFCC Unit

42. Table CareNet.dbo.InsulinType

#	Column Name	Data type	Comment
1	InsulinTypeID	tinyint	Identifier of insulin type
2	InsulinTypeName	nvarchar(100)	Name of insulin type
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

43. Table CareNet.dbo.MemberClinicalData

#	Column Name	Data type	Comment
1	MemberClinicalData-ID	numeric(18,0)	Identifier of member clinical data item
2	Member	uniqueidentifier	Reference to member table
3	ClinicalDataItem	numeric(18,0)	Reference to clinical data item table
4	ClinicalDataValue	float	Result of test for clinical data item
5	MeasureDate	datetime	Date of measurement
6	RelatedClinicalData	numeric(18,0)	Linked clinical data item
7	Annotation	nvarchar(2000)	Annotation from the user
8	Editor	uniqueidentifier	User that recorded this item
9	Edition	datetime	Date and time of recording

44. Table CareNet.dbo.MemberInsulin

#	Column Name	Data type	Comment
1	MemberInsulinID	numeric(18,0)	Identifier of member insulin table
2	Member	uniqueidentifier	Reference to member table
3	InsulinType	tinyint	Reference to insulin type table
4	InsulinDose	float	Dose of insulin
5	InjectionDate	datetime	Date and time of injection
6	Editor	uniqueidentifier	User that recorded this item
7	Edition	datetime	Date and time of recording

45. Table CareNet.dbo.MemberQuestion

#	Column Name	Data type	Comment
1	MemberQuestionID	numeric(18,0)	Identifier of member question table
2	MemberTest	numeric(18,0)	Reference to member test table
3	Question	numeric(18,0)	Reference to question table
4	Item	numeric(18,0)	Selected answer. Reference to question item table
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

46. Table CareNet.dbo.Members

#	Column Name	Data type	Comment
1	MemberID	numeric(18,0)	Identifier of member
2	MemberName	nvarchar(200)	Christian name of member
3	MemberSName	nvarchar(200)	Surname of member
4	MemDOB	datetime	Date of birth
5	MemGender	tinyint	Reference to gender table
6	AgeAtDiagnosis	tinyint	Age of diabetes onset
7	MemRace	tinyint	Ethnicity of member. Reference to race table
8	UserID	uniqueidentifier	User ID of member
9	Concent	bit	Flag for consent
10	InformDoctor	bit	Flag for informing the doctor
11	DoctorAddress	nvarchar(400)	Address of doctor
12	DataReuse	bit	Flag for data reuse permission
13	Relation	int	Relation to person with diabetes
14	Editor	uniqueidentifier	User that recorded this item
15	Edition	datetime	Date and time of recording

47. Table CareNet.dbo.MemberTest

#	Column Name	Data type	Comment
1	MemberTestID	numeric(18,0)	Identifier of member test table
2	Member	uniqueidentifier	Reference to member table
3	Topic	numeric(18,0)	Reference to education topic table
4	TestType	tinyint	Reference to test type
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

48. Table CareNet.dbo.QuestionItems

#	Column Name	Data type	Comment
1	QuestionItemID	numeric(18,0)	Question choice item identifier
2	Question	numeric(18,0)	Reference to question table
3	QuestionItemText	nvarchar(200)	Text of choice item
4	QuestionItemScore	float	Score of choice item

#	Column Name	Data type	Comment
5	Editor	uniqueidentifier	User that recorded this item
6	Edition	datetime	Date and time of recording

49. Table CareNet.dbo.Questions

#	Column Name	Data type	Comment
1	QuestionID	numeric(18,0)	Identifier of question table
2	QuestionText	varchar(100)	Text of question
3	QuestionTopic	numeric(18,0)	Education topic of question
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

50. Table CareNet.dbo.Race

#	Column Name	Data type	Comment
1	RaceID	tinyint	Identifier of Race Table
2	RaceName	nvarchar(50)	Name of Ethnicity
3	Editor	uniqueidentifier	User that recorded this item
4	Edition	datetime	Date and time of recording

51. Table CareNet.dbo.SNOMED-CT

#	Column Name	Data type	Comment
1	SCTID	numeric(18,0)	Identifier of SNOMED-CT Code
2	ConceptName	varchar(198)	Name of related concept
3	ParentSCTID	numeric(18,0)	Parent code
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

52. Table CareNet.dbo.TestType

#	Column Name	Data type	Comment
1	TestTypeID	tinyint	Identifier of the knowledge test type
2	TestTypeName	nvarchar(50)	Knowledge test type (Pre-test/ Post-test)
	Editor	uniqueidentifier	User that recorded this item

#	Column Name	Data type	Comment
4	Edition	datetime	Date and time of recording

53. Table CareNet.dbo.Videos

#	Column Name	Data type	Comment
1	VideoID	numeric(18,0)	Identifier of the videos table
2	VideoServer	int	Name of the server
3	VideoCode	nvarchar(100)	Unique code of the video on the server
4	Editor	uniqueidentifier	User that recorded this item
5	Edition	datetime	Date and time of recording

Appendix 2. Ethics Approval

Two applications were prepared for ethical approval:

- Application for City University ethics committee:

  We submitted this application to get the approval to recruit participants from diabetes related societies and foundations. Two diabetes related groups agreed to collaborate in this project and inform their members about it:

  - Juvenile Diabetes Research Foundation (JDRF)
  - Diabetes Research and Wellness Foundation (DRWF)

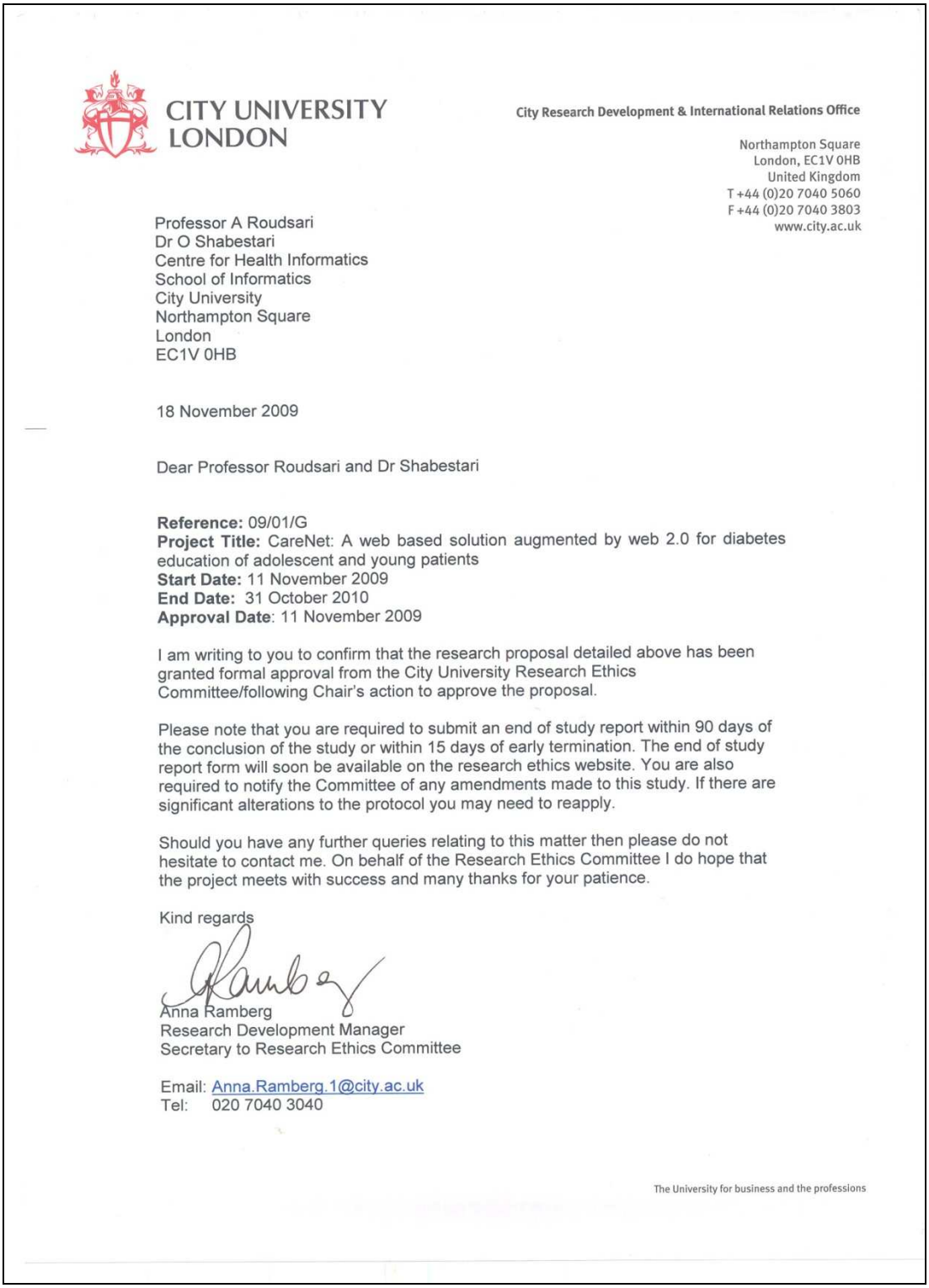
- Application for National Research Ethics Committee (NREC) in the NHS:

