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Designing patient education with distance learning

A design-based study on the needs and requirements of type 2 diabetes patients for an online learning environment

Author: Bastiaan Franssen

Author: Bastiaan Franssen, department of LIME, Karolinska Institutet

Supervisor: PhD, Nabil Zary, department of LIME, Karolinska Institutet

Supervisor: PhD, Italo Masiello, department of LIME, Karolinska Institutet

Supervisor: PhD candidate, Javad Jafari, department of LIME, Karolinska Institutet

Examiner: Professor, Sabine Koch, department of LIME, Karolinska Institutet



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Affirmation

I hereby affirm that this Master thesis was composed by myself, that the work contained herein is my own except where explicitly stated otherwise in the text. This work has not been submitted for any other degree or professional qualification except as specified; nor has it been published.

Stockholm, 08 June 2015

A handwritten signature in blue ink that reads "BASTIAAN". The signature is written in a cursive style with a large, sweeping initial 'B'.

Bastiaan Franssen



**Karolinska
Institutet**



Master's Programme in Health Informatics
Spring Semester 2015
Degree thesis, 30 Credits

Designing patient education with distance learning - *A design-based study on the needs and requirements of type 2 diabetes patients for an online learning platform*

Abstract

Background: Self-management is crucial among patients with diabetes. Increasing the levels of self-management may prevent patients from developing further complications related to their disease. Tailoring education to the patient needs, and providing them with follow-up education on the various topics of diabetes could significantly improve patient understanding. The inclusion of distance learning, and especially Massive Open Online Courses (MOOC), in diabetes education has not been significant though. What topics should a distance-learning platform focus on when offering patient education to type 2 diabetics? How do patients perceive such a platform? And what education method should be used to better reach patient understanding, ultimately helping diabetics to reach better self-management?

Objective: Describing the needs and requirements of type 2 diabetics for the development of an online learning platform. The study tried to analyse what topics patients need follow-up education on to reach better self-management and how. The study wants to get an answer where patients would use a knowledge-driven decision support method inside the patient centric learning model

Methods: A qualitative approach for this study included 6 participants, aged 30 to 65 years old. They were diagnosed with type 2 diabetes not earlier than 6 months before the start of this study and had no further diabetes related complications. They participated in an interview on the several topics related to diabetes, which identified where the need and requirements for education in is at. To help identify which topics patients wanted to receive follow-up education on the Diabetes Self-Management education (DSME) was used. The interview contained structured and unstructured questions, and was performed with a high level of involvement to provide relevant information related to diabetes throughout the interview.

Results:

Participants welcomed the idea of receiving education via an online learning platform. The incorporation of multimedia was highly recommended, and the method of receiving education was recommended to change per subject, not per topic. Overall, patient-centric learning was a preferred method in all topics, but knowledge-driven decision support was welcomed as an addition to some of the subjects.

Conclusion:

The current education offered is limited to providing basic understanding of performing self-management. Participants felt the need for follow-up education, but could not be provided with this. The proposed platform, with possibilities to access information whenever the patients needed, was seen as a welcomed addition to the current education offered in the different setups. Using patient-centric learning, combined with the integration of knowledge-driven decision support, could provide education and information whenever needed and benefit in increasing self-management levels among diabetics.

Keywords: Decision support; Diabetes Mellitus, Type 2; Self-care; Education; Self-Management

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Table of contents

List of abbreviations	I
List of figures	II
List of tables	II
1 Introduction	1
1.1 Diabetes, a worldwide epidemic	1
1.2 The importance of patient education.....	5
1.3 The Diabetes Self-management Education framework (DSME)	5
1.4 Education in the 21 st century	6
1.5 Problem description	12
1.6 Aims of the study.....	13
1.7 Research questions	13
2 Methods.....	15
2.1 Research methodology.....	15
2.2 Research approach and study design	15
2.3 Study context	18
2.4 Study participants and inclusion criteria	18
2.5 Time framing	19
2.6 Data collection.....	19
2.7 Data analysis methodology	21
2.8 Validity and reliability	22
2.9 Ethical considerations	22
3 Results	24
3.1 Results on the research questions.....	24
3.1.1 Research question 1:	24
3.1.2 Research question 2:	26
3.1.3 Research question 3	28
3.2 Proposed designs	28
3.2.1 Proposed education phasing	28
3.2.2 Proposed platform design	31
4 Discussion.....	38
4.1 Main findings.....	38
4.2 Discussion of the results.....	40
4.3 Discussions of the methods.....	40
4.3.1 Alternative methods:.....	41
4.4 Strengths and weaknesses of the study	42

4.4.1	Study limitations.....	42
4.4.2	Study strengths.....	43
4.5	Generalisability of the results.....	43
4.6	Future studies.....	45
5	Conclusion.....	47
	Reference.....	48
	Appendix 1 - Presented patient centred educational model.....	55
	Appendix 2 - Presented decision support model during interviews.....	56
	Appendix 3 - interview manuscript.....	58
	Appendix 4 - Planning.....	61
	Appendix 5 - Form study prototypes.....	62
	Appendix 6 - DSME topics presented to patients.....	68
	Appendix 7 - Data analysis approach.....	70
	Appendix 8 - Patient information leaflet.....	71

List of abbreviations

(C)DS	(Clinical) Decision Support
CVD	Cardiovascular Diseases
DSME	Diabetes Self-Management Education
DBR	Design Based Research
HbA _{1c}	Haemoglobin A _{1c}
HDL	High-density lipoprotein
HIIT	High Intensity Interval Training
HON	Health On the Net
ICT	Information and Communication Technology
KDDS	Knowledge-driven Decision Support System
LDL	Low-density lipoprotein
LIME	Dept. of Learning, Informatics, Management and Ethics at Karolinska Institutet
MOOC	Massive Online Open Courses
NCD	Non-communicable Disease
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
WHO	World Health Organisation

List of figures

Figure 1-1 - I.D.F. Worldwide statistics of diabetes patients in 2013 and estimated patients in 2035....	1
Figure 1-2 - Secondary diabetes complications.....	3
Figure 1-3 - Average HbA _{1c} in Europe.....	4
Figure 1-4 - Average HbA _{1c} in the United States	4
Figure 1-5 - DSME education approach.....	6
Figure 1-6 - A general MOOC course by Medical School Malaysia on Diabetes mellitus	7
Figure 1-7 - A MOOC course by Københavns Universitet on the challenges of Diabetes on Coursera....	7
Figure 1-8 - Evolution of MOOC from content delivery to face-to-face learning	8
Figure 1-9 - Data produced by blood glucose monitoring and registration apps.....	9
Figure 1-10 - Typical information flow for diabetes patients	10
Figure 1-11 - the knowledge gap between passive and active patients	12
Figure 2-1 - Interview model for design based study	17
Figure 2-2 - Visualised approach on the thematic content analysis	21
Figure 3-1 - Education phasing based on participant information	30
Figure 3-2 - Live chat interactions between groups and a healthcare professional	32
Figure 3-3 - Educational platform educating using the DSME framework	33
Figure 3-4 - Forum possibility to connect patients with each other and talk about their illness.....	33
Figure 3-5 - Knowledge-driven Decision Support System example 1 - foot treatment	34
Figure 3-6 - Knowledge-driven Decision Support System example 2 - glucose interpretation.....	35
Figure 3-7 - Mobile platform example of education platform (acute and chronic complications).....	35
Figure 3-8 - Exercise your knowledge by training. Specific questions related to DSME topics.....	36
Figure 4-1 - Predetermined learning path.....	39
Figure 4-2 - Flexible learning path.....	39

List of tables

Table 1-1 - Impact factors on blood glucose levels	4
Table 3-1 - Participants demographic data.....	24
Table 3-2 - Preferences of educational model (PC = Patient Centric - KDDS = Decision Support).....	27
Table 3-3 - Classification of DSME topics / 1 = Top priority - 9 = Low priority.....	28
Table 3-4 - Mean calculation of topic categorisation	29

EDUCATION IS THE
MOST POWERFULL WEAPON
WHICH YOU CAN USE TO
CHANGE THE WORLD

NELSON MANDELA

1 Introduction

1.1 Diabetes, a worldwide epidemic

Every year, the International Diabetes Federation (I.D.F.) publishes the Diabetes Atlas with an update on the status of diabetes worldwide. In the sixth edition of the diabetes atlas, the I.D.F. concluded that an astounding 382 million people are estimated to have diabetes⁽¹⁾. According to the latest publication, the number of adolescents and adults suffering from type 2 diabetes has been increasing at an alarming rate the past decades. It is estimated that in 2035 the number of people diagnosed with diabetes will increase to 592 million people worldwide. Also, approximately 179 million people worldwide haven't been properly diagnosed with diabetes yet⁽¹⁾.

Diabetes not only brings a significant burden by the increasing number of patients, but also on the growing number of premature deaths caused by the disease. Statistics published by the I.D.F. show that in 2013 alone, almost half of all deaths caused by diabetes in adults, were in people under the age of 60. In less-developed regions like sub-Saharan Africa these proportions rise to a staggering 75% of the population. Diabetes causes a great impact not only on the human- and social costs, but also on the economic costs of countries on all income levels⁽¹⁾.

IDF REGIONS AND GLOBAL PROJECTIONS OF THE NUMBER OF PEOPLE WITH DIABETES (20-79 YEARS) IN 2013 AND 2035

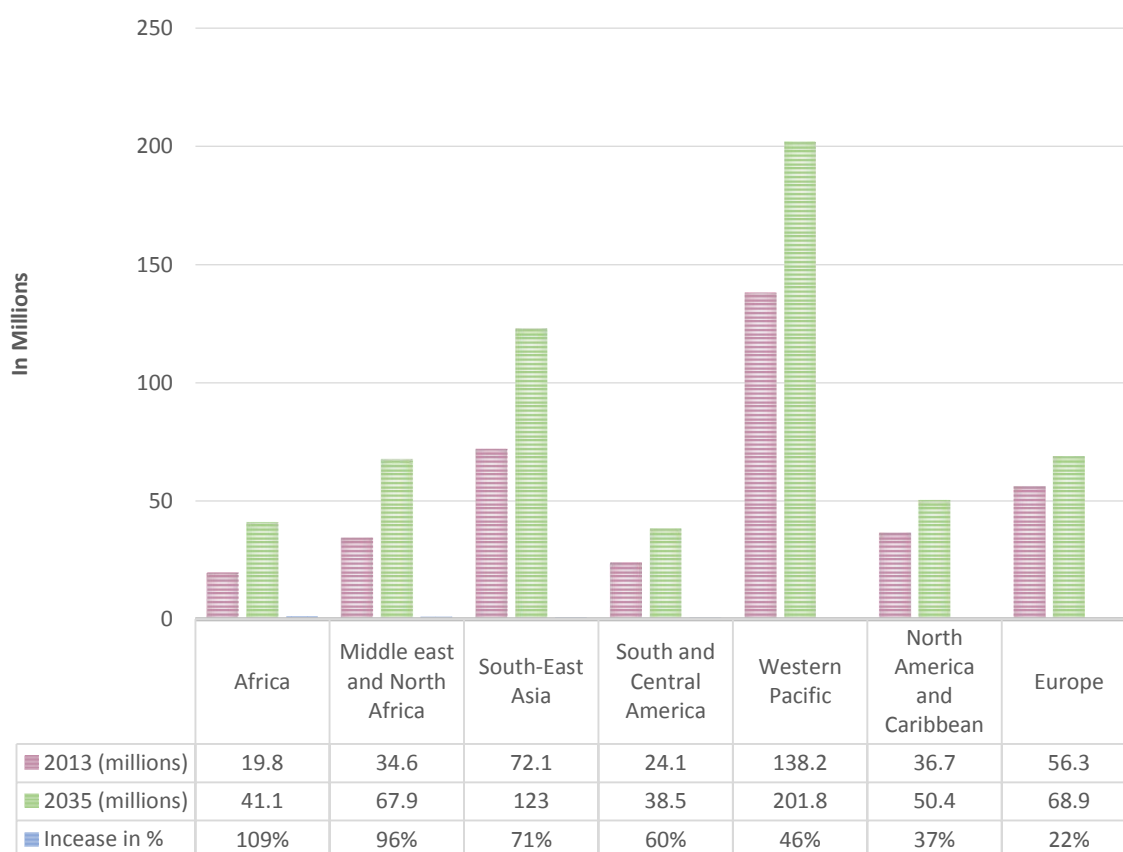


Figure 1-1 - I.D.F. Worldwide statistics of diabetes patients in 2013 and estimated patients in 2035

What is diabetes?

Diabetes is a metabolic disorder of multiple aetiology, which occurs when the body is not capable of producing the hormone insulin or cannot use the produced hormone effectively anymore. Insulin is a hormone that allows cells to take in glucose from the blood stream and use it as energy. According to the recent statistics published by the World Health Organisation (WHO), the ratio between type I diabetes and type II diabetes in newly diagnosed cases worldwide is 5% to 95%⁽¹⁾. The I.D.F. differentiates diabetes into three different types⁽¹⁾:

Type I diabetes (T1DM) is usually associated with an autoimmune reaction which caused the body to destroy the **islets of Langerhans** (*insulin producing β -cells*). Patients become completely insulin-dependent and experience many difficulties reaching so-called normoglycaemia (*normal blood glucose*)⁽²⁾. Patients with type I diabetes need to inject insulin subcutaneous either with an insulin pen, a syringe or an insulin pump. Also they have to follow a strict diet, exercise regularly, and intensely self-monitor their blood-glucose. As the body is not capable of producing any insulin, or only in very small proportions, patients that fail to provide the body with the necessary amount of insulin will suffer a wide variety of complications (*figure 1.2*), ultimately leading to premature mortality.

Type II diabetes (T2DM) patients take oral medication and are not necessarily dependent on insulin. This type of diabetes is usually associated with an unhealthy lifestyle (*lack of exercise, unhealthy eating habits*), leading to an insufficient production of insulin or the body losing the ability to properly respond to the produced insulin, ultimately leading to insulin resistance ^(1, 3-7). A family history with diabetes or the presence of **gestational diabetes** might also be possible causes of type II diabetes among adolescents and adults ⁽⁸⁻¹⁰⁾. In some cases, the body is still capable of using some of the produced insulin, but this depends a lot on the severity of the diabetes, the level of insulin resistance and willingness of the patient to change their lifestyle. This also means that complications and symptoms that patients might experience vary a lot from patient to patient and are very different to the symptoms type I diabetics experience. It is not unlikely that patients are unaware of their condition and expose their bodies to long-term damages caused by the low or high glucose levels in their blood^(8, 10).

Gestational diabetes occurs during pregnancy and oftentimes disappears after pregnancy when monitored intensively. Gestational diabetes can be of serious danger to both the mother and unborn child. It has also been proven that not monitoring gestational diabetes during pregnancy significantly increases the risk of developing type II diabetes for both mother and unborn child⁽⁹⁾.

Diabetes related complications

Complications can be subdivided into two groups; **microvascular** and **macrovascular**⁽¹¹⁻¹⁴⁾. Microvascular complications are associated with damage to the smallest blood vessels inside the body. Complications usually occur in the eyes (**retinopathy**), kidneys (**nephropathy**) and nervous system (**neuropathy**) and are very common among patients with elevated HbA_{1c} values. Studies concluded that retinopathy and nephropathy presents itself in every 1 out of every 5 diabetes patient^(15, 16). Retinopathy and nephropathy are the leading causes of blindness and end-stage renal diseases⁽¹⁵⁻¹⁸⁾. Every one out of every eight diabetes patient is diagnosed with neuropathy, ultimately affecting approximately 70% of patients with diabetes⁽¹⁹⁾. Neuropathy is a leading cause of non-traumatic lower extremity amputations among diabetics⁽²⁰⁾ caused by a combination of nerve damage and foot wounds. Macrovascular complications are associated with damage to the larger blood vessels inside the body and usually occur in the cardiovascular system leading to complications such as strokes, heart attacks and diabetic foot. It is estimated that 75% of diabetes patients die

prematurely from macrovascular caused cardiovascular diseases (C.V.D.)^(13, 21). Foot complications are caused by a combination of macrovascular and microvascular complications. Poor blood flow and nerve damage result in untreated cuts and blisters, possibly damaging the foot so severely that amputation is the only option left. Also, hearing impairment, skin conditions (*caused by bacterial and fungal infections*) and increased risks of cognitive conditions such as Alzheimer's disease⁽¹⁾ are associated with macrovascular complications.

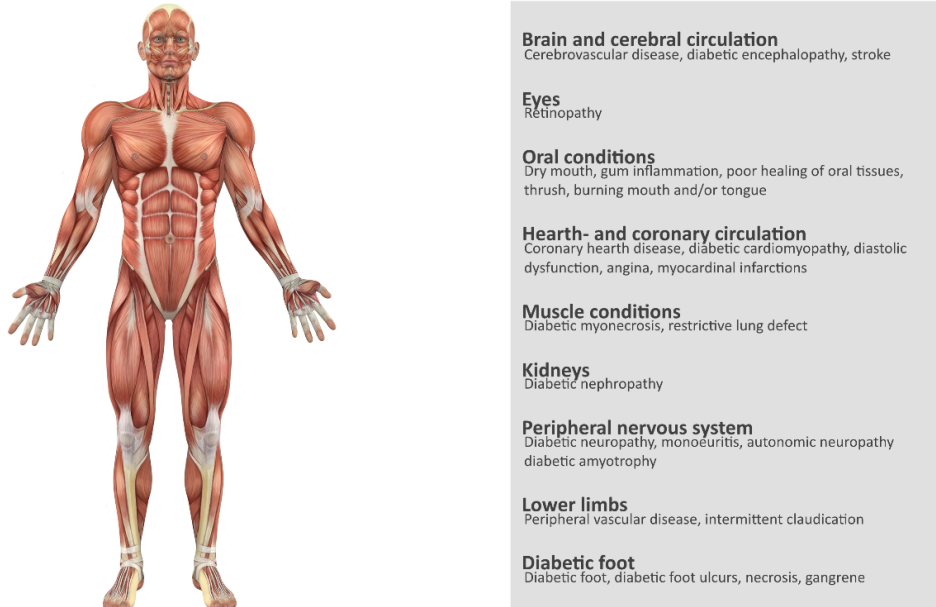


Figure 1-2 - Secondary diabetes complications

The best way to preventing further development of secondary complications is a combination of intensive self-management and monitoring of the blood glucose levels, eyes and feet and regular checks of the liver and kidneys⁽²²⁻²⁶⁾. Most of these checks are yearly recurring (*depending on the severity and presence of complications*), others have to be intensified based on the personal situation of the patient. The reason for these checks and continued monitoring is to prevent any further degradation of the body and to increase the overall quality of life of the patient. Not monitoring or treating diabetes related complications could lead to loss of vision, amputations of lower limbs, organ failures, degradation of cognitive state and in some cases sudden death^(22, 24, 25).

Preventing diabetes complications

The global organisations such as the W.H.O. and I.D.F. invests a lot of resources to raise public attention for the risks of having an unhealthy lifestyle and helps countries in developing strategies to prevent the further increased spread of diabetes⁽²⁷⁾. Change of eating habits, increasing the amount of daily exercise levels and promoting healthy lifestyles are just some of the possibilities the general population has to decrease the chances on developing type II diabetes.