  We submitted this application to get the approval to recruit participants from the NHS endocrinology departments. As it was previously mentioned three NHS sites agreed to participate in this project:

  - Diabetes department in Mayday Hospital- Croydon
  - Diabetes department in Chase Farm Hospital – London
  - Diabetes community clinic in Birmingham

City University Ethics Approval

Application for ethical approval from City University was submitted in 01/07/2009. The application was registered with reference number 09/01/G and was approved at 11/11/2009.



CITY UNIVERSITY LONDON

City Research Development & International Relations Office

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www.city.ac.uk

Professor A Roudsari
Dr O Shabestari
Centre for Health Informatics
School of Informatics
City University
Northampton Square
London
EC1V 0HB

18 November 2009

Dear Professor Roudsari and Dr Shabestari

Reference: 09/01/G
Project Title: CareNet: A web based solution augmented by web 2.0 for diabetes education of adolescent and young patients
Start Date: 11 November 2009
End Date: 31 October 2010
Approval Date: 11 November 2009

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the City University Research Ethics Committee/following Chair's action to approve the proposal.

Please note that you are required to submit an end of study report within 90 days of the conclusion of the study or within 15 days of early termination. The end of study report form will soon be available on the research ethics website. You are also required to notify the Committee of any amendments made to this study. If there are significant alterations to the protocol you may need to reapply.

Should you have any further queries relating to this matter then please do not hesitate to contact me. On behalf of the Research Ethics Committee I do hope that the project meets with success and many thanks for your patience.

Kind regards

Anna Ramberg
Research Development Manager
Secretary to Research Ethics Committee

Email: Anna.Ramberg.1@city.ac.uk
Tel: 020 7040 3040

The University for business and the professions

NHS Ethics Approval

Application for National Research Ethics Service (NRES) in the NHS was approved in Outer North London Ethics committee.

NHS
National Research Ethics Service
Outer North London REC
Northwick Park Hospital
Room 018, Level 7 Maternity Block
Watford Road
Harrow
Middlesex
HA1 3UJ

Telephone: 020 8869 3805
Facsimile: 020 8869 5222

23 December 2009

Dr Omid Shabestari
PhD Student
City University
Centre for Health Informatics
City University
Northampton Square, London
EC1V 0HB

Dear Dr Shabestari

Study Title: **Evaluation of a controlled collaborative solution based on Web 2.0 technology for diabetes education of patients.**
REC reference number: **09/H0724/42**
Protocol number: **1.3**

Thank you for your letter of 21 December 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

The Adult Information Sheet incorrectly quotes the reviewing REC as the "Outer London Research Ethics Committee" - please revise this to read "Outer North London Research Ethics Committee". Please submit a corrected version for our files.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		06 November 2009
REC application		30 October 2009
Investigator CV		04 September 2009
Supervisor's CV		04 September 2009
Indemnity agreement		04 September 2009
Summary/Synopsis	Flow Chart	01 November 2009
Interview Schedules/Topic Guides	User Guide	30 October 2009
Participant Information Sheet: Adult	2	23 October 2009
Participant Information Sheet: Young People	2.1	23 October 2009
Participant Consent Form: Adult	2	23 October 2009
Participant Consent Form: Young People	2.1	23 October 2009
Assent Form	2	
Response to Request for Further Information	by e-mail	21 December 2009
Protocol	1.3	20 December 2009
GP/Consultant Information Sheets	1.1	12 December 2009
Questionnaire	1.5	20 December 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk

09/H0724/42	Please quote this number on all correspondence

Yours sincerely

pp.

Mrs Rosemary Hill
Chair

Email: Mona.Shah@nwlh.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL- AR2 for other studies]*

Copy to:

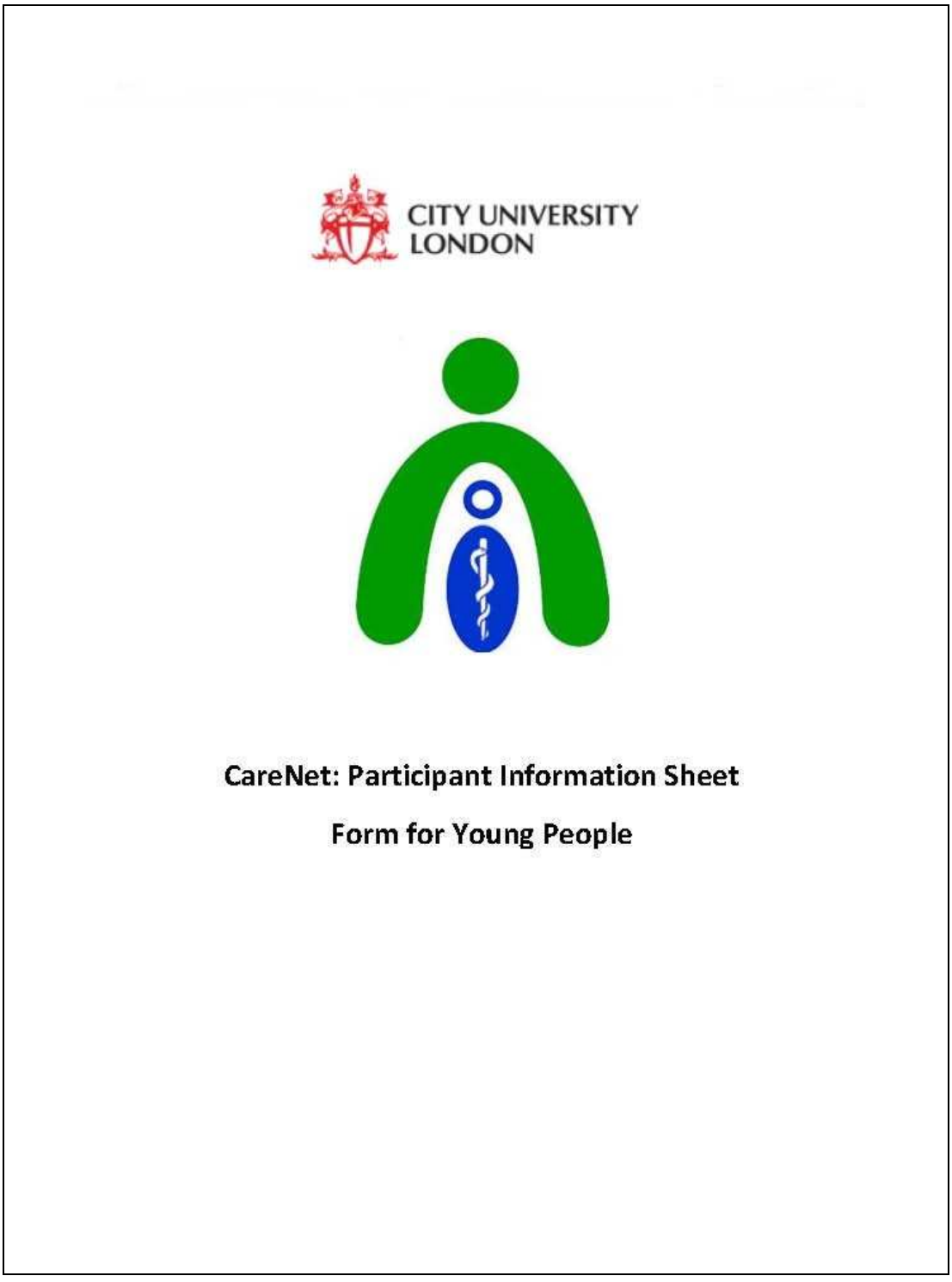
Professor Abdul Roudsari
Centre for Health Informatics
City University
Northampton Square
London EC1V 0HB

Mrs Angela Williams
NoCLoR
Room 3-17, 3rd Floor
West Wing
St Pancras Hospital
St Pancras Way
London NW1 0PE

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix 3. Patient Information Sheets

Two separate information sheets were provided for the participants. The first set was for the children under 16 years old and their parents who were attending the paediatric clinic. This information sheet was prepared with a language suitable for this age group and larger font size. At the end of this information sheet a consent form for the child and an assent form for the parent were included.



Version: 2 Date: 23/10/2009

We are asking if you would join in a research project to find the answer to the question:

"Is the Internet useful for learning about diabetes?"

Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, doctor or nurse if you want to. Ask us if there is anything that is not clear.

Version: 2 Date: 23/10/2009

Part 1:

Why are we doing this research?

We will provide you with some information about diabetes and will check if it has been useful for you.

What is being tested?

A web site with information about diabetes will be tested to see if it is useful for you and other diabetic young people.

Why have I been invited to take part?

You have been invited to join our study because you have diabetes. The doctors in your hospital agreed to help us in this project and thought that it could be useful for people who have diabetes.

Do I have to take part?

No. It is up to you. We will ask you for your agreement and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

What will happen to me if I take part?

For the successful implementation of a network on the Internet for diabetes education it is very important to find out which parts of the system are most important for users and how successful such system can be. We are doing this research to measure these factors.

This research will last until September 2010 and we are asking

participants to use this system for at least six months. You can access the research team anytime via my email address: omid.shabestari.1@soi.city.ac.uk .

This information will be treated as confidential and will be stored in a secure server at City University. This data is only used for this research project and no person-identifiable data will be shared with anybody else.

What will I be asked to do?

Upon your first access to the system you are asked to give your opinion about the level of importance for each aspect of the system. If your parents are helping you to complete this questionnaire, it is important that the response exactly reflect your opinion and not be affected by their own interpretation of your opinion.

Then you are asked to provide your feedback according to User Guide document of the project. This feedback includes short questionnaires about diabetes before and after accessing each education section and the level of usefulness of the information provided to you. You can propose to share any information about diabetes on the Internet that you have found useful. These resources will to be added to our system if they are useful for other members.

The other part is recording your blood glucose level, the dose of injected insulin (if you do), HbA1C and your height and weight according to your current treatment plan from your diabetes care team.

At the end of research we will ask you how much you liked different aspects of system.

Version: 2 Date: 23/10/2009

Is there anything else to be worried about if I take part?

No. This research will not affect any part of your treatment and you will receive your care the same as before.

What are the possible benefits of taking part?

You will have the opportunity to learn more about diabetes by the approved resources provided by other users and see how other people with the same disease are doing.

Thank you for reading so far – if you are still interested, please go to Part 2.

Version: 2 Date: 23/10/2009

Part 2:

What happens when the research study stops?

The approved resources will remain available via Internet after this research project and you will receive a free copy of the results of this research after their publication.

What if new relevant information becomes available?

If any new relevant information is added to the education sections that you have already completed, this will be available in the home page of the project web site. This page has a "new resources" section in which you can find them.

What if there is a problem or something goes wrong?

If you have a concern about any aspect of this study, you should contact the researchers who will do their best to answer your questions via omid.shabestari.1@soi.city.ac.uk . If you remain unhappy and wish to complain formally, you can do this via Centre for Health Informatics at City University of London.

Details can be obtained from
http://www.soi.city.ac.uk/organisation/chi/contacts.html

Will anyone else know I'm doing this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. Your GP and diabetes care team will be informed about your taking part in this research.

Who is organising and funding the research?

Version: 2 Date: 23/10/2009

This project is a part of PhD research project funded by City University of London.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Outer North London Research Ethics Committee.

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

You can withdraw from this research anytime you want, we will use the data collected up to the point of your withdrawal.

What will happen to the results of the research study?

The results of this research will be published in scientific journals and as a PhD research project. You will receive a simplified explanation of these results.

Further Information and contact detail:

Thank you for reading this. Please contact us if you have any questions about this research project.

Email: omid.shabestari.1@soi.city.ac.uk
Telephone Number: 02070408369
Centre for Health Informatics
City University
Northampton Square
London
EC1V 0HB

Version: 2 Date: 23/10/2009

CITY UNIVERSITY LONDON

ASSENT FORM

(to be completed by the parent/guardian)

CareNet Research Project

Research Site:

Name of Researcher:

Parent /guardian to circle all they agree with:

1.	Has somebody else explained this project to you?	Yes / No
2.	Do you understand what this project is about?	Yes / No
3.	Have you asked all the questions you want?	Yes / No
4.	Have you had your questions answered in a way you understand?	Yes / No
5.	Do you understand it's OK to stop taking part at any time?	Yes / No
6.	Are you happy to take part?	Yes / No

If any answers are "no" or you don't want to take part, don't sign your name!
If you do want to take part, you can write your name below

Your name: Date Signature

The doctor who explained this project to you needs to sign too: Date: Signature

Thank you for your help.