For those who have already been diagnosed with diabetes, intense education is necessary to decrease the chances of developing further diabetes related complications and prolonging life expectancy as much as possible. Ideally, diabetes education should be focussed on maintaining healthy haemoglobin A_{1c} levels. Yet, in both the United States and Europe, the general focus of diabetes education is not on reaching normoglycaemia. As shown in figure 1.3 and 1.4, the majority of patients in both the United States and Europe have haemoglobin A_{1c} levels that reach above the recommended values of 6.5% (EU) and 7% (US)^(28, 29). HbA_{1c} (*glycated haemoglobin*) is the marker used to identify the average blood glucose level over the past 3 months prior to the measurement point.

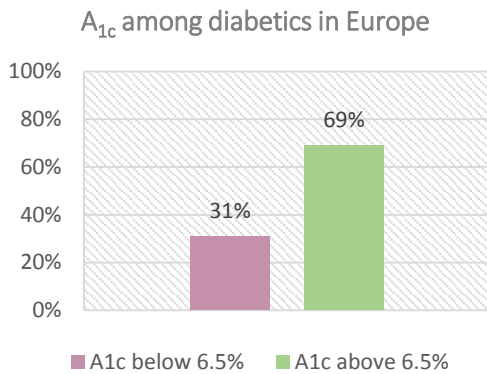


Figure 1-3 - Average HbA_{1c} in Europe

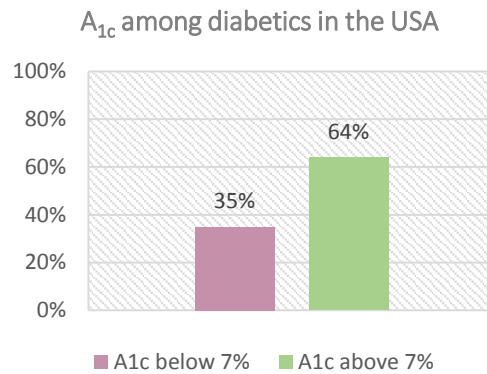


Figure 1-4 - Average HbA_{1c} in the United States

Diabetics need to take into account that there are various internal factors that can influence their blood glucose, but not only internal factors can prevent them from reaching normoglycaemias. There are a great number of external factors that have to be taken into account when managing blood glucose and altering medication when a patient is trying to reach normoglycaemias⁽³⁰⁻³⁶⁾. Some of these factors are:

Table 1-1 - Impact factors on blood glucose levels

Factor:	Elevating effects	Neutral effects	Decreasing effects
Food:	Carbohydrates, lipids (fat), protein, caffeine, alcohol	Protein, caffeine	Alcohol
Medication:	Medication dose & timing, medication interactions	-	Medication interactions, medication dosage & timing
Activity:	HIIT/moderate exercise	-	Light exercise, HIIT / moderate exercise
Biological:	Dawn phenomenon, infusion set issues, scar tissue & lipodystrophy, insufficient sleep, stress and illness, allergies, glucotoxicity, menstruation, smoking	-	Menstruation
Environmental:	Bad medication, inaccuracy in blood glucose meter	-	-

The different factors, complications and influences on the body requires the patient to receive education for the rest of their lives with diabetes. Education not only decreases the physical and mental burden on patients, it is also said to decrease the financial and social burden on countries and societies^(1, 10, 37). The approach in educating type I over type II diabetics is different. The focus on type I diabetes patients is oftentimes not the patient itself, as the majority of type I diabetics develop the disease in their childhood, therefore the focus is often on the parents⁽³⁷⁻³⁹⁾. Type II diabetics are different; although the age of onset of type II diabetes is drastically lowering, the majority of patients are adults; therefore the focus of education is directed towards the patient^(10, 28). This brings more possibilities in terms of educating the patient on the importance of performing intensive self-management.

1.2 The importance of patient education

The different factors that influence blood glucose differs per patient and requires good understanding of what these factors are and how they can be minimised or eliminated by the patient. That is why diabetics require very intensive and broad education on their disease⁽²⁸⁾. Patients need to understand in each situation how their body is reacting to specific situations and how they should anticipate on these situations by taking extra medication or glycogen (*dextrose tablets*). In table 1.1 some of the different in- and external factors were described which could have a positive or negative influence on the patient's blood glucose levels. This is just a small percentage of the things patients need to know to help them prevent exposure to acute complications (*hypo- & hyperglycaemias.*) Therefore, education of the patient has to start from the very first day after diagnosis, and develops itself together with the patient⁽²⁸⁾. There is a misunderstanding that there is such a thing as a "blueprint" for diabetes education. Different patients have different needs, expectations and requirements when it comes to their education. Some patients might be struggling with work, trying to get pregnant, going through a difficult exam, trying to increase their workouts or deciding to make healthier lifestyle choices. Others might have been recently diagnosed with a diabetes related complication and are in search for more information on alternative treatment plans or medications to eliminate the complications or decelerate further development of the complication. As one could see, information needs to differ a lot per patient, depending on the phase they are in in their lives, disease, career or their general health⁽⁴⁰⁻⁴²⁾.

Because chronic diseases, such as diabetes, are so invasive in a patient's life, they require a different approach from healthcare professionals when determining treatment plans. The multi-disciplinary fields patients are exposed to every day requires patients to know exactly how their bodies function. This knowledge brings great beneficial values to the further development and adjustments of their treatment plans⁽²⁸⁾. Patients need to be familiar with their ideal blood pressure, haemoglobin A_{1c} levels, cholesterol (*HDL & LDL*) levels, triglycerides, albumin to creatinine ratio, the presence of diabetic retinopathy, nephropathy and neuropathy and the condition of their feet⁽⁴³⁻⁴⁹⁾. Those who show no effort to change their lifestyle subject themselves to an increased risk of developing complications⁽¹⁾. How diabetes develops depends a lot on the amount of self-management patients invest in. Studies have shown that performing intensive self-management which includes maintaining a balanced diet, increased amounts of exercising, and trying to stop smoking and limiting drinking alcoholic beverages results in a decreased chances on getting diabetes related complications^(1, 19, 44, 50-52).

1.3 The Diabetes Self-management Education framework (DSME)

One of the common used frameworks to educate patients on their disease is the Diabetes Self-Management Education (*DSME*) framework, designed by the American Association of Diabetes Educators (*AADE*). DSME was first introduced in the 1940's and is widely adopted by many other medical organisations and patient education organisations worldwide⁽⁵³⁾.

DSME aims on reaching a sufficient level of understanding on how to perform self-management among patients with diabetes. The approach has been designed to provide knowledge and mediators that change behaviour and focus on short- and long- term health benefits (*figure 1-5*). This may lead to a higher quality of life and reducing medical costs for patients and healthcare institutions⁽⁵⁴⁾. DSME provides education in a variety of different forms, such as in gathering places, home education, etc. The framework consist of 9 different pillars (*topics*) that are continuously trained with the patient⁽⁵⁵⁾:

- Topic 1: Describing the diabetes disease process and treatment options;
- Topic 2: Incorporating nutritional management into lifestyle;
- Topic 3: Incorporating physical activity into lifestyle;
- Topic 4: Using medication(s) safely and for maximum therapeutic effectiveness;
- Topic 5: Monitoring blood glucose and other parameters and interpreting for decision making;
- Topic 6: Preventing, detecting and treating acute complications;
- Topic 7: Preventing, detecting and treating chronic complications;
- Topic 8: Developing personal strategies to address psychosocial issues and concerns;
- Topic 9: Developing personal strategies to promote health and behaviour changes.

DSME helps the patient to change their behaviour and provides them with psychosocial mediators⁽⁵⁵⁾. Some of these behavioural changes focus on helping patients to stop smoking, minimise alcoholic consumption, improve their diets, increase physical activity and intensify self-monitoring. These adjustments decrease chances of short-term complications such as high blood pressure, high lipid levels, high glycaemic levels and increased body weight. By focussing on the reduction of short-term complications, risks of long-term complications such as premature morbidity or mortality can be decreased significantly as well, which ultimately leads to a higher quality of life⁽⁵⁵⁾.

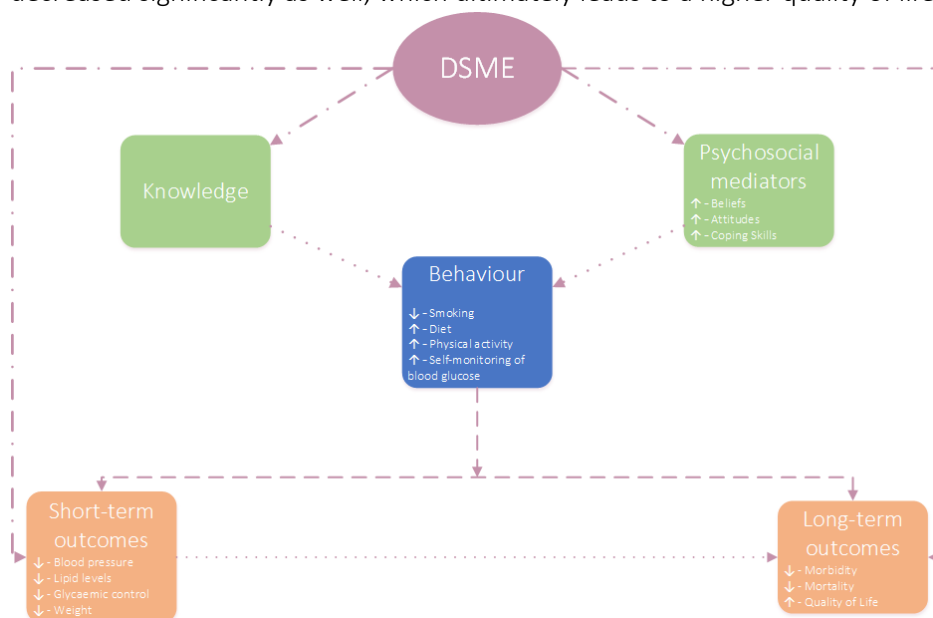


Figure 1-5 - DSME education approach

1.4 Education in the 21st century

The introduction of the internet and the wide adoption of smartphones, tablets, and the availability of broadband and mobile internet connections in most of the developed world has driven education into a new field^(56, 57). In a growing number of cases, classroom learning sessions are not required anymore to transfer knowledge, and the introduction of distance learning via the internet has provided learners with new abilities to specialise in a course or train for a new profession. With the introduction of Massive Open Online Courses (MOOC) in distance learning information is now available to anyone with an Internet connection. This leaves out the need for physically being at the learning facility and in most cases also including those who before lacked the ability to afford courses at a learning facility⁽⁵⁸⁾.

An increasing number of universities worldwide are investing resources in providing (free) courses for learners worldwide. Many universities offer a wide range of courses in different fields to learners via different popular MOOC platforms such as EdX, Coursera, FutureLearn, Udacity, Iversity and P2PU. These courses focus on different specialities, [figure 1.6](#) shows an example of a general diabetes course by Medical School Malaysia and [figure 1.7](#) shows a course on the global challenges of Diabetes by Copenhagen University on Coursera. These are just some examples of the different courses offered.

The availability of these tools has also changed the way learners look at education. Classic learning approaches where learners are required to be present at a school to acquire knowledge is unnecessary because of the availability of the internet. Since the early 1960's, distance learning has been present, but thanks to the introduction of the internet, smartphones and tablets, this method of learning has gained increasing popularity⁽⁵⁷⁾.

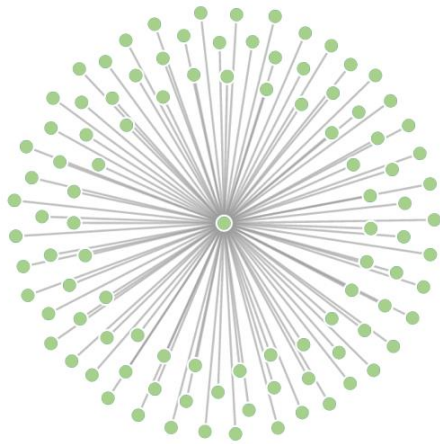
Figure 1-6 - A general MOOC course by Medical School Malaysia on Diabetes mellitus

Figure 1-7 - A MOOC course by Københavns Universitet on the challenges of Diabetes on Coursera

The previous method of using transactional learning, where the expert is the sending party and the learner the receiving party, is considered inefficient by many studies, especially when it comes to distance learning^(59, 60). Instead, a collaborative learning environment provides more opportunities and interactions between the different learners⁽⁶¹⁾. As it often happens, participants are on different entry levels when they join courses. More often than not it happens that experts in the field join online courses to update their knowledge, or just to see whether there are new developments in the field of their profession. By using the knowledge of these participants, combined with the expertise of the course expert, new and exciting questions and discussions often arise on the different fora of these course modules⁽⁶¹⁾.

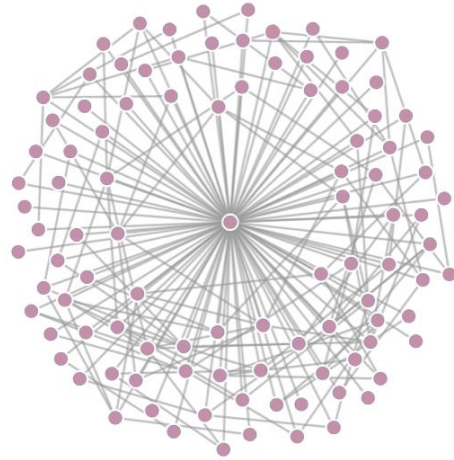
MOOC initially was designed with content delivery at its core framework⁽⁶²⁾. Although this initially worked for some courses, learners in the different MOOC courses started demanding a different approach in the way the MOOC courses were offered to them. They required more interaction between the different experts joining MOOC courses and were eager to help fellow learners with solving problems and found the lack of interaction between higher educated members a real issue⁽⁶³⁾. The further development of MOOC into a collaborative platform has resulted in the introduction of MOOC 2.0 based on 1-on-1 (*face-to-face*) learning with help from the different experts present in the MOOC courses. [Figure 1.8](#) shows an example of how the interaction takes place in the initial version of MOOC compared to the interaction between learners and professionals in MOOC 2.0.

MOOC 1.0



Focus of the first versions of MOOC
Content delivery

MOOC 2.0



Focus of the second versions of MOOC
1-on-1 (face-to-face) learning

Figure 1-8 - Evolution of MOOC from content delivery to face-to-face learning

Patient education hasn't been evolving in the same way as standard education did^(53, 57, 64-66). Nevertheless, education on diabetes has been developing itself the past couple of decades using many different other techniques resulting in education in many different forms. Patients are being educated in group settings, one-on-one conversations with diabetic nurses or diabetic educators or books and educational folders provided by the healthcare facility⁽⁶⁷⁻⁶⁹⁾. Only in the past couple of decades, the inclusion of computer technology in diabetes education has been slowly progressing, and different computer programs have been developed to educate patients on the importance of performing self-management and the progression of diabetes and development of complications^(70, 71). Although current developments are still in an early stage, the focus of diabetes education via computer still is on one-on-one education via offline software⁽⁶⁵⁾.

Surprisingly, at the start of this study, the MOOCs found in diabetes education have only been applied on a reasonable scale in the education of medical professionals, students and general public interested in the "challenges" of diabetes in fields other than the individual patient. The courses found on MOOC platforms such as Coursera, EdX and others provide education on the financial and environmental impacts of the disease, but finding a MOOC focussing on education of patients was very difficult. It is without doubt that the integration of MOOC in diabetes education could bring significant changes in this education field. Not only is there a course director (*a diabetes educator*) responsible for the information that is offered to the patients, there are also other experts involved in this knowledge shaping process to help patients receive answers to their questions.

Even more important is that the interaction between patients is encouraged in MOOC's using group-sessions. This opens up a lot of possibilities, as studies in group therapy for diabetes patients show that the interaction between patients is crucial to reach better self-management⁽⁷²⁻⁷⁴⁾. Moreover, have been proven to provide better results using fewer recourses⁽⁷³⁾. Another difference between MOOC and the current education approach is that the education itself is more scalable, therefore providing more possibilities for collaboration between patients and professionals⁽⁷⁵⁾. MOOC also provides possibilities to quickly assess knowledge and review different health topics, either via video lectures, audio lectures, presentations or live streaming with a health professional⁽⁵⁷⁾.

Figure 1-10 shows a summarised example of some of the information flows a diabetes patient receives, processes, analyses, evaluates and implements in their daily treatment plans. As one could see in the image, chronically ill patients depend on, consume and produce large quantities of data to help them reach those much desired normoglycaemic levels. Wearable devices, Wi-Fi and USB enabled blood glucose meters⁽⁷⁶⁻⁷⁸⁾, and in case of insulin-dependence, Wi-Fi enabled insulin pumps with continuous blood monitoring sensors provide the patient with significant data sets to help them alter their treatment plans on⁽⁷⁹⁻⁸¹⁾. The difficulties patients face is understanding these enormous amounts of data, not only from these devices, but also from healthcare facilities and general education on their disease.

Education on how to interpret this information is provided in many ways. This study wants to introduce patients to two models. Providing education via patient centric learning, or using a knowledge driven decision support system. Patient centric learning is a very broad method where the patient is provided with the information to make decisions on their own. This can be achieved via education using text, video, audio, or interaction between individuals⁽⁸²⁾. Knowledge driven decision support (KDDS) is focused on the decision making process in certain situations. It asks questions, and based on the provided raw data it offers instructions and answers. Moreover, a Knowledge Driven Decision Support system provides specialised problem solving using facts, rules and procedures⁽⁸³⁾.

In the case of a newly diagnosed patient suffering from an acute complication (*low-blood sugar*), a KDDS guides the patient in the steps they should take by 1) educating on what low blood glucose is, 2) recognising the symptoms, 3) evaluate the symptoms, 4) taking action, 5) implement treatment and eventually 6) evaluate the treatment (*see appendix 2*). KDDS could be seen as the digital version of a diabetic nurse showing a patient step by step what they should do in certain situations. It does not only limit itself to evaluating blood glucose, but also provide instructions on medication intake, traveling, diet, exercising, and many different fields.

The immense amount of information that patients produce and use to base their decision on not only makes it easier for a patient to provide a physician with all the necessary information to change treatment plans, it also makes them more aware of what is going on inside their bodies (*figure 1.9*)⁽⁸⁴⁾. The information need has driven patients to find their answers also in tools such as online patient fora. This introduced a certain risk since the lack of professional moderation or facilitation in most virtual communities may lead to inappropriate and disruptive use, or to the dissemination of inaccurate messages⁽⁸⁵⁾.

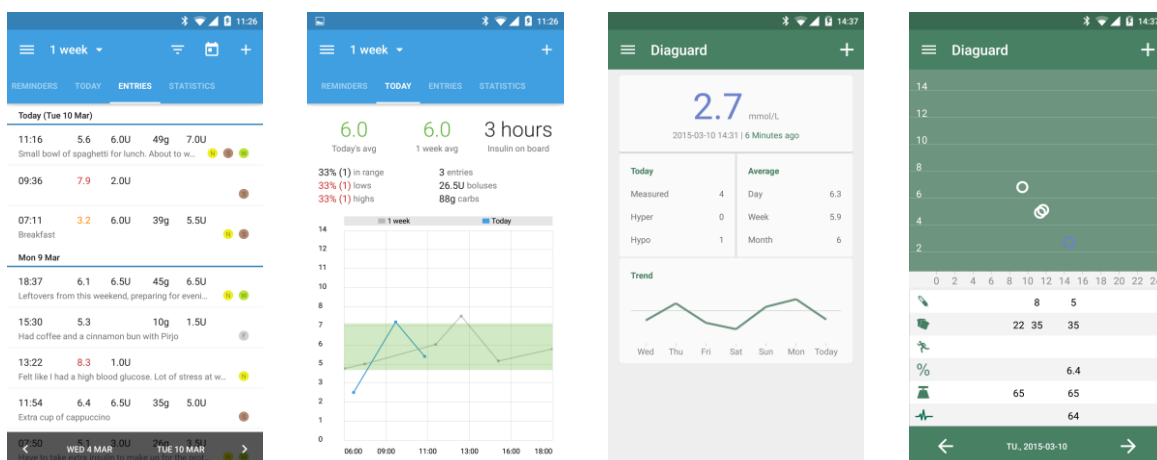


Figure 1-9 - Data produced by blood glucose monitoring and registration apps

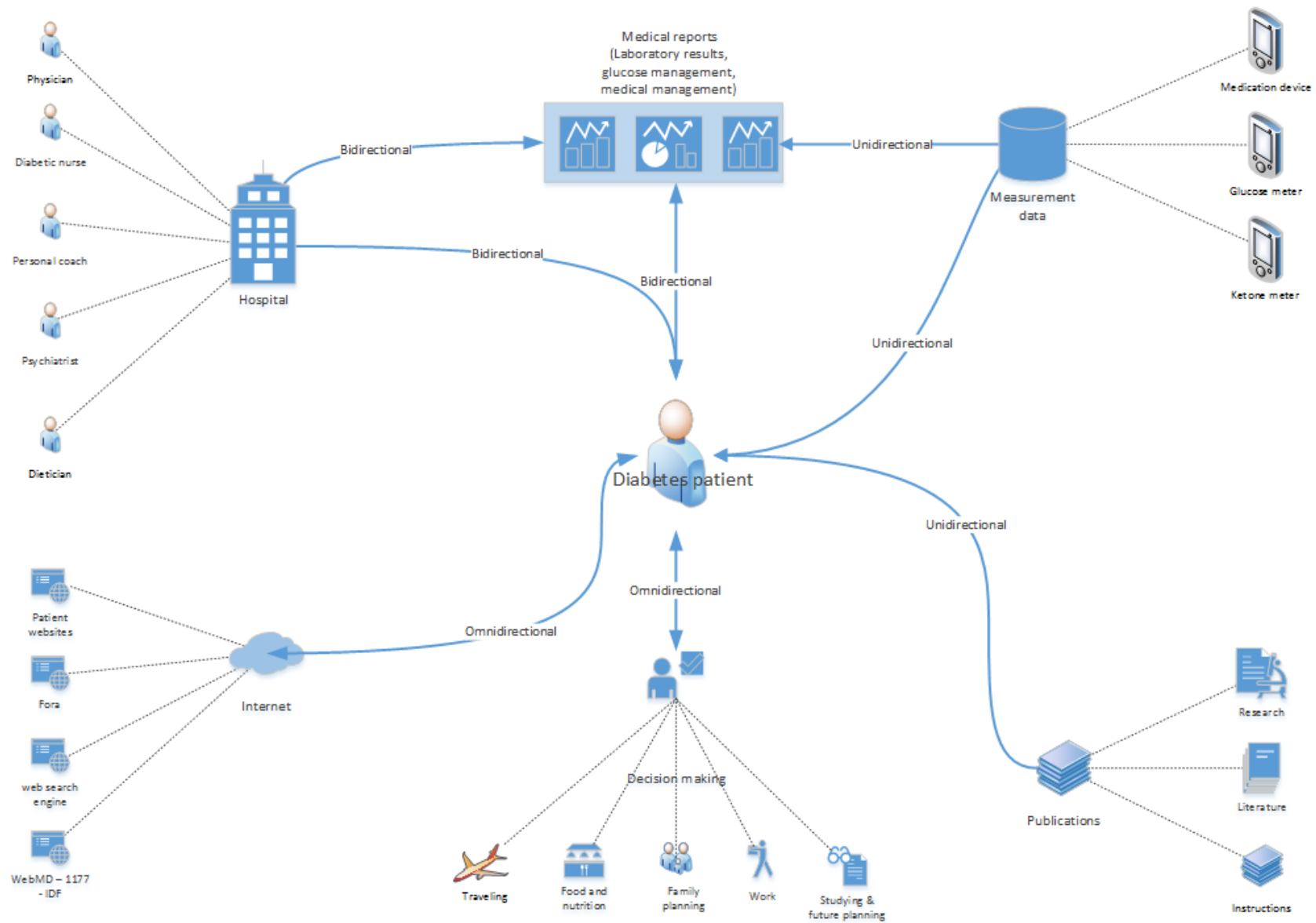


Figure 1-10 - Typical information flow for diabetes patients

The risks of uncontrolled internet education

One of the most used tools today among diabetes patients are online diabetes fora (*such as www.diabetesforum.com, www.diabetes.co.uk/forum/*). These websites are created, maintained and moderated by patient, or patient organisations and focus on questions related to diabetes. Patients who have questions or need some information from experienced patients can post their questions in the forum, and discuss opinions with others. These tools have led to better patient interaction and helped educate newly diagnosed patients that are in desperate need of answers or just some simple motivation in case their diabetic nurse, physician or diabetic educator is unavailable^(85, 86).

Although patients seem to be comfortable using these fora to find answers to their questions, one could wonder why the development of new learning platforms in patient education hasn't been flourishing as in other educational fields. Supposedly this may be caused by patient experience. Patients may experience different signs or symptoms during the onset of their disease, suffer more- or less often from acute complications such as hypo- and hyperglycaemia's, and have different needs and requirements when it comes to their education. As mentioned earlier, there is no such thing as a blueprint for patient education. Even the guidelines based in DSME are designed in such a way that interaction is possible. This individual approach with patients has made it very difficult to design a standardised set of education materials for patients with chronic diseases such as diabetes⁽⁸⁷⁾.

Patient education has to be based on clinically proven information. Different patient fora's oftentimes lack the moderation of medical professionals, ultimately risking the spread of myths and experiences from other patients as clinically proven information, which is based merely on personal experiences. Oftentimes, patient websites lack a certain form of ethical standards or certification to assure the validity of information and ensure the quality of education. The Health On the Net Foundation, founded in 1995, helps patient websites to achieve an ethical standard which focuses on providing qualitative health information. Websites that comply with the H.O.N. guidelines, receive a H.O.N. certification. These websites aim to be objective and useful, by focussing on transparent information⁽⁸⁸⁾. Most of the websites that were found to provide information to diabetes patients lacked this certification, exposing patients to information that might be biased.

A lack of this certification could be potentially dangerous to recently diagnosed patients who are still in the explorative phase of their disease, also patients who are in a situation they have never been in before are at risk (*those who are in the phase of pregnancy, surgery, puberty, etc.*)⁽⁸⁸⁻⁹⁰⁾. The lack of continuous review of information presented on the fora could be a possible risk factor, as the definitions of diabetes changes every time a new study is published. These changes might range between being either trivial or disruptive in the current knowledge of diabetes. In the early 2000's the I.D.F. announced that the current categorisation of diabetes is not accurate enough, therefore the W.H.O. in collaboration with I.D.F. introduced diabetes type 1.5⁽⁹¹⁾. Information like this is significant and should be used to adapt all the present information on fora that educate patients on their disease; but most information is still written using the old categorisation of T1, T2 and gestational diabetes⁽⁹¹⁾.

Could distance education turn uncontrolled knowledge in evidence-based science?

Looking back at the developments in other educational fields and the introduction of MOOC 2.0, distance education can provide new possibilities to present individualised information that connects to the needs of diabetes patients. Patients should be provided with tailored data, information and tools to help them acquire the necessary knowledge in the ways that suit them best. In an ideal situation the patient is an activated patient, which means that they can take action, seek information, make decisions, connect and provide themselves with sufficient support. Often though, recently diagnosed patients are still in the passive phase meaning they lack a certain amount of health literacy and communication skills; they feel helpless and isolated and put all their faith in the doctors' hands.

By bridging this gap as shown in figure 1.11⁽⁹²⁾ using distance learning techniques, patients cannot fall victim to faulty uncontrolled knowledge and receive education material that is written, reviewed and presented by professionals that are controlled by hospitals or medical facilities.



Figure 1-11 - the knowledge gap between passive and active patients

In addition, distance education platforms offer the ability to download education material locally on the mobile devices, which provides a lot of possibilities to learn via a mobile device (*computer, tablet or smartphones*) even when there is no internet connection available. Whenever a patients wants to review information, they can use a mobile device with the downloaded content while traveling home or to work. This also offers great possibilities for developing nations and rural areas where stable internet connections are not guaranteed. Therefore, distance education can provide patients also in rural areas with the same high quality education on their disease as patients in suburban areas do.

1.5 Problem description

We know the usage of distance education is beneficial to better self-management with diabetics ^(75, 93). But the current focus of MOOC and distance education in general is on professionals, rather than patients. This makes it difficult to know what patients really want in distance learning. Designing MOOC's can be easily done, but it only brings more fragmentation into an already chaotic online education environment if not done properly. Current online education is not based on patients' needs, but is the crucial to make patients want to use distance learning platforms or materials. That is why this study is trying to find and answer to what the needs are, which topics are relevant to them, what features they want, and whether or not they would trust a KDDS system to help them in times of need.. A similar study has not been done before, focussing on the integration of an online learning platform, combined with a knowledge-driven decision support system. But the benefits a patient centric model with support of KDDS provides could help improve the continuous education of diabetics, ultimately reaching better understanding of performing self-management to decrease further amplification of their disease, and provide them with a better future with less complications.

1.6 Aims of the study

The aim of this study is to identify the needs and requirements of participants (*a representative group of recently diagnosed type 2 diabetes patients*) when it comes to receiving education via an online platform based on distance learning. Which topics based on DSME do they see as most relevant in their attempt to reach better self-management, and what relationship can we find between the different topics to phase education in? Layered learning already has proven to be very beneficial to reach better understanding⁽⁹⁴⁾, but could it also be effective for the development of an online learning platform? Second, the study tries to analyse whether participants would see a knowledge driven decision support system (KDDS) inside of a patient-centric learning environment as useful? If it can provide them with the steps and decisions to take when they experience problems or have certain questions, would they be willing to trust and use it?

1.7 Research questions

The hypothesis that was formed during the definition of this study was *“Patients require new forms of intuitive and exciting education on their diabetes. An educational platform that provides them with enough interaction to keep them motivated and eager to receive education, and helps them take decisions using a knowledge driven decision support system”*.

In this, the following two research questions have been formed:

1. What are the needs and requirements in education using of T2D patients in an online education platform? *This research question aims to get a better understanding on what topics are most important to participants in this education platform. Also, it focusses on the method of content delivery; do they prefer to receive short or long videos, online presentations or text slides, Q&A sessions with specialists or other patients, quizzes or assignments?*
2. Which education approach do patients prefer to receive education? A patient-centric approach only, or patient-centric with the inclusion of KDDS? *By introducing the education methods (appendix 1, 2), the study wants to find out the approach participants prefer for receiving content, step-by-step via a KDDS, or rich-content based on patient-centric learning?*

A sub-question during this research that the study tries to find answers to is related to identifying an ideal education phasing. This sub questions is:

3. *What is the prioritisation of DSME topics for patients when receiving education? This research question is a supplement to the needs and requirements of patients, and aims to show a possible classification to design an education phasing. It can help understand the flow of educational material patients wish to use to receive the DSME topics.*

IMAGINATION IS
EVERYTHING; IT IS THE
PREVIEW OF LIFE'S
COMING ATTRACTIONS

ALBERT EINSTEIN

2 Methods

2.1 Research methodology

For this study, a design based research was chosen as the leading research methodology. Design based research is a methodology commonly used within learning environments and science of learning⁽⁹⁵⁾. The methodology is usually based on conventionalised interventions which are iteratively implemented in a natural setting (*such as a patient learning environment or an online educational platform*)⁽⁹⁵⁾. By providing participants with a base idea on how to solve a proposed problem, and ask them to “think out loud” and provide the study with their ideas, the ecological validity of the base solution was being tested^(95, 96).

Design based research is based on retrospective and cross iteration comparisons. This means also that the participant was presented with two learning (*education*) models⁽⁹⁶⁾. This helps to understand whether participants would prefer a platform that provides them with the knowledge and leaves the decision-making entirely up to the patient (*based on a patient centric design*⁽⁹⁷⁾), or that they prefer a platform that is based on taking them by hand and providing easy to make decisions based on the input the participant gave to the platform (*based on a knowledge driven decision support system*⁽⁹⁸⁾).

The research methodology provided the study with a framework that helped to reform patient education, conceptualise learning methods and supports further development of this online learning platform⁽⁹⁵⁾.

2.2 Research approach and study design

This study was at the beginning stage of the design based research, and because of time-constraints on the study it did not have any iterations. Instead, the single interviews were divided into three major phases. The cross-iteration comparison was performed by constantly reflecting back from one phase to another (*do you think that this could solve the problem you mentioned before?*) In the first phase, participants were asked which topics they felt like they lacked knowledge in, and were asked why they thought they lacked in this specific topic. This phase was the problem analysis phase of the interview. The second phase focussed on introducing the DSME framework (*appendix 6*) as the first artefact as a proposed solution for the educational gap. To bridge a connection between DSME and distance learning participants were introduced to the two learning methods (*appendix 1, 2*). This was the second artefact the participants were introduced to.

By asking participants which method of learning would be best suited to the different topics and subjects in DSME, the study got an idea of which learning method would be most suitable for which topic. The third part of the interview was the introduction of MOOC in distance learning. This third artefact was introduced for patients to understand what distance learning actually is, and what the possibilities are of such a system. After the introduction of MOOC's (*see more information in paragraph 2.6*), participants were asked to help conceptualise the ideas of what a learning platform should look like. By performing low-level drawings with participants, the study gathered ideas on the needs and requirements of features and graphical user interfaces.

These low-level drawings were later formed into mock-ups presented in figure 3.2 to figure 3.8. These mock-ups can be used by computer developers or designers to further develop this education platform. It not only provides a good understanding of what participants want in terms of education, but also in terms of functionality. The methodology required a qualitative approach^(95, 96). The

dependence of the methodology on presenting samples of the platform required the study to follow a qualitative approach⁽⁹⁶⁾. The approach was based on interviewing type 2 diabetics from Sweden and the Netherlands. Participants were asked questions based on an interview manuscript (*appendix 3*). This manuscript was subdivided into 6 main-parts, which were asked using an interview model presented in *figure 2.1*. These main parts are:

1. Introduction of the interviewer: *the study and the educational background*;
2. Introducing the interviewee: *their work, their family history and previous knowledge of diabetes*;
3. Identification: *of the difficulties patients are facing with self-management of their diabetes*;
4. Further in-depth interviewing: *on the issues they are facing with these difficulties (why, what, how)*;
5. Introduction of the distance learning platform and DSME education: *examples of distance learning were showed, participants were asked for ideas on what educational platforms for patients should look like. Also, patient learning models and prioritisation of the topics and preferred learning model: knowledge-driven model or patient-centric model were presented*
6. Patient reflection and conceptualisation of ideas: *describing the ideas and paper-based concepts*.

The semi-structured model of this interview left room for the patient to think out loud, and talk freely about the different aspects of diabetes. The third step was introduced to the interview to filter out any subjects participants weren't struggling with. The filtering step helped limit the time of the interview by not asking all 48 questions the interview consisted of, and limiting the average time per interview to 45 minutes instead of 90 minutes. This made it also possible to focus more on the quality of information rather than the quantity. It also brought more understanding of the difficulties participants faced.

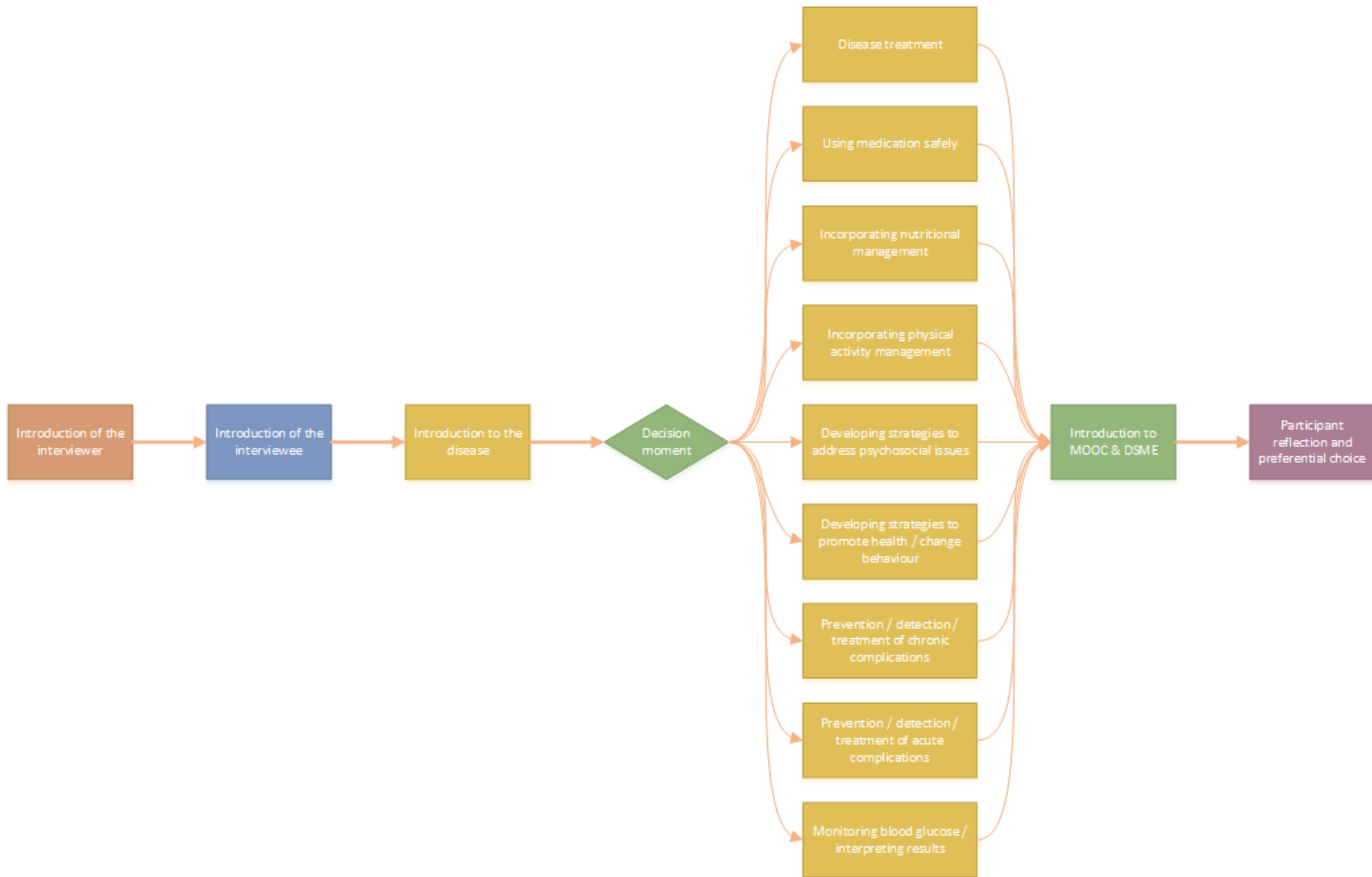


Figure 2-1 - Interview model for design based study

2.3 Study context

The study took place with patients from several hospitals in Sweden and the Netherlands. In Sweden, patients were gathered from Södersjukhuset (*Stockholm*) and Sophia Hemmet (*Stockholm*). Sophia Hemmet is a private clinic situated in the north-east of Stockholm and has a specialised department in diabetes care. Södersjukhuset, situated on the island of Södermalm, is the third largest hospital in Stockholm, and provides the education courses for recently diagnosed diabetes patients in Stockholm. The MUMC+ (*Maastricht*) hospital in the Netherlands is one of the largest diabetes hospitals in the region treating patients from the Dutch and Belgium provinces of Limburg and the German province of North Rhine-Westphalia. The hospital has one of the most specialised departments in diabetes care. The demographic data of the gathered participants is described in [table 3-1](#).