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Version: 2 Date: 23/10/2009

CITY UNIVERSITY LONDON

CONSENT FORM

(to be completed by the young person. If unable, use only parent assent form)

CareNet Research Project

Research Site:
Name of Researcher:
Child /young person to circle all they agree with:

1. Has somebody else explained this project to you?	Yes / No
2. Do you understand what this project is about?	Yes / No
3. Have you asked all the questions you want?	Yes / No
4. Have you had your questions answered in a way you understand?	Yes / No
5. Do you understand it's OK to stop taking part at any time?	Yes / No
6. Are you happy to take part?	Yes / No

If any answers are "no" or you don't want to take part, don't sign your name!
If you do want to take part, you can write your name below

Your name: Date Signature

The doctor who explained this project to you needs to sign too: Date: Signature

Thank you for your help.

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

The second set was designed for the young people aged above 16 to 30. In this information sheet only one consent form was included.

CITY UNIVERSITY LONDON

CareNet: Participant Information Sheet

Form for Adults

Version: 2 Date: 23/10/2009

We would like to invite you to take part in the CareNet research study.

The aim in this research is to evaluate the effectiveness of this system for patient learning about diabetes. We are also interested in measuring your levels of involvement in enhancing the system by sharing the information that you've seen on the Internet about Diabetes. The potential improvement of your clinical measurements will also be recorded.

Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 15 minutes. Discuss this study with others if you wish. Part 1 of this information sheet tells you the purpose and the process of this study should you take part. Part 2 gives more detailed information about the conduct of the study.

Please feel free to ask us if there is anything that is not clear.

Version: 2 Date: 23/10/2009

Part 1:

What is the purpose of this study?

This study is designed to evaluate the effectiveness of an Internet-based social networking environment for the education of diabetics.

Why have I been invited?

The diabetes team in the hospital that you've attended agreed to participate in this study and believed this research project could provide useful evidence for the education of diabetics. You have been introduced to this research by your care team.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

For the successful implementation of Internet-based social networks for diabetes education, it is essential to find out which aspects of the system are most important to users and how successful such a system can be. We are carrying out this research to measure these factors.

This research will last until September 2010 and we are asking participants to use this system for at least six months. You can access the research team anytime via my email address: omid.shabestari.1@soi.city.ac.uk .

The information collected in this project will be treated as confidential and will be stored in a secure server at City University. This data is only used for this research project and no person-identifiable data will be shared with anybody else.

What will I have to do?

Upon the first access to the system you are asked to tell us the level of importance of each aspect of the system from your point of view.

Then you are asked to provide your feedback according to the User Guide document of the project. This feedback includes completing short tests about your diabetes knowledge before and after accessing each educational section and letting us know the level of usefulness of the information provided to you. You can propose to share any information about diabetes available on Internet that you have found useful. After careful evaluation of the proposed information by the CareNet team, this will be shared in the system for others to read.

The other part of this project involves recording measurements of blood glucose, injected insulin (if it is part of your treatment), HbA1C and your height and weight according to your current treatment plan from your diabetes care team.

Version: 2 Date: 23/10/2009

At the end of the research we will ask you about the level of your satisfaction with different aspects of the system.

What are the alternatives for diagnosis or treatment?

This research is carried out in parallel to your normal treatment and does not affect your current treatment.

What are the possible disadvantages and risks of taking part?

All the information you receive from proposed sources by other users are reviewed by the CareNet research team before being shared to ensure their safety and reliability. This process will prevent any risk or misinformation in this project.

What are the possible benefits of taking part?

You will have the opportunity to increase your knowledge about diabetes using the approved resources provided by other users.

What happens when the research study stops?

The approved resources will be available via Internet after this research project is finished. Also you will receive a free copy of the results of this research after their publication.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

Version: 2 Date: 23/10/2009

Part 2:

What if new relevant information becomes available?

If any new relevant information is added to the education sections that you have already completed, this will be available in the home page of the project web site. This page has a "new resources" section in which you can find them.

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

You can withdraw from this research anytime you want, the data collected up to your withdrawal will be used.

What if there is a problem?

If you have a concern about any aspect of this study, you should contact the researchers via omid.shabestari.1@soi.city.ac.uk. They will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this via Centre for Health Informatics at City University of London.

Details can be obtained from http://www.soi.city.ac.uk/organisation/chi/contacts.html

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. The information is stored in a secure server in City University and person-identifiable information will not be published or shared with any other organizations.

Involvement of the General Practitioner/Family doctor (GP)

Your GP will be informed about your participation in this research.

What will happen to the results of the research study?

The results of this research will be published in scientific journals and as a PhD research project. The participants will have the option of receiving a simplified explanation of these results or the published article.

Who is organising and funding the research?

This project is a part of PhD research project funded by City University of London.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Outer North London Research Ethics Committee.

Further Information and contact detail:

Version: 2 Date: 23/10/2009

Please contact us if you have any questions about this research project.

Email: omid.shabestari.1@soi.city.ac.uk
Telephone Number: 02070408369

Centre for Health Informatics
City University
Northampton Square
London
EC1V 0HB

CITY UNIVERSITY LONDON

CONSENT FORM
CareNet Research Project

Research Site:

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated 23/10/2009 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from City University where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree to my GP being informed of my participation in the study. ☐

5. I agree to take part in the above study. ☐

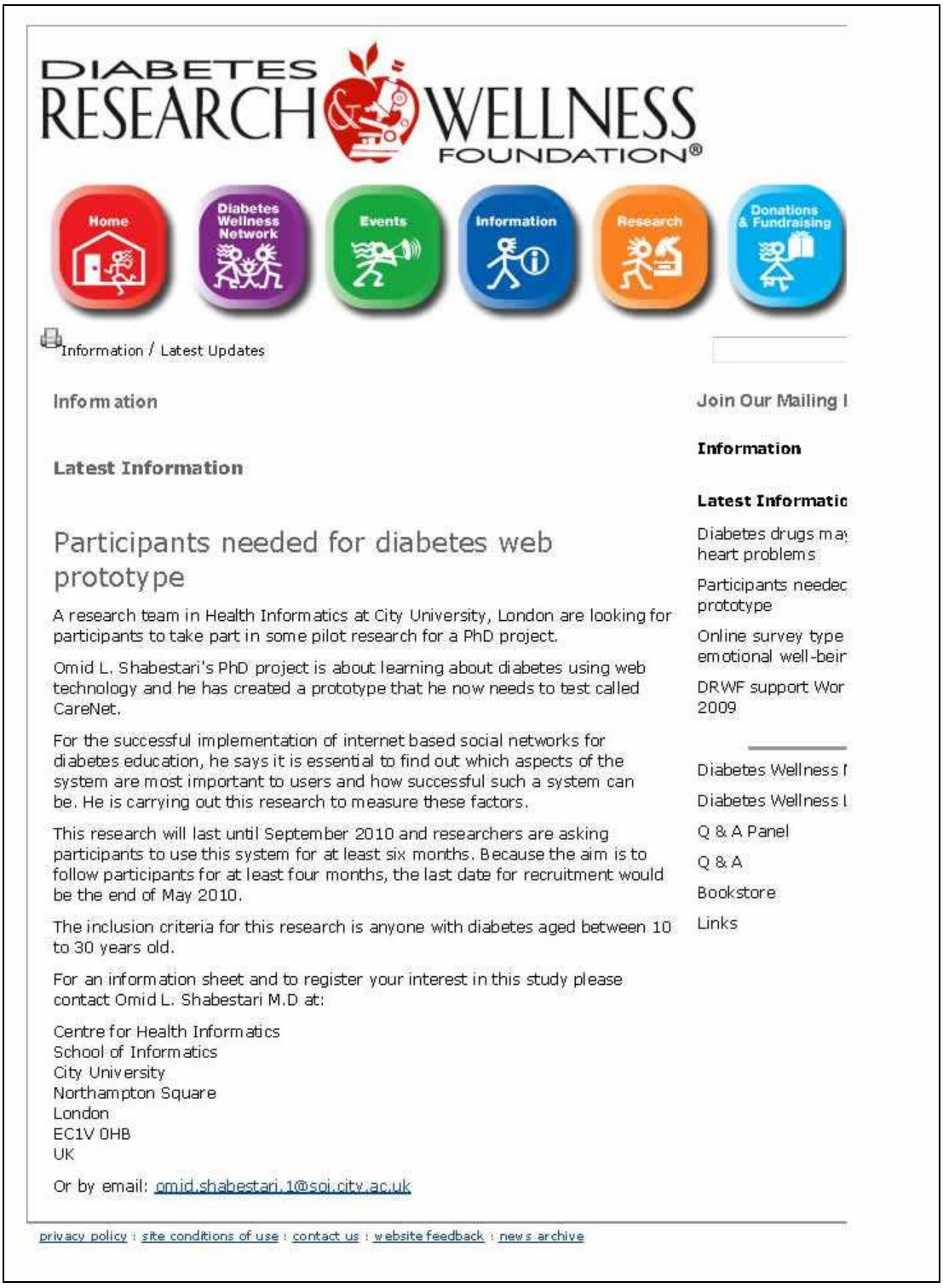
Name of Participant:	Date	Signature:
Name of Person taking consent:	Date:	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix 4. Advertisements