Participants from Södersjukhuset and Sophia Hemmet have been gathered via a research nurse also responsible for the intensive education course for diabetics held at Södersjukhuset. Patients who are under treatment of a diabetic nurse, or an endocrinologist and have difficulties with self-management are signed up for this course that teaches them the basic understanding self-management with diabetes. This 3-day course focusses on the nutrition (*based on the Swedish recommendable daily food intake guidelines*), exercising and answers some of the questions that patients have in a group setting. Also, there was one patient who had not attended this educational course, just like the Dutch participant. The influence of this intensive course was monitored during the interviews, and the high-level of involvement prevented that the interviews would move away from the research questions.

2.4 Study participants and inclusion criteria

For the qualitative study purposive sampling took place to gather participants based on the inclusion criteria relevant to the research questions. The inclusion criteria for the participants were:

- Patients should be between the age of 30 - 65 years old;
- Patients should be diagnosed with type 2 diabetes;
- Patients should be diagnosed with diabetes at least 6 months ago;
- Patients should not have been diagnosed with a secondary diabetes related complication(s);

These inclusion criteria ensured the study would gather a representative group of participants. The inclusion criteria were based on using the following reasoning:

Age: Lehman et al. (2003) concluded that diabetes type 2 patients between the age of 30 and 65 were most active in searching for information regarding their disease via the internet^(99, 100). Arguably, people aged younger than 30 were also more likely to use internet to help them find information about their illness, but the amount of recent diagnoses with type 2 diabetes in this group was smaller than in the group of 30 to 55 years old⁽¹⁰¹⁾.

Disease: The focus of this study is on type 2 diabetics so this was an obvious inclusion criterion. The information needs for type 2 diabetics are very different to those of type 1 diabetics^(41, 42, 102). The treatment of symptoms is very different to both groups and information about the treatment of acute complications written for type 2 diabetics could be potentially dangerous for type 1 diabetics and vice versa⁽¹⁰²⁾.

Disease duration: The reason why this study is focusing on patients that have been diagnosed with their diabetes longer than 6 months is based on a study by Wilson et al. (2013). This study concluded that the information needs for patients 6 months after onset are still focusing on reaching self-management of their disease⁽⁹⁹⁾.

Disease complications

To prevent any possible bias from disease related complications caused by macro- or microvascular conditions, patients are only included if they are not diagnosed with conditions such as retinopathy, neuropathy or nephropathy. Also patients with Cardio Vascular Diseases related to diabetes are excluded from this research. The reason why these patients are not included in the study is because the information needs for patients with complications change drastically compared to patients without complications. The future focus is to design an educational platform that provides patients with education to prevent complications and promote health. Complications require specific individualised care, which can currently only be provided by healthcare professionals or diabetic nurses.

Language proficiency

For the Swedish participants, the language proficiency was put into place because the interviews would be held in English. This makes further usage of results in international set-ups possible. Also, the researcher was non-Swedish and did not master the Swedish language enough to conduct the interviews in the Swedish language.

2.5 Time framing

In order for the study to finish in a reasonable time, a time plan was put into place. This plan divided the study into 5 major milestones. These milestones helped the project to stay on track and consisted of multiple tasks and prerequisites:

1. Handling the prerequisites (*problem definition, aims, resources, supervisors, project plan*);
2. Preparation of the study (*literature research, defining methodology, analysis, interviews*);
3. Data acquisition (*performing the interviews*);
4. Data analysis (*analysing outcomes, prototyping, defining educational model*);
5. Thesis writing (*writing the thesis according to IMRaD definitions and defending study*).

The study started at 01/12/2014 and officially finished at 11/05/2015. Because some of the milestones were running parallel, the following dates were used for the deadlines of the milestones:

1. 15/02/2015 (*milestone was reached in the amount of time planned*);
2. 04/02/2015 (*milestone was reached in the amount of time planned*);
3. 14/04/2015 (*milestone wasn't reached, pushed through to the 29th of April*);
4. 20/04/2015 (*milestone wasn't reached, pushed through to the 7th of May*);
5. 11/05/2015 (*milestone was reached in the amount of time planned*).

The deadline for the data-acquisition phase was flexible to leave more room for gathering more participants in case saturation could not be reached. This assured the study could reach a better level of saturation. A more detailed time plan can be found in [appendix 4](#).

2.6 Data collection

The data collection used for this study was based on semi-structured interviews with a high level of involvement. The high level of involvement was performed by the interviewer by steering the conversation back to the topics related to diabetes whenever the topic was unrelated to DSME. Studies have shown that when performing qualitative research in medical education, in-depth interviews are the best tools for data-acquisition^(103, 104). Especially the usage of a semi-structured approach can bring large amounts of qualitative data from the participants. The high-level of involvement during the interview was needed to ensure that the interview would not drift away from its core topics⁽¹⁰³⁻¹⁰⁵⁾.

The interviews were performed in two languages. People living in the Netherlands were interviewed in Dutch, as this was also the primary language of the interviewer. For people living in Sweden, who were confident enough to speak English, the interview was held in English. All the technical- and medical terms were translated by Swedish professors at Karolinska Institutet and brought to the interview in case the participants did not understand the terminology for diabetes in English. The data collection focussed on multiple parts. In the 4th interview phase, the focus was on finding the gaps in the current education plan of diabetics. By asking specific questions, participants had to think out loud on all the problems they were facing during their self-management.

After going deeper into these topics, participants were asked how they solved their need for education at this moment. The path patients follow differ a lot per person. Personal preferences have a major impact on the method patients use to receive education⁽¹⁰⁶⁾. This brought a good understanding of the path participants have to go through to find answers to their questions.

In the 5th phase, DSME was introduced to help the participants identify the topics they were struggling with the most. This helped to find a possible education *phasing*. These phases was used to design the educational model presented in [figure 3.1](#). After the classification, participants were asked on their preference of receiving education per topic; either via knowledge transfer (*patient centric model*) or decision support (*knowledge driven decision support system*). Hereafter, participants were presented with some examples of online learning platforms, a set of video's¹ showing the possibilities of distance education, and the mobile version of EdX and Coursera on an Android phone and tablet. Before moving to the next phase, participants were asked if they would rely on the judgement of an online education platform when it comes to decision-making. In phase 6, after the introduction of the learning platform, the interviewer connected the different topics that are mentioned in phase 3 to the possibilities this learning platform should offer (*presented in phase 5*). Participants were asked to think out loud in what way they would like to receive their education (via video, audio, text, interactive sessions) and conceptualise their ideas together with the interviewer.

All the interviews were recorded using a memo recorder. The participants were notified before the interview took place and agreed to the recording. The recording started after the introduction of the interviewer and interviewee. The first two phases of the interview, as mentioned in paragraph 2.2 were designed to introduce the researcher and participant to each other. This also was meant as a so-called icebreaker to form a connection before the actual interview took place. During the 3rd and 4th phase of the interview (*the daily struggles of the participant, and the in-depth interview*) notes were taken to follow-up on certain topics if necessary.

In the 5th and 6th phase the comments and ideas the participants had were drawn on paper ([appendix 5](#)), recorded via a memo recorder and notes were taken. Also, participants received a document that explained the 9 topics of DSME ([appendix 6](#)); together with some examples of how the topics were covered by diabetes educators. Comments and prioritisation of the participants were noted on the document. Microsoft Office OneNote software was used to create a separate sheet for every participant where all the notes were written down. For the transcription of the interviews, Microsoft Office Word and recording software for Skype was used (*for interviews in the Netherlands*).

¹ Video's shown are available via: Iversity: https://youtu.be/b_N_NHbC80E - West-Middlesex Hospital: <https://youtu.be/9DcEYJq2ZmE> - Stuff Made Simple: <https://youtu.be/MGL6km1NBWE> - Liberty Medical: <https://youtu.be/PAwtAtMBOWA>

2.7 Data analysis methodology

Thematic content analysis is a much used methodology in qualitative studies, and was performed on the interview transcriptions^(96, 107). Thematic content analysis consists of a number of steps to identify themes that are related to the research question. The steps to extract the information from the interviews are:

- Collecting, sorting, and transcribing audio from interviews committed with participants. This is part of the data preparation and organisation step;
- Analysing the data from notes and transcripts;
- Sorting out data, categorise data by labelling, segmenting and coding the outcomes;
- Identifying the correct themes, categories and data input;
- Relating and connecting the data with the research questions.

Figure 2.2 shows a visualised approach of how thematic data-analysis took place. In appendix 7, a more detailed image can be found of how the data-analysis connected the design based approach to the problems and how it tried to find correlations in the qualitative information and the ideas and propositions of the participants in terms of designing the educational platform.

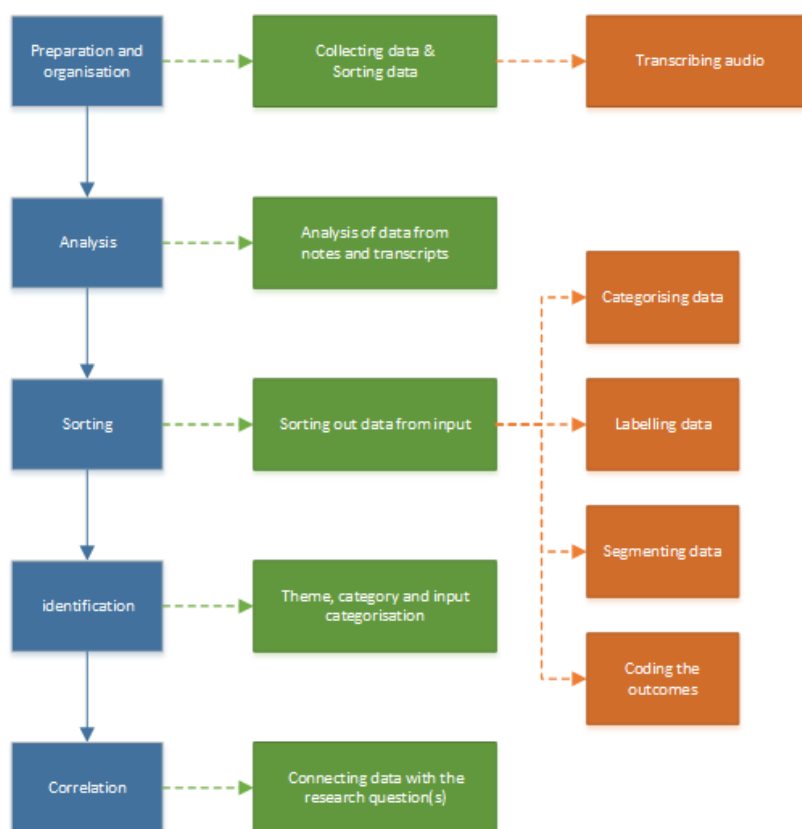


Figure 2-2 - Visualised approach on the thematic content analysis

An individualised approach was used for all participants, this means that participants were introduced with a problem they came up with themselves (*based on the struggles they had on reaching normoglycaemia*). The interview proposed a solution in the form of a distance-learning platform via internet. After the solution was presented, in combination with the introduction to using a KDDS driven system and a classification based on a DSME education structure, participants were asked for their ideas on and requirements of the educational platform using distance learning. The input was eventually used to form prototypes which are presented in figure 3.2 to figure 3.8.

2.8 Validity and reliability

The validity of the interview manuscript was checked in collaboration with the head of education from Södersjukhuset in Stockholm, and the head of department of learning at Karolinska Institutet in Stockholm. By test running the questionnaire, both online and used for the semi-structured interview, on doctoral students and master students from Karolinska Institutet, Royal Institute of Technology (KTH), Uppsala University and Dalarna University the quality of data was tested by multiple (neutral) sources.

2.9 Ethical considerations

Before the data acquisition took place the participants were presented with a patient information leaflet that explained in detail what the interview was going to be about and any ethical considerations. The information leaflet, attached in [appendix 8](#), explains to the patient what the interview would be about and that it would be focused around the education about their disease. Also, information on what to do if the participant wishes to disenroll from the interview is explained in the leaflet. The information leaflet was again presented before the interview, and the interviewer asked the participant if there was anything unclear written in the leaflet.

The participant was also notified that the interview was going to be recorded and that the recording would be completely anonymous. However, the instructions on how the interview was going to take place were given before the actual interview started and checked with the participant whether they agreed with the details or not. The patients provided the researcher with oral consent before the interview started.

DO NOT GO WHERE
THE PATH MAY LEAD;
GO INSTEAD WHERE
THERE IS NO PATH AND
LEAVE A TRAIL

RALPH WALDO EMERSON

3 Results

The results coming from the qualitative study were used as the only source of data for this thesis. The interviews that have been held with participants from Sweden and the Netherlands were the source of input for the identification of needs and requirements of patients suffering from type 2 diabetes.

A total of 6 participants joined the study before a certain level of saturation parts of the study needed was reached. The majority of participants came from two hospitals in Sweden; Sophia Hemmet (2 participants) and Södersjukhuset (3 participants). Both hospitals allowed the study to use their research nurses to get in touch with possible participants. One participant came from outside of Sweden and was contacted via the Maastricht University Medical Centre (MUMC+). The demographic data of the participants is described in table 3-1 - "Participants' demographic data".

Participant	Gender	Age	Country	On-set diabetes
Pa 1	Male	49	Sweden	2 years ago
Pa 2	Male	39	Sweden	9 months ago
Pa 3	Male	61	Sweden	9 years ago
Pa 4	Male	57	The Netherlands	5 years ago
Pa 5	Female	41	Sweden	14 months ago
Pa 6	Male	62	Sweden	7 months ago

Table 3-1 - Participants demographic data

The thematic data analysis that was performed on the interviews, focussed on finding three main topics.

1. What are the struggles patients have in reaching self-management (*determining the needs and requirements in education and reflect those to the DSME framework*);
2. Do participants think that distance education might be a solution for them to receive more or better education so that they can reach better self-management of their diabetes;
3. Do participants prefer to receive education using a knowledge driven decision support system, or a patient centric model? And what topics do they think are the best for using one over another.

By analysing the conversations, the main findings of the results were that participants all feel a major lack of knowledge in the nutrition and exercising topics. Diabetes puts a lot of stress on the choices in food and exercising, and not following a healthy lifestyle can significantly increase the chance of complications. The analysis showed that participants feel a certain fear for complications, and want to know what the best thing is that they can do against these complications. Also, the interpretation of blood results and how medication works was mentioned several times in the interviews with all patients. The other results from the thematic analysis are discussed in chapter 3.1 below.

3.1 Results on the research questions

3.1.1 Research question 1:

The needs and requirements of type 2 diabetics: All participants in this study seemed to have a fairly positive opinion of the education they received on their diabetes. Most of the participants had a general understanding of what diabetes was, and could explain to a certain extent why it is so important for them to reach normoglycaemia in order to prevent further damage to the body or degradation of the vital organs. Most of the participants agreed that more exercise and dietary

changes in their lifestyles might actually improve their health even further, but they also mentioned that recurring education is essential on these topics as food and exercise levels change over time.

A recurring fact during the interview was that most of the participants were familiar with the risks they were taking with not measuring blood glucose on a regular basis, or increasing their levels of exercise and changing their eating behaviours. Participants were excited about the development of an educational platform that they could reach at all times, and also the possibilities of such a platform resulted in surprisingly mesmerising discussions about the possibilities of such an educational platform. The needs and requirements of patients were very clear and will be discussed further in this paragraph.

The general needs and requirements of education

Participants mentioned there was a need for repeating education on the importance of achieving a healthy diet and increase workout activities. The amount of education they received in not only Sweden, but also in the Netherlands was limited, and information overload during the educational weeks caused the majority of guidelines and nutrition related recommendations often to be forgotten.

“I think helping people understand why you should eat healthy is crucial to diabetics. I have been using less and less medication for some time now because I decided to change my eating behaviour. I don’t forbid myself to eat something I really like, even though it is unhealthy, but I know that small portions are much more desirable, which I re-learned recently in an update on how to eat healthy” (participant 4)

“I am a person who likes food, I don’t care at all about food and the consequences it has on my diabetes. It can’t be that bad. But I am afraid though that my love for food is going to present itself as complications for the future as well. No one really taught me anything about eating healthy. I really miss that” (participant 1).

“I have cured my diabetes (an equivocal term) by finding information on nutrition myself. The education was so strange because I know that my body does not coop with the Swedish guidelines on food intake. When I eat carbs from potato or pasta I jump into a hyperglycaemia, that’s why I’m on the “Low-carb High-fat” diet. That works for me, but all dieticians and documentation say I’m crazy” (participant 5).

Five out of six participants were unaware of any side-effects medication could cause and possible alternative medications. Without mentioning the medication topic, participants mentioned that they were not sure whether metformin or any of the other available oral, inhaling or subcutaneous anti-diabetic alternatives could cause any of the side-effects they experienced during or after the onset of their diabetes. They related this to a lack of education on the medication itself.

“I heard that metformin is a necessary bad, I have no idea what that means in my situation. Should I keep on taking it? On the internet I can find a lot of horror stories on what metformin does to your liver, that’s why I only use it once a day. But I have no idea whether these stories are true or not...” (Participant 2)

“Is it true that metformin is poison? I heard that recently somewhere on the television and it makes me a bit scared about using the medication!” (Participant 5).

All participants were struggling to reach or maintain the daily recommended levels of physical activity. Recurring education on the importance of performing physical exercising on a regular basis, and instructions on the different forms of physical activity that could be suitable for the different levels of entry is a necessary topic that all participants wanted to see in this platform.

The interviews also showed that there was a need for an individualised approach on delivering education. All participants were going through different phases of information needs depending on the progression of their diabetes. The information needs per participant differed a lot depending on the situation that caused the onset of diabetes, such as a family history, unhealthy lifestyle, eating disorders, etc. Also, the current progression of their diabetes (*regressive or progressive*) made the type of information needed differ a lot per participant.

This was clearly visible in the results of the participant in this study. Only three topics reached saturation, where topic 3 (*incorporating physical activity into lifestyle*) and topic 2 (*incorporating nutritional management into lifestyle*) had an absolute position on 1st and 2nd place respectively, and topic 8 (*developing strategies to address psychosocial issues*) was considered last by 4 out of 6 participants. The results indicate that forming a predetermined learning path is difficult in this group of patients. This also emphasised the importance of flexible learning, as the ability to choose courses, skip lectures and find specific information answers directly to the needs of individualised learning.