To inform the potential participants about this project invitation messages were posted on two related website.

The first website was Diabetes Wellness Research Foundation.



DIABETES RESEARCH WELLNESS FOUNDATION®

Home | Diabetes Wellness Network | Events | Information | Research | Donations & Fundraising

Information / Latest Updates

Information

Latest Information

Participants needed for diabetes web prototype

A research team in Health Informatics at City University, London are looking for participants to take part in some pilot research for a PhD project.

Omid L. Shabestari's PhD project is about learning about diabetes using web technology and he has created a prototype that he now needs to test called CareNet.

For the successful implementation of internet based social networks for diabetes education, he says it is essential to find out which aspects of the system are most important to users and how successful such a system can be. He is carrying out this research to measure these factors.

This research will last until September 2010 and researchers are asking participants to use this system for at least six months. Because the aim is to follow participants for at least four months, the last date for recruitment would be the end of May 2010.

The inclusion criteria for this research is anyone with diabetes aged between 10 to 30 years old.

For an information sheet and to register your interest in this study please contact Omid L. Shabestari M.D at:

Centre for Health Informatics
School of Informatics
City University
Northampton Square
London
EC1V 0HB
UK

Or by email: omid.shabestari.1@soi.city.ac.uk

Join Our Mailing l

Information

Latest Informatic

Diabetes drugs ma heart problems

Participants needec prototype

Online survey type emotional well-beir

DRWF support Wor 2009

Diabetes Wellness I

Diabetes Wellness l

Q & A Panel

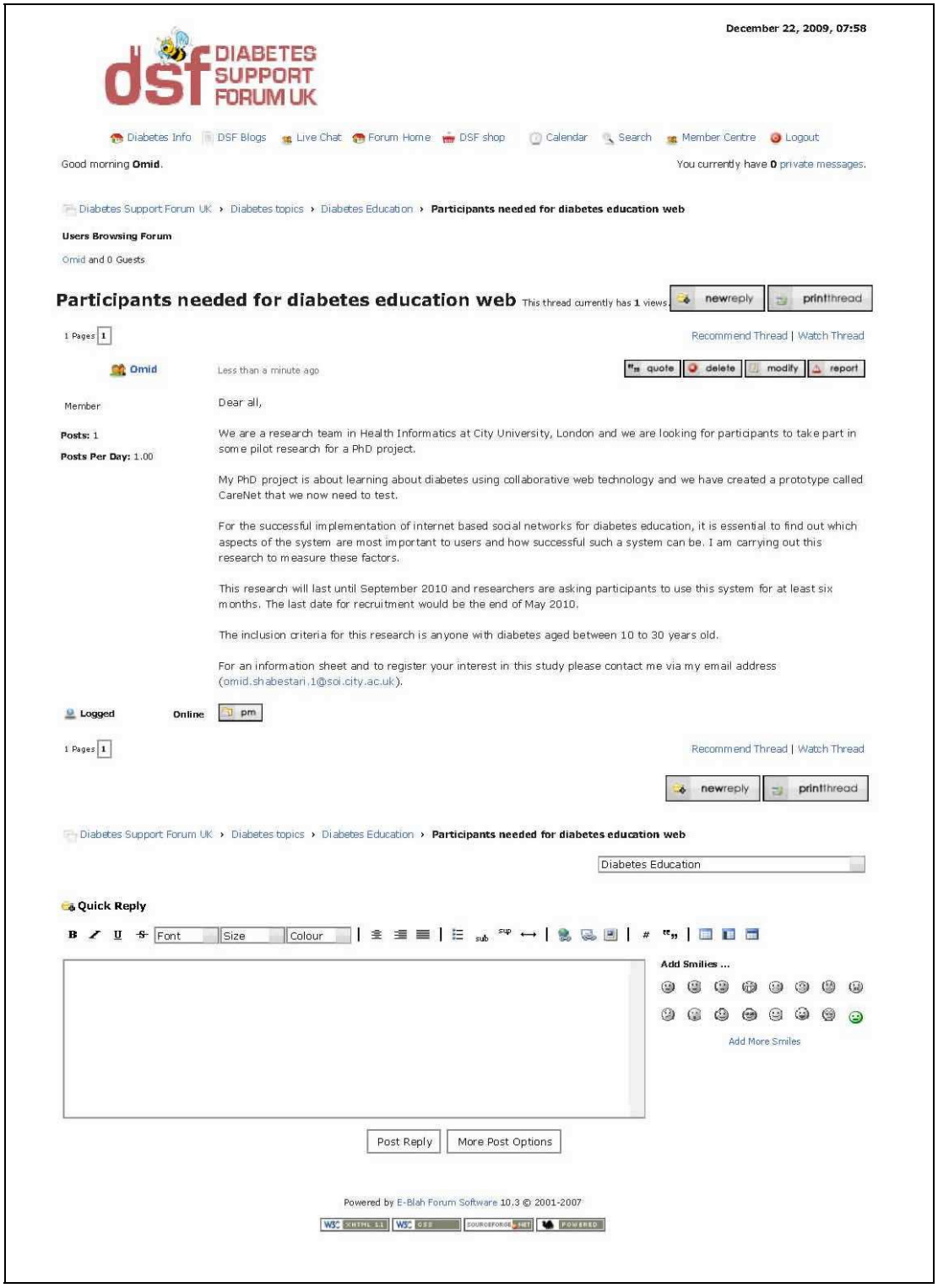
Q & A

Bookstore

Links

privacy policy | site conditions of use | contact us | website feedback | news archive

The second website was Diabetes Support Forum UK.

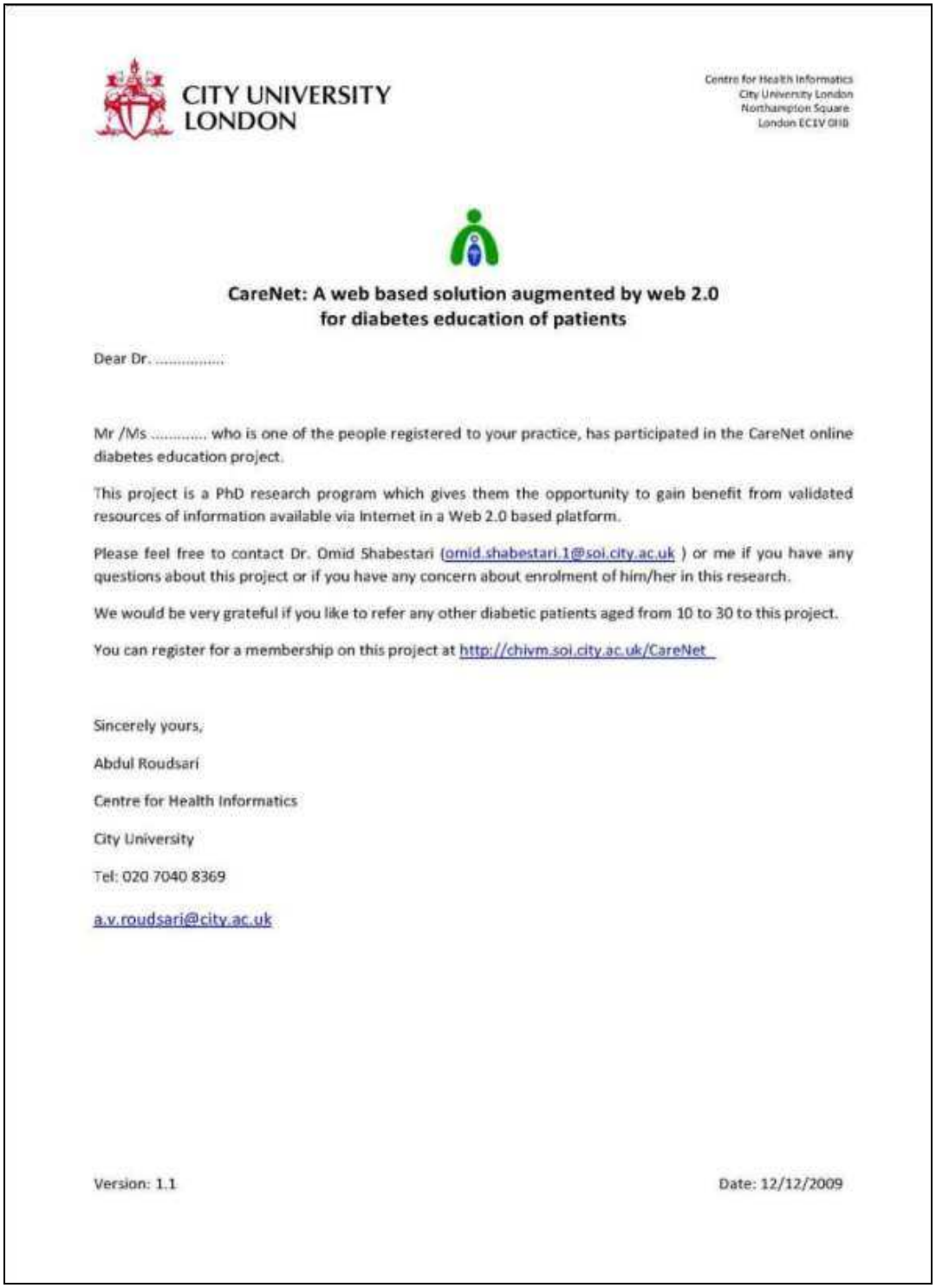


Also two posters were prepared for the students in City University and the patients in the collaborating hospitals.


CITY UNIVERSITY LONDON
Centre for Health Informatics
CareNet
Join our online diabetes community
Learn about diabetes
Share your knowledge with others
Visit http://chivm.soi.city.ac.uk/carenet and watch a five minute video about this project.
For more information ask your diabetes consultant or send an email to omid.shabestari.1@soi.city.ac.uk

Appendix 5. GP Information Letter

For each of the participants who were recruited from the Internet and consented to inform their doctor; a letter was sent to their GP informing them about this participation.



CITY UNIVERSITY LONDON

Centre for Health Informatics
City University London
Northampton Square
London EC1V 0HB

CareNet: A web based solution augmented by web 2.0 for diabetes education of patients

Dear Dr. .....

Mr /Ms ..... who is one of the people registered to your practice, has participated in the CareNet online diabetes education project.

This project is a PhD research program which gives them the opportunity to gain benefit from validated resources of information available via Internet in a Web 2.0 based platform.

Please feel free to contact Dr. Omid Shabestari (omid.shabestari.1@soi.city.ac.uk) or me if you have any questions about this project or if you have any concern about enrolment of him/her in this research.

We would be very grateful if you like to refer any other diabetic patients aged from 10 to 30 to this project.

You can register for a membership on this project at http://chivm.soi.city.ac.uk/CareNet