During the interviews, participants were also asked to think about how they would prefer to receive education on the topics that they had mentioned. Participants were encouraged to think out of the box and not let them limit themselves by technological or current educational limitations. Using a piece of paper, a pen and some creativity, ideas were put on paper ([appendix 5](#)) which resulted in the proposed prototypes of the education platform displayed in [figure 3.2](#) to [figure 3.8](#). The needs and requirements are further discussed in detail in this paragraph. Also, the needs and requirements have been reproduced in the prototypes as much as possible. Summing up the general needs and requirements of the participants, the study came to the following recommendations for the educational platform. Participants want a platform that:

- Is easy to use, does not have too much information is easy to navigate;
- Provides flexibility, ability to choose specific courses the learner is interested in;
- Shows multimedia, preferably audio and video lectures with examples on the topic;
- Is available on desktop, laptop, tablet and mobile devices and provides a unified design;
- Is up-to-date, and interactive, providing new courses on updated knowledge;
- Brings clarity to the learners, possibly by using small tooltips to help understand definitions;
- Scales to a reasonable size, this enhances the maintenance and input to the platform;
- Has downloadable content (multimedia and text) to use while traveling or on holiday.

In [paragraph 3.2.2](#) further details on the platform are described and visualised using prototypes.

3.1.2 Research question 2:

Which type of education model do patients prefer per topic? It was clear that identifying an ideal method to use in the education platform as a whole would be an impossible task to do. The differences in prioritisation of the different DSME topics were too different between the participants ([paragraph 3.1.3](#)) By modifying the original research question and not focussing on using one model for the whole design of the platform, but on the integration of KDDS into patient centric learning, the study managed to use feedback from this question to answer the aim of the study.

Participants received a short introduction on the two education methods (patient centric learning & knowledge driven decision support system). The models were explained to the participants as:

- Patient centric model: *the user will be presented with all the information they need to base their decisions upon;*
- Knowledge driven decision support: *Using the provided input from the user to guide them through the decision making.*

Both models were explained using the following statements:

The patient-centric model provides you with the information specifically for this topic. It provides the information you need to make a decision on the situation yourself. It is focussing on different methods, such as video- audio- and text lectures and focusses on helping you learn everything you need to feel confident about this topic.

The knowledge driven decision support system asks you for input, and provides you with the best follow-up step for this situation. You will be giving the system the input, and the platform responds to the input with questions, and recommendations.

The topics were abbreviated in the table the following way:

- T1. Disease and treatment process;
- T2. Incorporation of nutritional management into lifestyle;
- T3. Incorporation of physical activity into lifestyle;
- T4. Using medication safely;
- T5. Monitoring blood glucose and interpreting results;
- T6. Prevention, detection and treatment of acute complications;
- T7. Prevention, detection and treatment of chronic complications;
- T8. Developing strategies to address psychosocial issues;
- T9. Developing strategies to promote health and change behaviour

Participants came up with these preferences of their ideal learning method to use in subjects inside of the different DSME topics:

Table 3-2 - Preferences of educational model (PC = Patient Centric - KDDS = Decision Support)

	T1	T2	T3	T4	T5	T6	T7	T8	T9
Pa 1.	PC	PC	PC	PC	KDDS	KDDS	PC	PC	PC
Pa 2.	PC	PC	PC	PC	KDDS	KDDS	PC	PC	PC
Pa 3.	PC	PC	PC	PC	KDDS	KDDS	PC	PC	PC
Pa 4.	PC	PC	PC	PC	KDDS	KDDS	PC	PC	PC
Pa 5.	PC	PC	PC	KDDS	KDDS	PC	PC	PC	PC
Pa 6.	PC	PC	PC	PC	KDDS	KDDS	PC	PC	PC

All participants preferred to receive a patient-centric approach on subjects in topic 1-3 and topic 7-9. All participants except one preferred receiving a patient-centric approach on subjects related to topic 4, also all participants except one preferred receiving help from a knowledge-driven decision support on subjects related to topic 6. Lastly, all participants preferred receiving education using a help of a knowledge driven decision support system on subjects related to topic 5.

3.1.3 Research question 3

T10. **Prioritisation of the DSME topics:** After the introduction of the DSME framework; the participants were asked to prioritise the topics in order of ranking which the participants thought receiving education upon was most important. The reason why this question was asked was to better understand the focus during the self-management courses. The topics in the results are categorised the same way as listed in paragraph 3.1.2.

Table 3-3 - Classification of DSME topics / 1 = Top priority - 9 = Low priority

	T1	T2	T3	T4	T5	T6	T7	T8	T9
Pa 1.	5	1	2	3	4	7	8	9	6
Pa 2.	4	5	1	6	7	3	2	9	8
Pa 3.	6	1	2	3	5	7	8	9	4
Pa 4.	7	2	1	4	8	5	9	6	3
Pa 5.	9	1	3	4	2	6	7	8	5
Pa 6.	4	2	1	3	7	8	9	5	6

As shown in [table 3.3](#), the diversity in prioritisation of DSME topics among participants is large. Although it is impossible to reach saturation in this research question, the outcomes emphasised that: patients cannot be served with a pre-designed education plan on their disease. This also indicates that the information needs per patient are incredibly diverse hence why the education platform should offer flexible learning at its core, meaning a patient can choose from subjects and topics they feel they like to receive education about.

This was also something that all participants mentioned in the general needs and requirements of the platform as well. In [paragraph 3.2.1 - Proposed education phasing](#), a mean calculation was performed to determine if phasing of the education could establish relationships between DSME topics, and help understand which topics needed more focus than other in the platform.

3.2 Proposed designs

3.2.1 Proposed education phasing

During the interviews, participants helped to determine the possibilities of follow-up education and determining possible relationships between the 9 topics of DSME by phasing the education into 4 main topics. The outcomes in [table 3.3](#) show a categorisation based on the input from participants which helped to determine what DSME topics were most relevant to the participants.

By performing a mean-calculation on the results, an attempt to design a phased education plan resulted in the proposed design shown in [figure 3.1](#). There are four phases in this education plan (1. *Daily lifestyle*, 2. *Understanding the disease*, 3. *Preventing complications* and 4. *Future concerns*.) These phases were formed with the input from the participants when discussing the relationship between the topics during the interview, and with help from the thematic analysis of the transcriptions.

Converting the preference numbers (*1 = top priority - 9 = low priority*) into grades (*1 = high, 9 = low*), and calculating the total scores of the topics and dividing it by the number of participants, using a mean calculation results in a possible education phasing format. [Table 3.4](#) shows the calculation of the mean results, used to form a taxonomy of topics based on DSME education.

Table 3-4 - Mean calculation of topic categorisation

	T1	T2	T3	T4	T5	T6	T7	T8	T9
Total grades	35	12	10	23	33	36	43	46	32
Participants	6	6	6	6	6	6	6	6	6
Result	5.83	2	1.6	3.83	5.5	6	7.16	7.66	5.33

The results from this calculation helped to determine the taxonomy of the DSME topics in this way:

- | | | | |
|------------|-----------------------------|---|--|
| 1. Topic 3 | 1. Daily lifestyle | - | Physical activity; |
| 2. Topic 2 | 1. Daily lifestyle | - | Nutrition management; |
| 3. Topic 4 | 2. Understanding disease | - | Using medication safely; |
| 4. Topic 9 | 2. Understanding disease | - | Promoting health / change behaviour; |
| 5. Topic 5 | 3. Preventing complications | - | Monitoring blood-glucose and results; |
| 6. Topic 1 | 2. Understanding disease | - | Disease and treatment process; |
| 7. Topic 6 | 3. Preventing complications | - | Understanding acute complications ¹ ; |
| 8. Topic 7 | 3. Preventing complications | - | Understanding chronic complications ² ; |
| 9. Topic 8 | 4. Future concerns | - | Addressing psychosocial issues. |

¹ Understanding complications: preventing, detecting and treating the complications

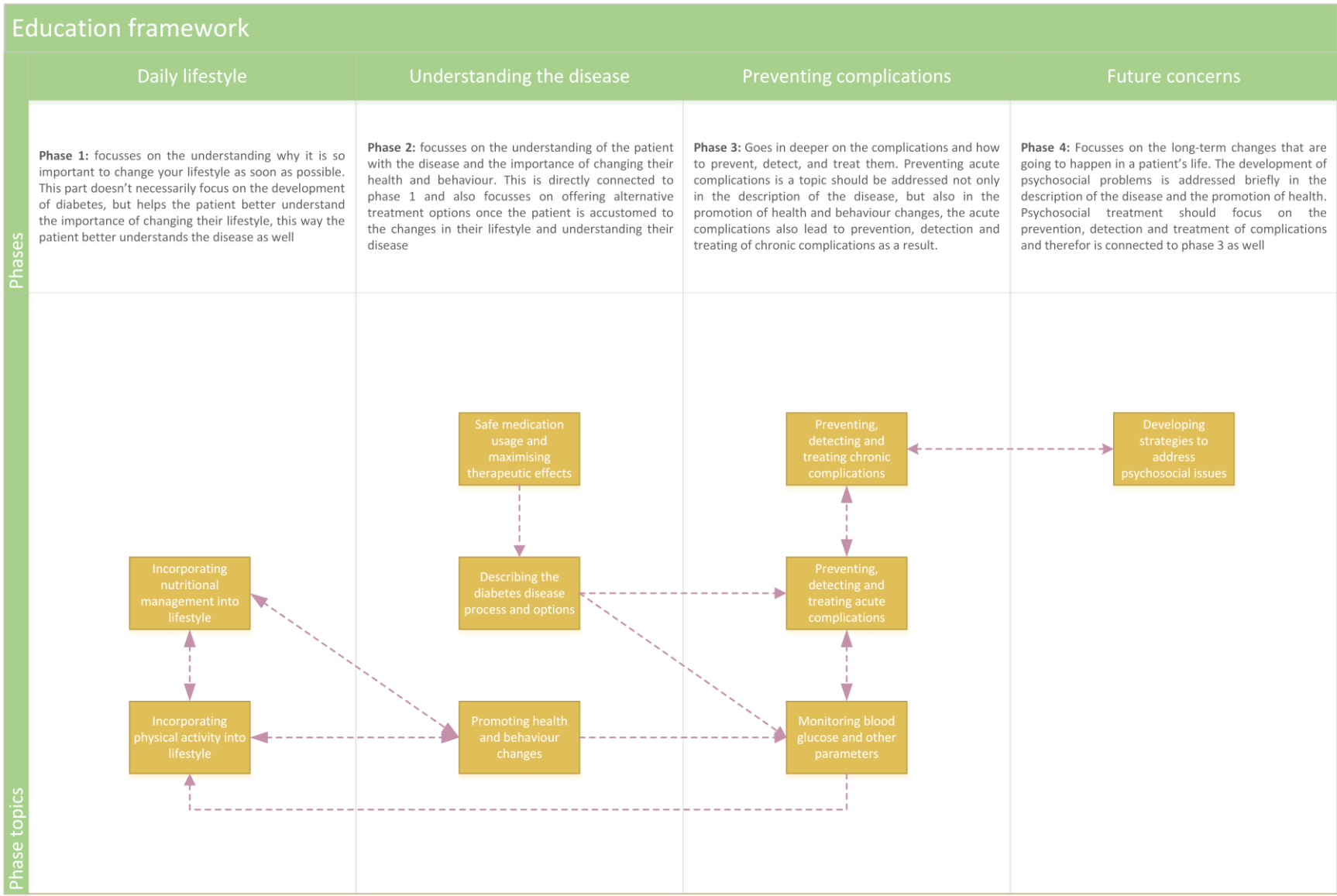


Figure 3-1 - Education phasing based on participant information

3.2.2 Proposed platform design

In [paragraph 3.1.1](#), the results on the needs and requirements of the participants for the development of the learning platform are discussed. These results provide an overall view on the primary functionalities that the learning platform should provide. In order for developers to understand what participants like to see in this platform, some proposed educational platform designs have been created based on the input from participants. The proposed designs have been created using two techniques. First, form study prototypes have been created together with the participants after the interviews.

Form study prototypes help software developers to identify the best way of designing the platform. They provide basic understanding of size, look and feel of the product without having to simulate anything. They also help in understanding the visual aspects and their relevance to the final product, and can be used by the software engineers for further development. Participants were asked what features they thought were crucial for this platform to be a success. [Appendix 5](#) shows these paper based designs which have led to the form study prototypes discussed below..

“I think a system like this should not be a replacement of the first introductory course we had at Södersjukhuset. I think me, and many other patients with me, need to sit in front of an actual doctor who explains what you should do, how you should do it and what the purpose of it is. Using an online website to find more information or to re-assess your knowledge is an excellent idea though, but not as a replacement”. (Participant 4)

“I think it is a very good idea for this system to focus on people in their early 30’s to 50’s first. They are still very active on the internet, and they want to get to know as much information as quick as possible. For a guy in my age, this could be helpful as well, but I think I would need some help understanding how the system works, and what the benefits of using them are. Don’t get me wrong, I don’t think I wouldn’t use the system, I just don’t see myself going to a doctor or diabetic nurse now already, I doubt I would be using it so enthusiastic if I don’t know how the system really works”. (Participant 3)

Participants mentioned that group sessions could be very helpful. Especially asking questions in a group setting and receiving answers were in their opinion easy and efficient. If there was a possibility to have such a group conversation using Skype or a similar chat mechanism, the participants would definitely make use of this functionality. Participants mentioned that using this feature could be a time- and money saving solution for both the users as well as the healthcare professionals.

This platform could provide the possibility to join a group meeting where I can ask questions and listen to questions other people are asking. This functionality certainly would help me to be more confident. Often when I go to my doctor, I have some questions and sometimes I forget about half of them. When you forget to ask a question in a group set-up, chances are that another person asks a similar question. A win-win situation for me, other participants and the doctor (participant 5).

In [figure 3-2](#), a prototype is shown focussing on the live-chat features of the platform. This feature was designed around the needs of group sessions and the feeling of comfort these group-meetings have for patients.

The prototype shows a scenario where the patient (*John Doe*) has joined a session with a dietician (*Dr. Doe*). In the middle of the screen the person that is speaking at that moment is shown. Underneath the video screen, a bar with all the participants is shown so that the learner can see who is with them. The screen also has a notes section which allows the patient to write down notes during the sessions. Sessions should include not only dieticians, but also psychiatrists, ophthalmologists, paediatrics, podiatrists, physicians, diabetic nurses, activity therapists, pharmacists, and other diabetes specialists.

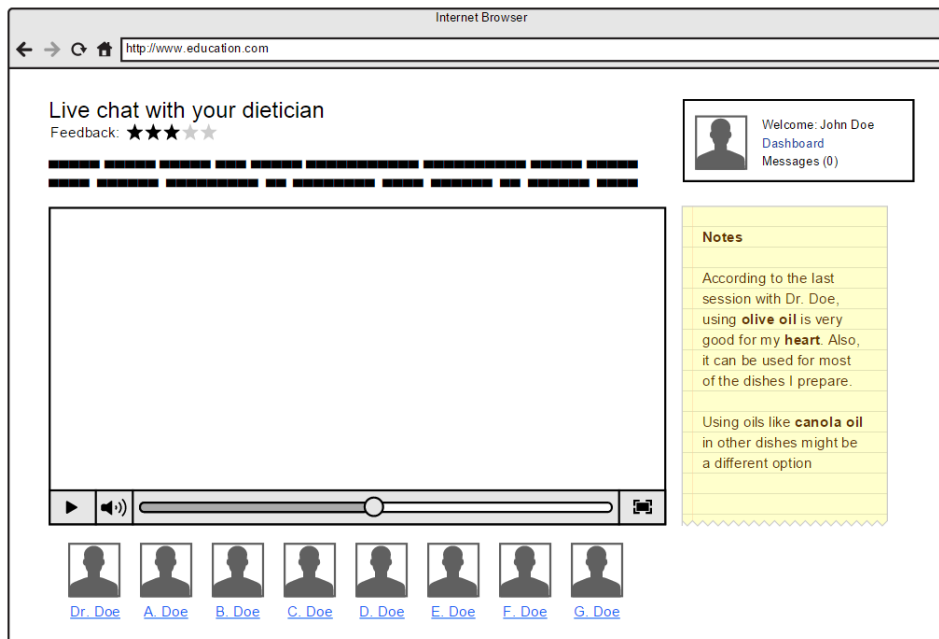


Figure 3-2 - Live chat interactions between groups and a healthcare professional

The set-up of courses should be focussed on easy to understand, short, powerful videos that cover relevant topics for diabetics. Participants were asked to visualise how they would like to receive their education on the different topics. Based on this input, the prototype in figure 3-3 was created. The education phasing on the right side of the screen will be based on DSME taxonomy in figure 3.1.

I think receiving education via this platform should be focussing more around providing short and powerful videos. Bothering patients with text makes no sense, because you need to get quick answers to your questions. I think videos should last no longer than 5 minutes each, and the slides should also have a bit of text that is relevant to the video. Browsing between the different topics in the sessions would be very helpful to review something that is mentioned in the video (participant 1).

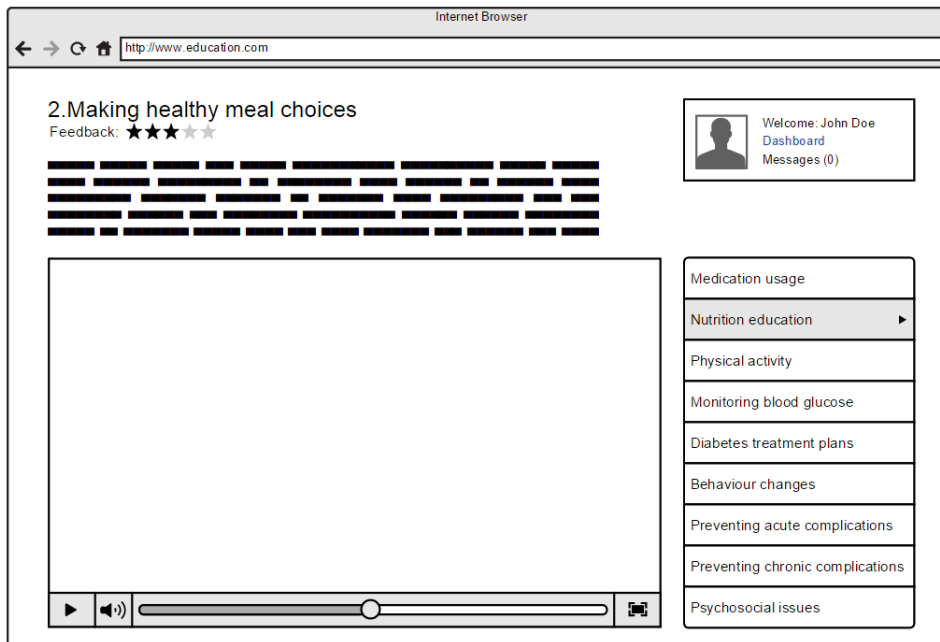


Figure 3-3 - Educational platform educating using the DSME framework

One of the features that patients seem to appreciate from the current platforms in place is the possibility to connect to other patients. Figure 3.4 was created to answer the needs of patients to connect to other patients and share their ideas and ask questions outside of the live-chat sessions as shown in figure 3.2. Some of the participants mentioned that this forum needs to be monitored by a moderator who removes posts that are not relevant to the topic or claims and recommendations from self-proclaimed “experts” from the forum.