Sincerely yours,

Abdul Roudsari

Centre for Health Informatics

City University

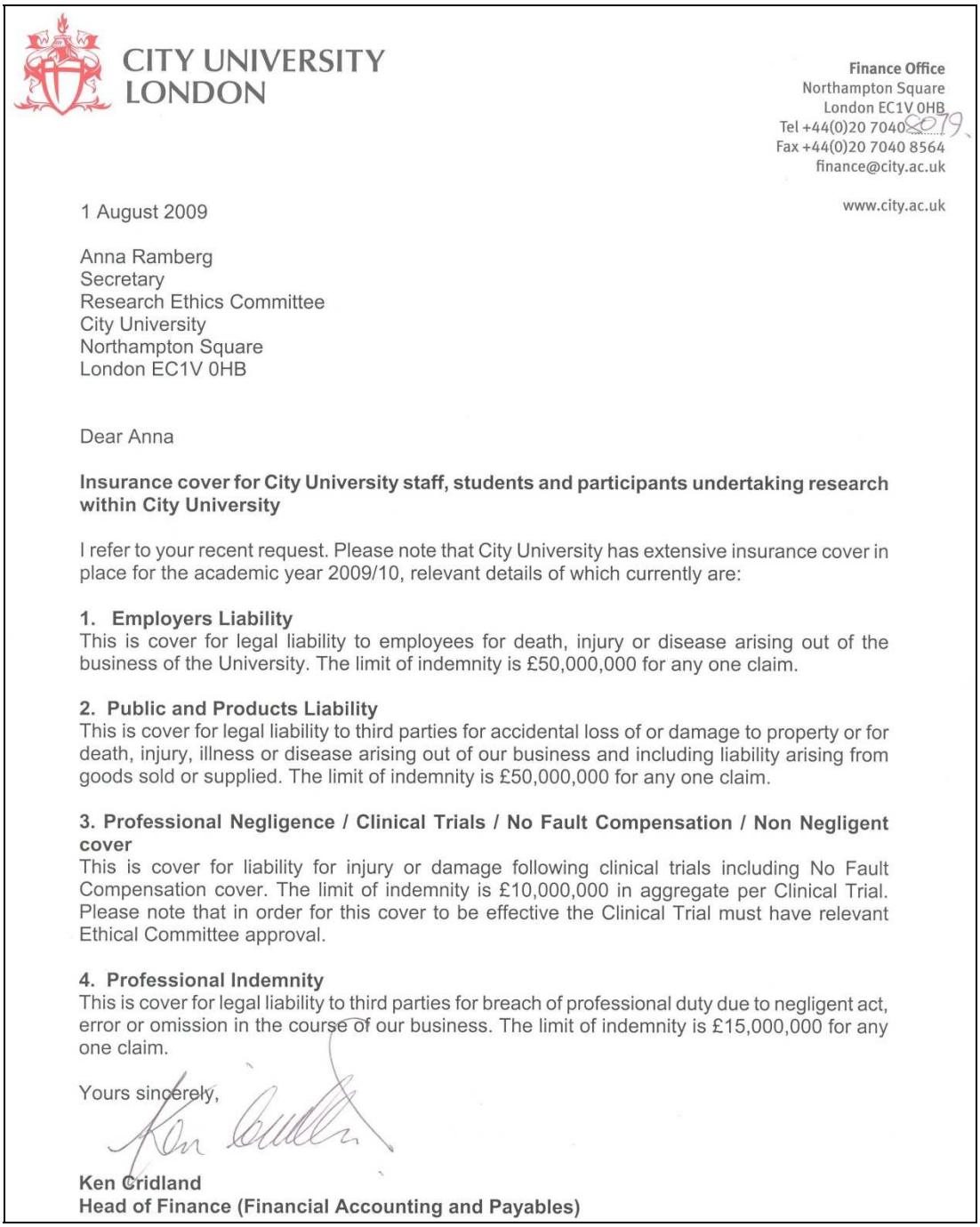
Tel: 020 7040 8369

a.v.roudsari@city.ac.uk

Version: 1.1 Date: 12/12/2009

Appendix 6. Statement of Indemnity Agreement

This research project was covered by the insurance provided by City University.



CITY UNIVERSITY LONDON

Finance Office
Northampton Square
London EC1V 0HB
Tel +44(0)20 7040 8019
Fax +44(0)20 7040 8564
finance@city.ac.uk

www.city.ac.uk

1 August 2009

Anna Ramberg
Secretary
Research Ethics Committee
City University
Northampton Square
London EC1V 0HB

Dear Anna

Insurance cover for City University staff, students and participants undertaking research within City University

I refer to your recent request. Please note that City University has extensive insurance cover in place for the academic year 2009/10, relevant details of which currently are:

1. Employers Liability
This is cover for legal liability to employees for death, injury or disease arising out of the business of the University. The limit of indemnity is £50,000,000 for any one claim.

2. Public and Products Liability
This is cover for legal liability to third parties for accidental loss of or damage to property or for death, injury, illness or disease arising out of our business and including liability arising from goods sold or supplied. The limit of indemnity is £50,000,000 for any one claim.

3. Professional Negligence / Clinical Trials / No Fault Compensation / Non Negligent cover
This is cover for liability for injury or damage following clinical trials including No Fault Compensation cover. The limit of indemnity is £10,000,000 in aggregate per Clinical Trial. Please note that in order for this cover to be effective the Clinical Trial must have relevant Ethical Committee approval.

4. Professional Indemnity
This is cover for legal liability to third parties for breach of professional duty due to negligent act, error or omission in the course of our business. The limit of indemnity is £15,000,000 for any one claim.

Yours sincerely,

Ken Cridland
Head of Finance (Financial Accounting and Payables)

Appendix 7. NHS R&D Approvals

Mayday Healthcare NHS
NHS Trust

Mayday University Hospital
530 London Road
Croydon
CR7 7YE

Switchboard Tel: (020) 8401 3000

Research & Development
Direct Line Tel: (020) 8401 3610
Direct Fax: (020) 8401 3172
Email: aline.cook@mayday.nhs.uk

14th January 2010

MM/AMC/CM

Dr Omid Shabestari
Mayday University Hospital

Dear Omid

Full title of project: Evaluation of a Web 2.0 based solution for diabetes education

09/H0724/42 R&D 10-01

Thank you for your email and enclosures. I am happy to give Chairman's action to approve this study locally.

Please inform the R&D office when your study has been completed. Also we would like to receive a summary of your overall findings and ask that you submit a report in **April 2010** and annually thereafter should your study last longer than one year.

Yours sincerely,

Dr Mike Mendall
Chairman
Research & Development

Barnet and Chase Farm Hospitals NHS
NHS Trust

R&D Department
Clinical Governance & Risk Offices
2nd floor, Clocktower
Chase Farm Hospital
The Ridgeway
Enfield
EN2 8JL

Direct Phone: 020 8375 2189/1347

Dr Omid Shabestari
Phd Student
City University
Centre for Health Infomatics
City University
Northampton Square
London
EC1V 0HB

Date: 05th February 2010

Dear Dr Shabestari

Re Study: **Evaluation of a controlled collaborative solution based on Web 2.0 technology for diabetes education of patients**

Thank you for your application requesting for this Trust's approval of the above mentioned research project. Following the ethical approval, I am pleased to confirm that on behalf of Barnet & Chase Farm Hospitals Trust I approve your research project to take place within our organisation.

If you have any further questions please do not hesitate in contacting our R&D department on:

Tel: 020 8375 1721/1347
Email: research.development@bcf.nhs.uk or

Andy Nicol on 020 8216 5296
Email: Andy.Nicol@bcf.nhs.uk

Yours sincerely

Dr Andy Nicol
Associate Medical Director and Trust Lead for Research
Barnet & Chase Farm Hospitals Trust

Chairman: Baroness Margaret Wall
Chief Executive: Averil Dongworth

Birmingham and the Black Country
NIHR Comprehensive Local Research Network

NHS
National Institute for Health Research

Dr Omid Shabestari
Centre for Health Informatics
City University
Northampton Square
London
EC1V 0HB

Birmingham and the Black Country Comprehensive Local Research Network
Unit 1, West Wing
Institute of Research and Development
Birmingham Research Park
Vincent Drive
Birmingham
B15 2SQ

Tel: 0121 627 2843
Fax: 0121 627 2178

Website: http://bbc.ukcrn.org.uk
Email: BBCCLRN@uhb.nhs.uk

Tuesday, 16 March 2010

LETTER OF RESEARCH MANAGEMENT AND GOVERNANCE (RM&G) AGREEMENT for PARTICIPATION IDENTIFICATION CENTRES (PICs)

***RM&G Agreement* has been granted by the CLRN RM&G Consortium Office on behalf of the BBC CLRN RM&G Consortium Trusts. The Chief Investigator named in this letter has the agreement of the NHS Trust(s) identified below to act as a PIC for this research and the identification of participants is able to commence in the locality area where they have a "Duty of Care".**

Chief Investigator Name: **Dr Omid Shabestari**

Date of Issue: **16/03/10**

Project Title:	Evaluation of a controlled collaborative solution based on Web 2.0 technology for diabetes education of patients		
Consortium RM&G Ref IDs:	**R&D:** 1347	**UKCRN ID:** N/A	**IRAS Code:** 27922
Project Start/End Dates:	**Start Date:** 16/03/10	**End date:** 15/09/10	
Chief Investigator:	Dr Omid Shabestari		
Chief Investigator Employer:	City University		
Funding & Funding amount:	No funding		
Sponsor:	City University		

NHS Trust Registered:	**Local Collaborator:**	**Participating Identification Centre(PIC):**	**Date of Issue:**
NHS Birmingham East and North (BENPCT)	N/A	PAK Health Centre	16/03/10
Trust Service/Directorate:	Community Diabetes Services		

Thank you for informing the BBC CLRN RM&G Consortium of the above research.