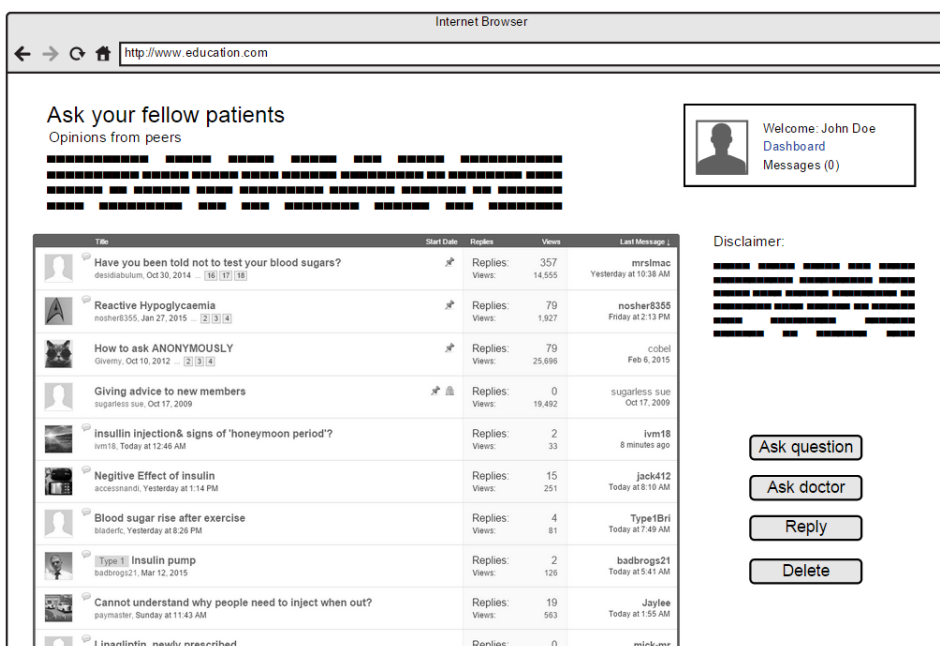


Figure 3-4 - Forum possibility to connect patients with each other and talk about their illness

Figure 3-5 shows an example of the integration of a KDDS model. This example is based on the input of the participant on how they would like to receive help from the platform. The focus in this prototype is on the foot-treatment to analyse whether the patient should go in for foot treatment or not. Also in this situation, the short videos were preferable next to short how-to and relevant information during the steps. The KDDS steps are based on the decision support model attached in appendix 2.

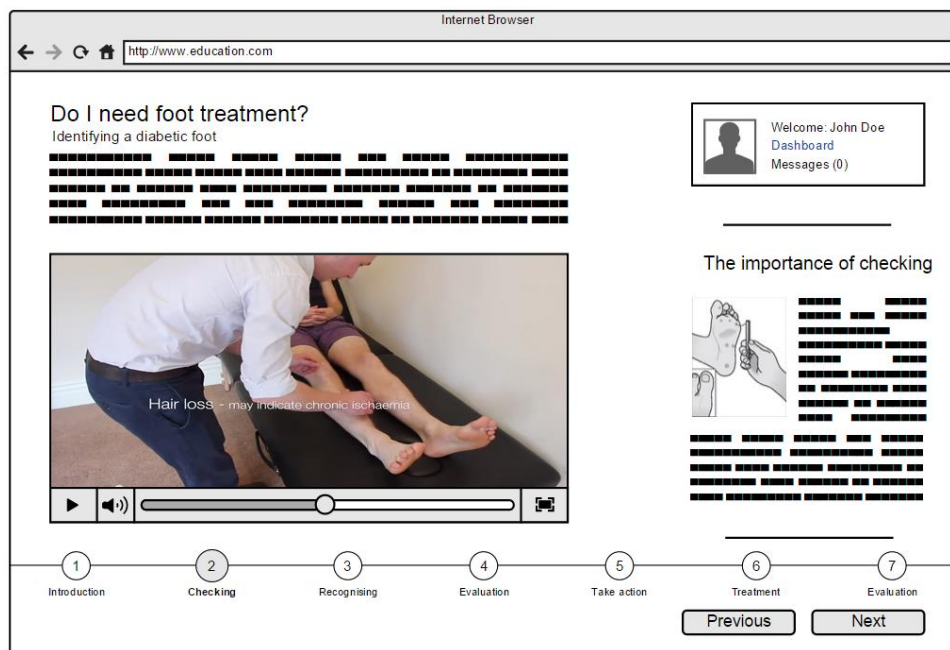


Figure 3-5 - Knowledge-driven Decision Support System example 1 - foot treatment

Figure 3.6 shows another example of the integration of a knowledge based decision support system where it displays the “take action” step to help identify whether the patient is suffering from a hypo- or hyperglycaemia. This screen shows a table that has follow-up steps based on the glucose value the patient puts into the platform.

I would use a system that can help me identify what my values are. When I just began measuring my blood glucose I did not know what the results meant, and how to follow up on them either. Even up until today, years after my diagnosis, I still don't know how my blood glucose should be. I know it's fine, I think, but just out of curiosity checking if your glucose is within the desired range, and knowing what the follow-up steps would be in case of a low- or high blood glucose would make me rethink my strategy on measuring my blood glucose. (Participant 3)

Also in this case, the platform makes use of the knowledge driven decisions support system attached in appendix 2. The small blocks of information on the right side of the platform make it easy for patients to find reference material in case they forgot how to measure their blood glucose, or how to do tasks that are required for the platform to provide a correct output. Clean design, and not too many blocks of text where preferable, but participants also mentioned that in this case, the follow-up steps could just as well be text with some images related to the outcome.

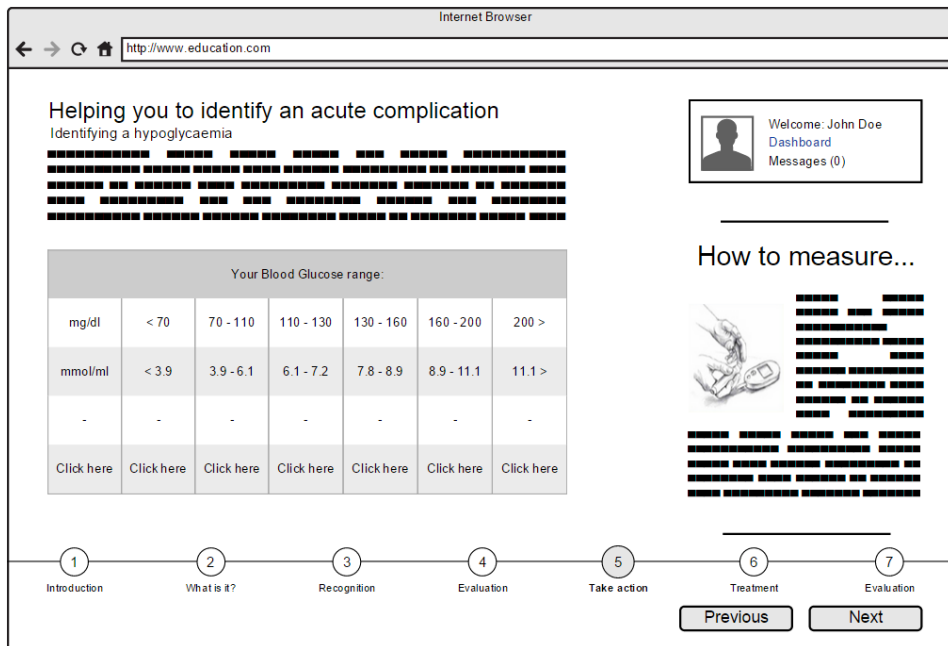


Figure 3-6 - Knowledge-driven Decision Support System example 2 - glucose interpretation

The usage of mobile device among the participants was at a 100%. All participants owned either one or multiple mobile smartphones or tablets. This also made them aware of the availability of information on these devices as well. Some educational platforms already have an app available providing knowledge on the go. Participants all mentioned that they would love to receive the information from the education platform on the go as well. Learners want to experience the platform on a mobile device the same way as they would experience on the web-platform on their laptops or desktops. Figure 3.7 shows an example of the mobile platform with clean and easy to read instructions and videos.

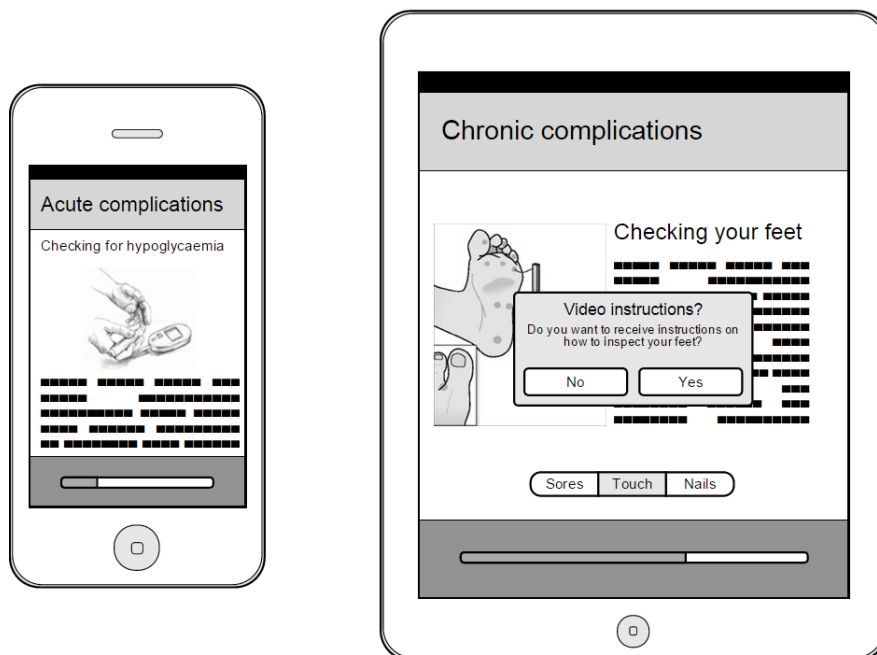


Figure 3-7 - Mobile platform example of education platform (acute and chronic complications)

One example of the knowledge assessment participants mentioned is a test your knowledge section in figure 3.8. This section provides the possibility to pre-assess knowledge on diabetes before the user starts using the platform. By asking questions with multiple choice answers, and some time to think about the answers, the user can pre-assess their knowledge on the topic and receive further education.

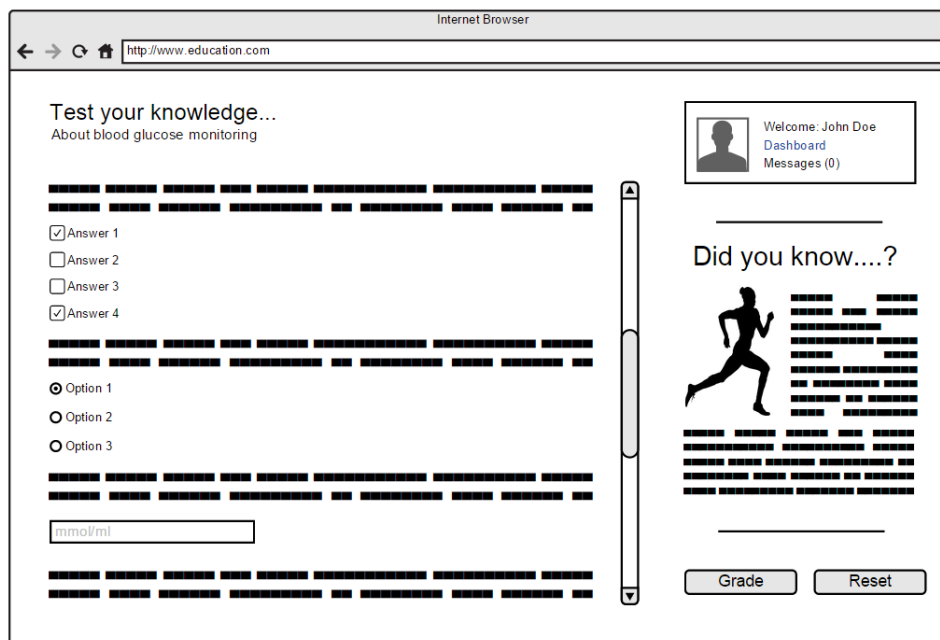


Figure 3-8 - Exercise your knowledge by training. Specific questions related to DSME topics

The system should pre-assess knowledge. This way, you can skip topics that you already know, and not get cluttered with unnecessary information. Give some time to think about answers, because it's not a test for school, you don't have to decide in seconds with your diabetes in general anyway. (Participant 2)

DON'T RAISE
YOUR VOICE
IMPROVE YOUR
ARGUMENT

DESMOND TUTU

4 Discussion

This chapter is categorised into six sections and provides the researcher's reflections on the study, the methods used to collect the data, the results and interpretation of them and recommendations. This discussion is essential to reflect on the possible alternatives for the study, and the strengths and weaknesses of the study in general.

4.1 Main findings

One of the limitations of this study is the amount of participants. The six participants provided the study with a general understanding of the problems in the current education of diabetes patients on the importance of self-management, and provided a certain amount of saturation of the results. Nevertheless, the generated data in this study helped understand the needs and requirements of patients for a learning platform and how to offer education based on DSME to type 2 diabetes patients. It also emphasised that the participants are enthusiastic about using a learning platform that is new, exciting and keeps them motivated and eager to learn new things related to their disease. The results show that patients prefer to receive education via a patient-centric model, but the integration of a knowledge-driven decision support system to help them make more educated decisions, was seen as a great addition to some of the subjects inside of the topics.

A group of participants clearly mentioned that they were a bit worried about using the platform if they don't know how to use it. This is one of the biggest challenges the designers have to tackle before designing the platform. How can they make the platform accessible for as many groups as possible? Arguably, by involving the users during the development process of the platform, the probability of them using the platform is most likely going to be much higher than by not including them in the development phase^(108, 109).

It is well known that users in different age categories have different needs and expectations, moreover they also have different understanding of what the platform should look like. A different design on a mobile platform, tablet, laptop or desktop pc could lead to confusion. This is why a unified design, meaning one design for all platforms (*bootstrapping*), is a good way for users to fully understand how the platform flow works⁽¹⁰⁸⁾.

Also, the introduction of a forum to connect patients with healthcare professionals and other patients brought up the discussion about validity of information and prevention of self-proclaimed "experts" spreading personal opinions as a medical facts. Participants were wondering how the quality of information could be guaranteed, and the proposition of an indicator to see when a user is part of the hospital was seen as a good alternative, but still brought certain questions up as well. Would an indicator actually prevent the patient from misunderstanding personal opinions for medical facts? Would it make it easier for patients to understand who is a medical professional (*providing a reliable source*) and who is a fellow patient (*giving their personal opinion*)? The need to provide a way for patients to verify the validity of information is also discussed in a study by Sillence ET. al. (2006) on understanding opinions from advices in web-based medical health systems⁽¹¹⁰⁾, this also emphasised the importance of including a verification method for an online forum as well.

Participants see the integration of a KDDS system as a solution to some activities, but they also stated that providing knowledge develops power, and they firmly believed that a patient-centric model provides better education than a KDSS system could provide. Only in a situation where the patient completely lacks the self-confidence in making decisions a KDDS system could provide them a helping hand.

The study also identified a possible structured phasing of education, as figure 3.1 shows. Phasing the education could help guide patients with the education in a more understandable way that is leaning towards the expectations of the platform as the prototypes in figure 3.2 to figure 3.8 show. The results are considered to be in line with the results of other studies performed in the same field⁽¹¹¹⁻¹¹³⁾. Participants did show great enthusiasm in the development of the learning platform, and were very excited and eager to receive education via this system that could assist them in learning new topics, receive guidance during the decision-making process and use the interactive options the platform could provide on learning from the various topics inside of the DSME.

Previous studies have shown that creating an ideal learning path for learners is very difficult⁽¹¹⁴⁻¹¹⁶⁾. Instead, and that is also what the results show, the ideal situation would be a platform that is providing learners with information loosely following a learning framework that gives them a semi-structured learning approach with the possibilities to choose freely from different courses inside the predetermined topics within the learning environment. Figure 3.1 showed how topics can be divided into phases, which can help the learners to find connections between the different topics. This also has been proven to be more beneficial in online learning than forcing learners to follow a predetermined path⁽¹¹⁷⁻¹¹⁹⁾.

Figure 4.1 shows the predetermined learning path where the learner has to follow the path from topic to topic without having the choice to move from one topic to another. Arguably, this would be an ideal method to create basic understanding with, for instance with fresh learners. Figure 4.2 shows the flexible learning path that offers the possibility to start wherever the learner wants. For a chronically ill patient, this might be a better solution. As the results show, the information needs per patient are very different, and a flexible learning path might be the best solution for this.

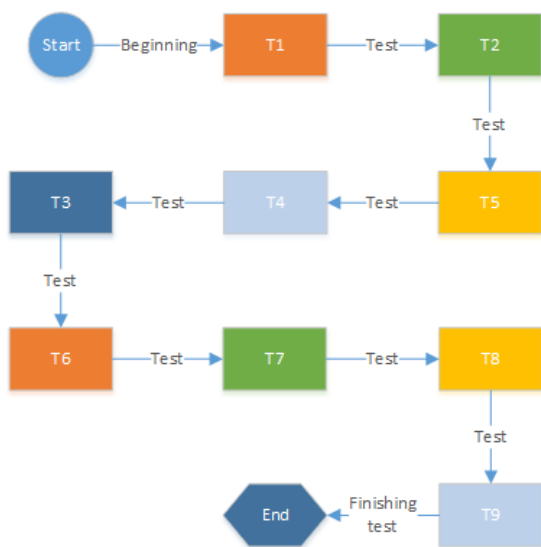


Figure 4-1 - Predetermined learning path

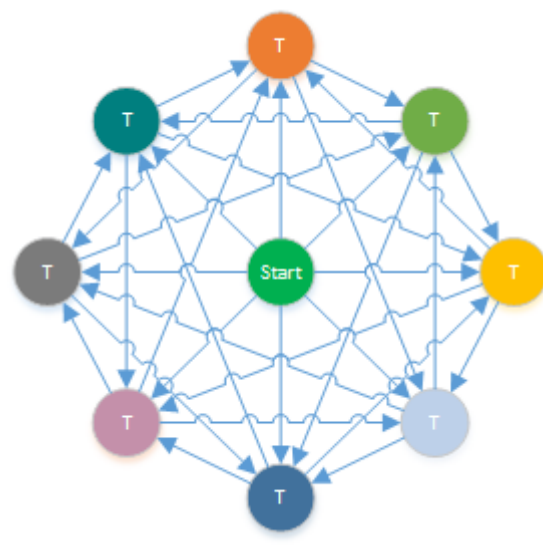


Figure 4-2 - Flexible learning path

4.2 Discussion of the results

The results of this study are subjected to some bias. All participants from the Swedish setting were very positive about the educational weeks provided at Södersjukhuset, but also mentioned that they still felt like they lacked some general knowledge on reaching the best self-management levels ultimately helping them to aim for normoglycaemic blood glucose values. The results show that there is a need for further education which all participants agreed with. The lack of follow-up education on certain topics (nutrition and physical activity) was one of the biggest concerns of all patients. They mentioned that this is a very personal learning process, as every person is different in how they want to perform physical activity and how they want to live their lives with diabetes.

Only the first question reached saturation, but the overall results show that all participants were tremendously interested on the introduction of an online learning platform where they can find modules to educate themselves on the different DSME topics, and participants would gladly be included in a follow-up study on the implementation of the education platform as well. The study focused on introducing the participants to an online platform only, and left out any other methods of receiving education, such as group-settings (*these were already used in the Swedish setting*), peer-to-peer learning, knowledge transferring from diabetic nurse to diabetic patient, and other methods. The reason why the focus was set on the online platform was to see if it was feasible to introduce this learning platform as a complement or as a replacement of the current education plans.

4.3 Discussions of the methods

The focus of this study was to determine the needs and requirements of type 2 diabetes patients for the development of an online learning platform. During the definition of the research questions, it was clear that the study had to deliver two products:

- A proposition for the best learning method for diabetes patients using an online platform;
- A preliminary design based on the needs and requirements analysis of participants in this study.

In order to propose the first product, the development of an ideal learning method; the study had to search for a basic education framework. The first education framework that resulted from a search on the different methods for raising self-management among diabetes patients was DSME. DSME has been implemented in many patient education facilities, and used by diabetes educators not only in the Americas, but also in a variety of different African, Asian, Caribbean, European, Middle Eastern and Pacific countries as well⁽¹²⁰⁻¹²⁴⁾. The second part of the study was focussed on understanding the needs of participants for receiving education, and conceptualise these into a proposed design for the learning platform. It was also used to identify any flaws in the current patient education, and as a categorisation on the topics that should be represented on this online platform.

The study focussed on providing participants only with education using an online platform. In order for this to be implemented, the current education method should be changed significantly. That is why this study was based on design based research (*DBS*). A study based on *DBS* is commonly used in the field of learning science. This study used DSME as a framework to pinpoint the topics that patients should receive education on for them to reach a good level of self-management. Secondly, during the interview, the lack of knowledge in the specific topics of DSME was identified and the study tried to identify what the possible causes are of this lack of knowledge. As mentioned in the results, the lack of follow-up education was the primary reason for this problem, and the possibility to offer follow-up education via an online learning platform was seen as a possible solution. This is what was presented as an artefact to the participants, and it was assessed if it was a possible solution for the lack of follow-up education.

The methodology had some limitations though. The decision was made to choose for this methodology because it provided an excellent framework to determine the needs and requirements of patients for this new way of education. A design based approach, as mentioned in the methodology part, is oftentimes used in the introduction of changes in learning. By having multiple iterations with participants, and cross-referencing these iterations, a conclusive result can be achieved by using the feedback from participants for changes that are gradually introduced and reflected upon. Because of the time-constraints in this study (*6 months in total and 3 months of effective data-gathering and analysing*) all the benefits of this methodology could not be used.

Also, the approach had to be changed slightly, as multiple iterations were important, the study tried to turn these iterations into interview phases, and reflect on each phase every time when another phase was introduced. This way, the feedback on the proposed changes was included, and the participants provided the study with a problem. It focussed with a reflection on the problem, a way of receiving education to reach the goal (self-management), and continued with a reflection on the way to receive this education. This led to focussing on the method used to receive education (patient-centric or KDDS) and another reflection on the two methods which ultimately resulted in a needs and require analysis on the functionalities and approach of the platform supported by performing low-level drawings at the end of the interviews.

Arguably, these phases do not provide the same qualitative results as pure iterations would do, but the information that was produced by participants, was seen as good input for the interview, and provided relevant information to the research questions.

4.3.1 Alternative methods:

Observational studies: In this, the participants are analysed during their education weeks and followed during the month(s) after the education takes place. This might provide deep information regarding the problems participants are struggling with, but also cost a lot of time. This type of study provides the research with highly personalised information on the patient struggles, but does not provide the study with enough information in the limited time space that this study was in. Observational studies usually work in long-term observations, where a new situation is implemented into the current setting⁽¹²⁵⁾. In this situation that would mean that the participants would be observed before the new educational platform would be implemented, and three groups of patients would be followed. One group would be following the classic way of education, and followed over the course of time, another group would be following the new educational method (the online platform), and followed during the same course of time. Then a third group would act as a control group. In this, the study setting has to be provided with a working platform already. This method would be very helpful in determining whether the new method is actually providing better education compared to the old method, but due to time constraints, this method could not work for this study.

Case studies: In this, participants are asked to participate in a case study scenario. In a case study methodology, an analyses of persons, events, decisions, periods, projects, policies, institutions, or other systems that are studied holistically by one or more methods is performed⁽¹²⁶⁾. This case might be a group of participants receiving education and the study focuses on identifying how participants receive the education and how much they actually use the education compared to the information they receive. This could help to identify whether the participants need more follow-up education or not. Another case might be the analysis of the education methodology. In here, the manner of education is analysed and assessed. This gives a deeper insight into the pros and cons of the method used to provide education, how the participants respond to the education and how the methodology could be changed to improve patient understanding. A positive part of this is that it creates real-life

situations, and assesses the problems during these situations. It provides a lot of detailed information and allows the study to identify flaws in certain scenarios⁽¹²⁶⁾. A problem caused by this methodology is that it is very time-consuming because an analysis of an educational method is very broad. In here, multiple case studies would be necessary which would mean serious time-constraints. Also, the setting would be very local, since the researcher has to create cases with participants. Going to different countries and cities to assess the cases with different participants would be considered very resource consuming^(127, 128).

Qualitative study using surveys: Questionnaires quickly provide statistical data in a relatively short time⁽¹²⁹⁾. In order for the study to understand what the underlying cause is of the needs and requirements of the participants, a deeper analysis is necessary. With questionnaires, statistical data can be easily generated. Participants in a questionnaire can provide a study with information on which topics they felt like they were lacking in knowledge, but it would be difficult to provide in the reasoning why they felt like they were lacking in a particular field of knowledge. Questionnaires do provide good statistical information, and would have been a welcoming addition on top of the study, but the information could not be used as a replacement of the qualitative part to the study.

4.4 Strengths and weaknesses of the study

During the study, some strengths and weaknesses were identified that could have influenced the results as a whole. These strengths and weaknesses have to be taken into account when using the results of this study to develop a learning platform with.

4.4.1 Study limitations

Before taking any of the results on this study into consideration, the researcher has to acknowledge that the study has limitations that might have cause the results being influenced in a positive or negative way.

A group of patients that met the inclusion criteria was selected. All, except two, participants had recently joined an intensive 3-day diabetes education course at Södersjukhuset which educated the participants on the some of the importance of self-management. This was often expressed by the participants during the interviews. The instructions that participants received during this introduction week were based on patient education that was designed by Södersjukhuset itself.

The question *“what is it you are struggling with most during the self-management of your diabetes”* asked at the beginning of the interview oftentimes was misinterpreted. This made the researcher change the approach on how to ask this specific question. Before the interview started, the researcher mentioned to all participants that they should not feel limited to talk about the medical difficulties only, but also to think about personal, work and other diabetes-related difficulties. The fact that almost all of the participants received an educational course before the interview took place was considered to be a bias to the study, as it provided the same experience with the majority of participants (*4 out of 6*), but it also provided a strength to the result, as it showed where the current education failed in the case of participants from Södersjukhuset.

The researcher searched for another source as an addition to the interview. By contacting a diabetic nurse at the Maastricht University Medical Centre (*MUMC+*), the research got hold of a type 2 diabetes patient from the Netherlands who did not receive the same education on his diabetes as patients in Sweden did recently. This participant was presented with the exact same questions and the exact same approach was used to ask the questions.

After this interview, the results of this participant were compared to the results of the 5 other participants. The conclusion was that the allegedly present bias caused by the educational week was not as significant as thought before, as the participant from the Netherlands was actually facing the same problems and shared the same opinions and ideas as the Swedish participants had during the interviews in Sweden. Arguably, one participant cannot make any significant difference to the results, but it does provide some insight on the presence of these educational problems elsewhere.

Not using any other framework than DSME for this study might be considered bias as well. There are multiple frameworks to educate diabetes patients on their diabetes, but DSME has been proven to be successful in reaching a level of self-management ^(120, 124, 130-132), henceforth this framework was chosen for this study setting. Although none of the diabetes nurses at the clinical settings in Sweden had heard of DSME before, most of them saw it as a good starting point to base this platform upon. The diabetes nurse in the Maastricht hospital, was aware of this framework, and highly recommended it as an education structure.

Another limitation of the study was the amount of participants that joined the study. The total of six participants provided a good amount of information on the needs and requirements of the participants, but it is considered that including more participants might have brought saturation for this study in research question 2 and 3. The diversity in personal opinions between the participants was so high that there was no possibility to come to saturation in the third research question.

The language used for the interviews might be a limitation as well. Oftentimes patients did not reply to invitations because they realised the interview was going to be held in English. The introduction leaflet notified patients beforehand that the interview would be held in English, and the researcher also carried a leaflet with the Swedish translation of medical diabetes terms during the interviews, but still this was not enough to convince participants to join the study. This might also be the reason why 5 participants refused to respond to the invitations after the research nurse at Sophia Hemmet and Södersjukhuset brought them in contact with the researcher. Arguably, performing the interviews in Swedish might have gathered more participants, but this was not the primary language of the researcher. So English was also an inclusion criterion for Swedish participants as well.

4.4.2 Study strengths

A positive point of the study was that it involved patients with different stages of diabetes and different onset-dates of the disease as well. There were participants included in the study that were recently diagnosed with diabetes, up to patients that were diagnosed with the disease over 10 years ago. This provided the study with a multi-angled and multi-staged point of view over the disease. It concluded that the information needs differ a lot per participant depending a lot on the current patient situation. The inclusion of a foreign patient provided the study with some understanding on how patient education is abroad, and how it reflects on the patient education in Swedish healthcare facilities. The results from that acknowledged that the problem in diabetes education is not limited to Swedish facilities, but also occur in other healthcare facilities as well.

4.5 Generalisability of the results

Even though the study has limitations and bias, there is possibility for the results to lead to general conclusions. One of the main conclusions is that the approach on how education is offered to patients is seen by the majority of patients as inadequate and lacking in some areas. Some of these areas are concentrated around the inclusion of nutritionists and exercise physiologists in the follow-up education of patients.

Patients generally feel like they lack the knowledge of how to work on including exercising into their lifestyle routines. Since type 2 diabetes is frequently diagnosed with people suffering from (morbid) obesity, inclusion and adaptation of exercising can be considered very difficult for this group. The incorporation of an exercise physiologist into the education is recommended by many different studies⁽¹⁾. This not only decreases the risk of further progression of the disease, but also increases the overall mental and physical health of the patient, leading to better results of medication or even decreasing intake of medication in general⁽¹⁾. The inclusion of a nutritionist, capable of further educating patients on what is best for them to eat, can be also beneficial in many ways. The study recommends using an online platform, but one-on-one education or group-education could be considered practical options as well.

Another conclusion from the results is that diabetes patients are considered a group of multidisciplinary healthcare users, who have different approaches on their diabetes, different questions at different times, with different needs and requirements as time passes. The only way for this platform to actually be a success, is by taking the example of platforms like Coursera and EdX, and combine this with education based on DSME. Patients want to be provided with subjects inside of topics, which change from time to time, and which can be new and exciting to follow. Treatment plans change, diets change, medication changes, the health- and age of a patient changes, that's also why the education should change with them. Two of the participants stated this very important quote that pinpoint this need:

"I don't want to sit in front of a dietician when they are going to tell me this story that the Swedish government once told them is good for diabetic patients. I am a woman, who is working in a psychosocial institution, I have a rough day at work where I carry patients from and to bed, and according to the Swedish recommendations I should eat some potato, meat and vegetables. But this does not work for my body, the low-carb high-fat diet has proven to significantly lower my blood glucose, and my endocrinologist agrees with me as well. If only the nutritionist could listen to me as, instead of forcing me to use a diet that doesn't work on me. I hope your platform will provide us at least with some options that we could try, of course with consent of the diabetic nurse or doctor". (Participant 5)

"I don't like working out the way the hospital tells me to work out. I wished there were some alternatives the hospital recommends. I found some myself though, but my doctor does not want me to do this. I am on one hand afraid that this type of training is not healthy for me, but it is helping my blood glucose stay low. Why can't they see that this is helping me? Why can't we find a solution based on something that works for me as a person? It doesn't have to work on the whole population!" (Participant 4)

This states that participants are very upset with the lack of alternatives in nutrition and physical activity. A successful approach on educating patients on the importance of improving their lifestyle could be depending also on the inclusion of different nutrition programmes or exercise programmes in their education. One last thing that was concluded is that patients want to move forward. They agree that the current educational system is outdated and is at its last run. The group therapies were helpful to most of the participants, but there was a resolute agreement among all participants that improvement should be made. All participants were highly enthusiastic about the proposed platform, especially after introducing them to the possibilities of MOOC and the capabilities of distance learning. This suggests that patients unquestionably are opened to the change, they want to see the possibilities of such a platform, and want to experience it as soon as possible.

There is undeniably a need for further study on the implementation of this education platform, and especially when considering the implementation, healthcare facilities should not abandon their current education setting before the new platform is fully in place and offers a comprehensive choice in different courses. This is crucial to let the patient come back to the platform, to keep them interested and to keep them focussed on further educating themselves.

4.6 Future studies

In order for this platform to be further explored, additional studies should take place. Since there are certain limitations in this study that could have affected the outcomes, a similar study with more participants could take place to provide deeper understanding of the needs and requirements. Patients, as the results have shown, undeniably want the development of the platform. Also, diabetes educators, and diabetes nurses showed great interest in this solution. In order for this platform to be implemented further, different studies should be considered to ensure that this platform is going to provide patients with enough knowledge and confidence to perform their own self-management on their diabetes.

A cross impact analysis should be considered to identify whether the inclusion of DSME as a standard for education is changing the decision-making and understanding of consequences of lifestyle decisions among diabetes patients. Cross impact analyses are a great way to identify how relationships between patient-related events such as complications, changes in diet, changes in exercise or other similar lifestyle decisions could impact the regression or progression of their diabetes and how it could reduce patient insecurities in nearby future⁽¹³³⁾. By performing this study, the impact of the education method can be measured on the patients.

Another study that has to be considered for the further development of the platform is technology road-mapping combined with a trend analysis. A technology roadmap can help the development team to reach an agreement on what the needs and the technology requirements are to answer to patient needs and requirements, while providing a mechanism to predict the developments and providing a framework to plan and organise these developments⁽¹³⁴⁾. The trend analysis can be used as an addition to the roadmap to provide users with a platform that is in line with the current trends, and possibly even slightly ahead of future trends in both technology and education to keep the platform appealing to users⁽¹³⁵⁾.

ONE WORTHWILE
TASK CARRIED TO A
SUCCESSFUL CONCLUSION
IS BETTER THAN 50
HALF-FINISHED TASKS

B.C. FORBES

5 Conclusion

Designing an education platform for normal learners is a difficult task to carry out. Different factors, learning methods and requirements of learners have to be taken into account while designing a product that takes the education from the classical setting into the home environment. Education is in ordinary setting subjected to ongoing changes where new technologies and methodologies are being introduced, revised and let go. Just like ordinary settings, distance education faces these changes as well. Arguably, distance learning platforms need to take a lot more into account when introducing new content, methods or technologies to the learners, than in classical settings, which makes it extremely important for designers to perform enough research on the needs and requirements of learners before actually introducing any changes to such a platform. When looking at general education, one could say this is already subjected to many different factors. Patient education, on the other hand, is on another level when it comes to identifying the needs and requirements of learners.

Education on diabetes involves multidisciplinary fields of specialisations that are needed for success. The aim is to help patients decrease the risks on developing future complications and reaching normoglycaemic blood levels by performing intensive self-management. The study helped to determine the needs and requirements of patients, and to develop a platform to educate diabetics on their disease. The results and conceptualisation of ideas concluded that patient education based on distance-learning (based on DSME) is feasible.

Patients do acknowledge that the education they have received recently was significant enough to give them basic understanding of performing self-management. However, further education on topics like exercising and nutrition were definitely welcomed. In order for this platform to succeed, flexible learning should be leading. This is emphasised by the different entry levels patients come into the system with. Some patients might use the platform as a referencing system, other might use it as an essential guide to learn everything about their disease. Flexibility in choosing topics freely and choosing subjects inside the topics is seen as crucial by all participants. The new and exciting ways to transfer knowledge, and not focusing only on blocks of text, also has to include video lectures, audio lectures, quizzes, printable material and tips and tricks for certain situations. The platform should scale itself into a larger education system, as participants mentioned that the inclusion of "group sessions" via video-chat and fora is a welcoming feature to the platform.

Conclusively; patients refuse to continue to receive their education, on something that is as important to them as their diabetes, via an outdated platform, method or using outdated material much longer. The introduction of a continuously changing environment is key to creating a platform that can be an successful alternative to the current learning method. Patients will be committed to learning everything that is relevant to them on their disease, and receive better support on reaching self-management in their diabetes.