Confirmation of RM&G Agreement

On behalf of the BBC CLRN RM&G Consortium, I am pleased to confirm RM&G Agreement has been granted for the Consortium Trust(s) and Participating Identification Centre(s) as stated above.

Conditions of RM&G Agreement

This agreement is subject to the following conditions being met prior to the start of the study:

1. NHS management permission or R&D approval must be obtained from each NHS host research organisation prior to the recruitment of participants to the study at the PIC site concerned.

NIHR CRN

2. A favourable ethical opinion applies to all NHS sites taking part in the study, which is subject to management permission being obtained from the appropriate NHS R&D office prior to the start of the study.
3. Compliance with the conditions as set out in the attached *BBC CLRN RM&G Consortium Standard Conditions for Research Management & Governance (RM&G) Permission* document. You are advised to study the conditions carefully.

If you require any further assistance, please call the CLRN RM&G Consortium Office stating your **RM&G Reference Number 1347**.

We wish you success on completing your research.

Yours Sincerely,

pp

Susie Fisher
CLRN RM&G Operational Manager (Consortium)
BBC CLRN RM&G Consortium

Documents Enclosed:

(1) RM&G Permission Letter

(2) Standard Conditions of RM&G Permission for the BBC CLRN RM&G Consortium & RM&G Reporting Form for Research Incidents

Scanned Copy of Documents sent to:

Dr Omid Shabestari – Chief Investigator

Abdul Roudsari – Sponsor's Contact Point

Andrea Docherty – R&D Lead for BEN PCT c/o PA

Dr Waqar Malik – Other member of the research team / BEN PCT Community Diabetes Consultant

Appendix 8. Rating questionnaire for diabetes education websites

CareNet Rating Tool for Diabetes Education Websites

This survey tool is designed for rating of the current diabetes education website.

Please tell us your level of satisfaction with each characteristic by putting a X mark in the related cell in front of each item in the below table

Thank you very much for your valuable feedback.

Group	Characteristic	Extremely unsatisfied	Very unsatisfied	unsatisfied	satisfied	Very satisfied	Extremely satisfied
System Content	Availability of educational content						
	Amount of material in the site						
	Interesting subject matter						
	Difficulty of subject matter						
	Availability of other content (objectives assignment)						
	Enjoyment from the education						
	Quality of the content in the system						
	Ease of use						
	Similarity of interface across the system						
	Gathering information quickly						
	Organization of the system						

Group	Characteristic	Extremely unsatisfied	Very unsatisfied	unsatisfied	satisfied	Very satisfied	Extremely satisfied
Human Coach	Amount of coach –learner interaction						
	Amount of learning from coach						
	Quality of coach-learner interaction						
	Freedom of learning						
Technical issues and System Support	Quick answer from technical support by e-mail						
	Quality of technical support						
	System operation time (up-time)						
	Reduced system errors						
	System security						
	Accessibility of the content						
	High network ability and low Internet traffic						
	Learning flexibility						
	Different system tools						
	Access of all courses from one area (Dashboard)						

Group	Characteristic	Extremely unsatisfied	Very unsatisfied	unsatisfied	satisfied	Very satisfied	Extremely satisfied
Learner	Amount of learning from the system						
	Amount of interaction with other learners						
	Comfort with online learning and technology						
	Internet and computer skills						
	Self-discipline and time management						
	Reduced travel cost and time cost						
	Family support						

Appendix 9. Published peer-reviewed papers from the CareNet study

1) Shabestari O, Roudsari A. Potentials of Web 2.0 for diabetes education of adolescent patients. Proceeding of eHealth 2008: Electronic healthcare for the 21st century. 2008: 205-7.

   Abstract: Diabetes is a very common chronic disease which produces complications in almost all body organs and consumes a huge amount of the health budget. Although education has proved to be useful in diabetes management, there is a great need to improve the availability of these courses for the increasing number of diabetic patients. E-learning can facilitate this service, but the current education system should be tailored towards e-learning standards. Amongst diabetic patients, adolescents as computer natives are suggested as the best target to e-learning diabetes education. With regards to its features, Web 2.0 can be a very good technology to build a framework for diabetes education and consequent evaluation of this education.

2) Shabestari O, Roudsari A. Potential Return on Investment (RoI) on web-based diabetes education in the UK. Stud Health Technol Inform. 2009; 143:258-63.

   Abstract: Diabetes Mellitus is a growing chronic disease in UK. As most of diabetes care is performed by the patients themselves, encouraging their responsibility by structured education is a proven method to achieve effective care. Continuous e-learning via Internet can be used as one of these methods of diabetes education which has been proven to be useful. To calculate the cost benefit of this method, “Return on Investment” can be used as a good indicator, which is the ratio of money gained or lost on an investment relative to the amount of invested money. This article uses system dynamics modelling to predict the flow of the patients in education system and the cost of their care comparing traditional and web-based educational systems. Separate models were developed for each educational method and simulated until 2020 with one year interval. The population of diabetic patients was updated based on the diabetes incidence rate as an increasing factor and diabetes mortality rate as a restricting factor in each cycle. The population of the educated diabetic patients

was calculated based on the education capacity and literacy limits in each method. The cost of diabetes care was calculated based on the report from NHS considering the difference of cost between uneducated and educated patients in literature. An inflation rate of 3% was added to the costs in each year. The population of UK diabetic patients will be increased dramatically in the duration of this modelling leading to 3.3 million patients until 2020. The web-based model has 63.47% more successful coverage in educating diabetic population at the end of simulation. The annual cost of diabetes care in traditional model will increase to £3.67 billion in 2020 whereas the web-based model will keep this cost to £3.39 billion. Return on Investment (RoI) in this study will be equal to 3233%. Considering the shift of diabetes toward younger people, web-based system is more compatible with the life style of this generation. These are the people who are considered as computer native and more familiar with computer technology in comparison with the previous generations and can adopt this technology much easier. So investment on web-based diabetes education is not only a matter of benefit but also a requirement to reduce the cost of diabetes care for NHS.

3) Shabestari O, Roudsari A. A requirement engineering framework for application of Web 2.0 technology in healthcare. MedInfo. 2010

Abstract: Web 2.0 is a concept that provides the potential of more interaction in the web environment. Traditional requirement engineering models are mostly based on initial development of requirements and consequent continuous management, whereas recent advances in web programming has facilitated the opportunity to collect data for requirement management via the system itself or even smart systems that play an active role in requirement management and tailor the system on the basis of user feedbacks. User feedback collection can be active or passive. Health care systems have special demands which should be considered during the requirement engineering process. This article proposes a step-by-step guide through a framework for this process.

4) Shabestari O, Roudsari A. A requirement engineering approach for improving the quality of diabetes education websites. ITCH. 2011

Abstract: Diabetes Mellitus is a major chronic disease with multi-organ involvement and high-cost complications. Although it has been proved that structured education can control the risk of developing these complications, there is big room for improvement in the educational services for these patients. e-learning can be a good solution to fill this gap. Most of the current e-learning solutions for diabetes were designed by computer experts and healthcare professionals but the patients, as end-users of these systems, haven't been deeply involved in the design process. Considering the expectations of the patients, this article investigates a requirement engineering process comparing the level of importance given to different attributes of the e-learning by patients and healthcare professionals. The results of this comparison can be used for improving the currently developed online diabetes education systems.