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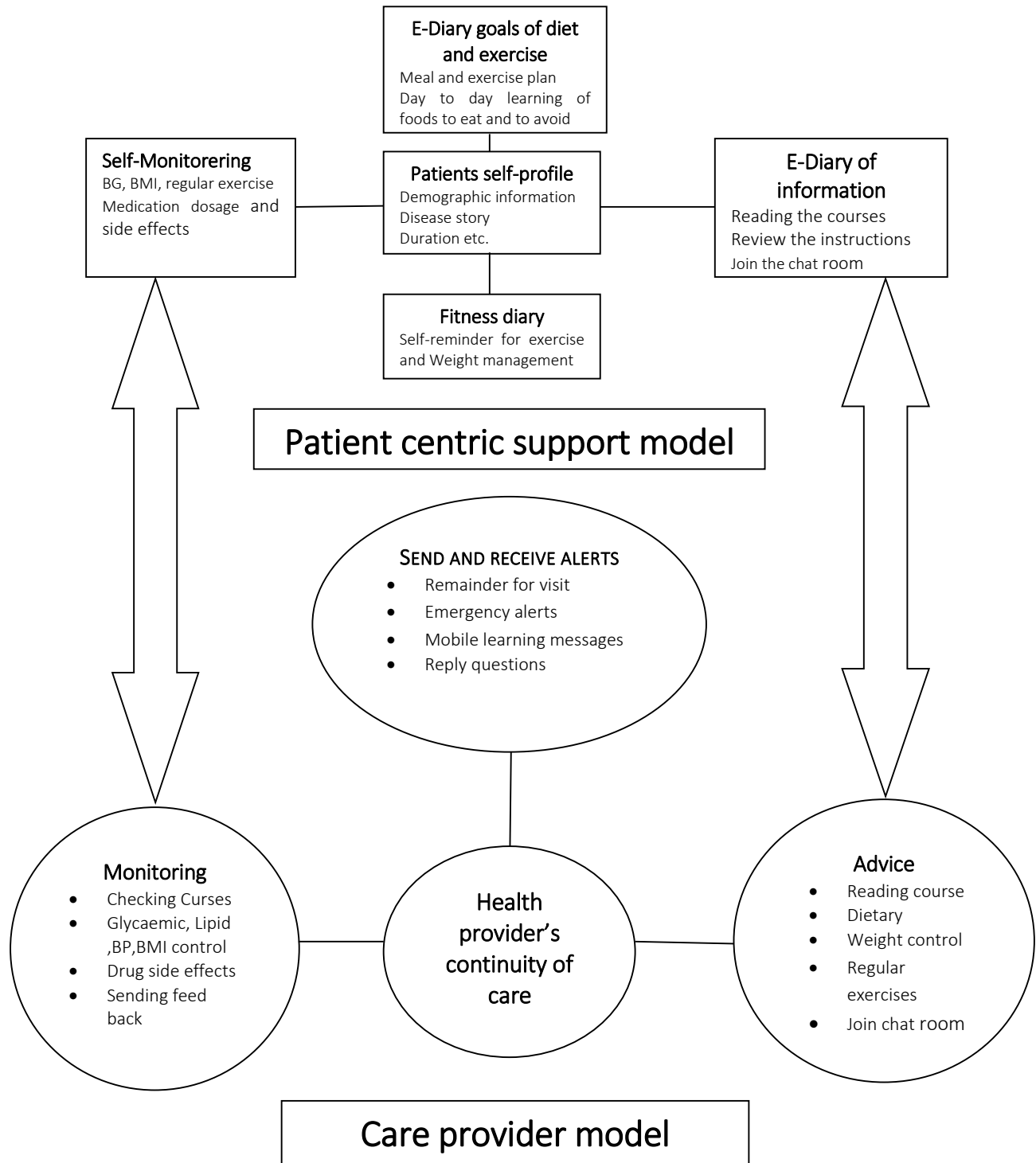
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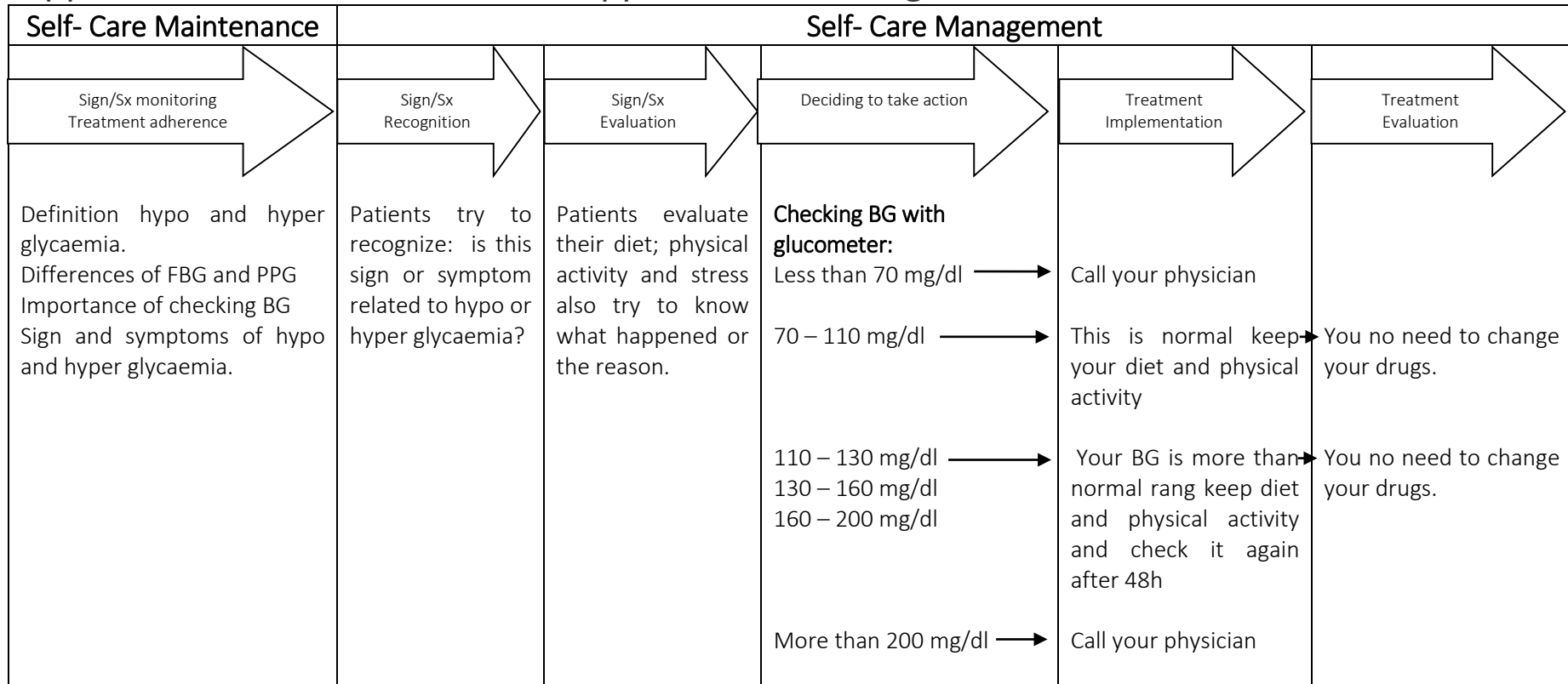
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Appendix 1 - Presented patient centred educational model

Interaction between patient and care provider models



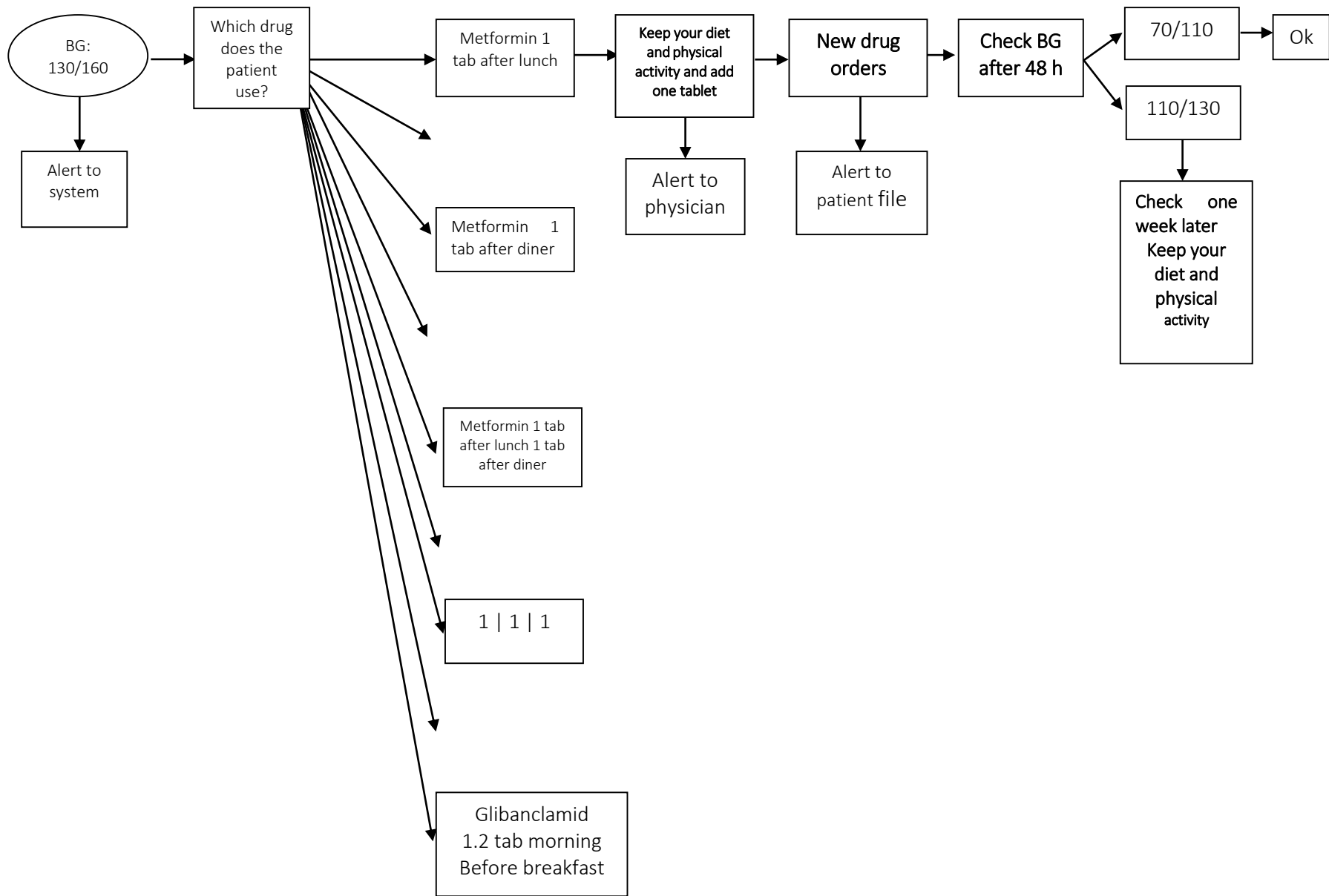
Appendix 2 - Presented decision support model during interviews



Patients will have access to:
 Educational website for diabetic patients
 Educational materials

Inclusion criteria:
 1-diabetes type 2
 2- No complications
 3- Patients who using drug A or B

Patients Electronic file:
 Name, age, gender, BMI,
 Drugs
 Last drug order.
 Lab exam.



Appendix 3 - interview manuscript

This document describes the manuscript that is being followed during the interviewing of patients. The questions are numbered and up to question 3 are asked to every participant. After phase 3, introduction of the disease, the interview follows the topics the participant is struggling with mentioned in question 1. After topic 3 the standard flow of the interview continues.

1	Introduction of the interviewers
	<i>In this part, the interviewer introduces himself. The interviewer talks about the background, the reason why we are doing this study, and what we are trying to figure out with this study. Also, the interviewers introduces a bit about their background and why this interview is important to them. Also, the interviewer mentions that the memo recorder is not going to be switched on until the actual interview (step 3) (this is helpful to loosen up the interview).</i>
2	Introduction of the interviewee
	<i>In this part, the interviewer asks the interviewee to introduce him- herself. By asking questions such as: How did you find out you were diabetic? Did your family have a history with diabetes? Can you tell me a bit about your work?</i>
	<i>Start of the memo recording</i>
3	Introduction of the disease
	<i>In this part, the introduction to the disease and its affection to the participants' daily life is going to be described. First, the interview wants to get a decent understanding about the struggles participants have, questions such as: (1)Can you describe me what the aspect of your diabetes are which you are struggling with most?, (2)What examples do you have of how these topics are affecting your life?, (3)How did you experience the support of your physician, diabetic nurse or dietician (depending on the field) you have received? Then, depending on the topics participants address the interview can follow itself into the following sub-sections</i>
3.1	Subtopic questions (starting the questions with: you mentioned that....how do you feel about:)
	<ul style="list-style-type: none"> • <i>Disease and treatment process of diabetes: (4)The importance of your diabetes treatment? Why do you think is so important about intense diabetes treatment? Followed with: (5)Have you received education on what is important in diabetes treatment, ending with: (6)Do you have an example of why this is important?</i> • <i>(7)Can you tell me about how your family is included in the education on your disease? Followed by: (8)Do you think they really understand what you are going through? And for instance how to help you when you are experiencing acute complications like a low- or high blood glucose?</i> • <i>Using medication safely: (9)The guidance you received in using, storing and the working - mechanism of your medication? When the participant is positive continue with: (10)when you want to review some information about the usage, storage or working of your medication, how do you do that? When the participant is negative continue with: (11)How did you receive the necessary information to take your medication then? Continued with going back to the follow-up question for a positive outcome (reviewing information)</i> • <i>Incorporating nutritional management into lifestyle: (12)The way you received help on changing your diet? Do you feel you have enough knowledge to</i>

	<p><i>change your lifestyle by yourself, or do you require more help on certain parts? If participant needs more help continue with: ⁽¹³⁾could you tell me what these things are then?</i></p> <p><i>Followed with: ⁽¹⁴⁾I would like to ask you about something else, what would you do when you aren't sure you are allowed to eat something specific or not? Followed with ⁽¹⁵⁾have you experienced this yourself? And ⁽¹⁶⁾How did you solve this?</i></p> <ul style="list-style-type: none"> <i>Incorporating activity into daily lifestyle: ⁽¹⁷⁾the way you received guidance to change your daily workouts and come up with a workout goal? Followed with, ⁽¹⁸⁾in what way did your body reacted to these changes? ending with ⁽¹⁹⁾have you received instructions on how to anticipate on these changes? Like for instance, changing your diet, changing your medication?</i> <i>Developing strategies to address psychosocial issues: ⁽²⁰⁾the impact diabetes has had on your psychosocial state. Have you experienced any changes in your behaviour, like for instance, have you become more anxious, angry, depressed? If the participant says yes, ⁽²¹⁾do you have examples of these (...)? Followed with: ⁽²³⁾How did you experience your education on how to deal with these situations? Followed upon with: ⁽²⁴⁾Is it correct that I interpret that you feel (better / worse) with/without receiving your education about how to handle psychosocial issues?</i> <i>Developing strategies to promote health/change behaviour: ⁽²⁵⁾the way your education has helped you change your behaviour in terms of making healthy decisions, and to promote your own health through, for instance, working out? Followed with ⁽²⁶⁾Have you incorporated these changes yourself?</i> <i>Prevention / detection / treatment of chronic complications: ⁽²⁷⁾the way your doctor or diabetic nurse has informed you about how to prevent, detect and treat any diabetic related chronic complications? Followed with ⁽²⁸⁾ do you feel that the education you received has helped you understand how complications form and what (<u>not</u>) to believe about diabetes related complications? Followed with ⁽²⁹⁾What do you fear most when it comes to long-term complications? Is it the lack of knowing what to do to prevent them, or is it the lack of knowing what to do when you have them? Possibly continuing with ⁽³⁰⁾Could you give me an example of that?</i> <i>Prevention / detection / treatment of acute complications: ⁽³¹⁾the way your doctor or diabetic nurse has informed you about how to prevent, detect and treat low- or high blood sugar? Followed with ⁽³²⁾Do you feel like you know what to do when you experience a low- or high blood sugar? Or do you still experience insecurities? Followed with ⁽³³⁾does your spouse, family or co-workers also know what to do when you experience a low- or high blood glucose? Did you educate them yourself on that?</i> <i>Monitoring blood glucose, interpreting the results and using them: ⁽³⁴⁾the way you received guidance to interpret your blood glucose and handling upon them? Followed with ⁽³⁵⁾Do you understand why it is so important for diabetics to monitor their blood glucose regularly? Ending with ⁽³⁶⁾How do you believe monitoring your blood glucose can help your diabetes?</i>
4	Introduction of the DSME framework
	<i>In this part, the participant will be introduced with the DSME framework, and the nine topics will be introduced to the participant. The participant will receive the topics he has highlighted during the introduction of the disease (3) part, and will be told that it seems that the participant has difficulties handling with these topics. These will be prioritised first for the participant. The reason why the DSME framework will be introduced, is because the research wants to prioritise certain topics as well.</i>
4.1	Prioritisation of the topics

	<i>Together with the participant, the interviewer will go through the DSME framework, and the meaning of the topics.</i>
5.	<i>Introduction of Distance learning</i>
	<i>The participant will see two video's, one about the basic education of patients, and one about the questionnaire between the patients and the experts. Also, the participant will be introduced to a MOOC shown on Coursera (since there are no specific course in diabetes yet, we will pick a random course in health). By showing them the possibilities of such a platform, we can reach a clear understanding of the participant on what MOOC's are.</i>
5.1	<i>Questions</i>
	<i>(37)Now that you have seen the Diabetes Self-Management Framework, and the examples of MOOC and two video examples of distance learning for diabetics, can you tell me your thoughts about receiving education via such a platform? Followed with (38)The topics we discussed about earlier, can be integrated into a MOOC platform like this. By implementing a so-called decision support module, such platforms can provide you with information to make decisions upon. If we could offer you education on these topics via this platform, in what way would you want to receive this education? Would you prefer video, audio, questionnaires, fora, or would your preference still go to personal education with your health professional? Followed with: (39)So it is safe for me to assume that you would (not) use a platform like this for your education? Ending with (40)Could you say something more about why (not)?</i>
6.	<i>Summary</i>
	<i>In this part, the interviewer will briefly summarise the interview, the topics that have been spoken about, and the opinion about using MOOC for education, and the needs and requirements of the participant in terms of an educational platform for diabetics. The interviewer will ask the interviewee if that is correct, and will thank the interviewee.</i>

Appendix 4 - Planning

Study timeline- Project Tracking

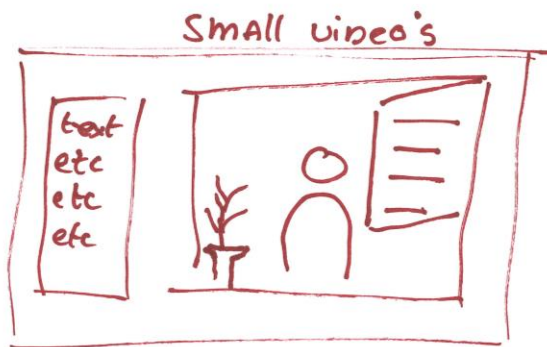
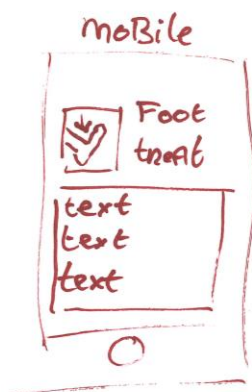
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Prerequisites																																		
Definition of problem, aims and purpose	01/12/2014	04/01/2015	25	100%	25																													
Proposing title supervisors and resources	20/12/2014	09/02/2015	32	100%	32																													
Handing in project plan	20/12/2014	15/02/2015	40	100%	40																													
Preparation																																		
Literature study	05/01/2015	15/02/2015	30	100%	30																													
Defining study methodology	15/01/2015	17/01/2015	2	100%	2																													
Defining data analysis	15/01/2015	19/01/2015	3	100%	3																													
Preparing interviews and resources	25/01/2015	04/02/2015	8	100%	8																													
Data acquisition																																		
Questionnaires online	04/02/2015	14/04/2015	50	100%	50																													
Interviews	15/02/2015	31/03/2015	32	100%	32																													
Data analysis																																		
Data analysis	31/03/2015	20/04/2015	15	100%	15																													
Educational model designing	31/03/2015	15/04/2015	12	100%	12																													
Identifying needs for mock-ups	05/04/2015	12/04/2015	5	100%	5																													
Low-level prototyping	12/04/2015	16/04/2015	4	100%	4																													
Wire framing	16/04/2015	20/04/2015	3	100%	3																													
Thesis writing	01/02/2015	11/05/2015	71	100%	71																													
Handing in preliminary thesis	13/05/2015	13/05/2015	1	100%	1																													
Thesis defending and examination	19/05/2015	21/05/2015	3	0%	0																													
Reviewing comments and suggestions	21/05/2015	07/06/2015	12	0%	0																													
Handing in final thesis	07/06/2015	08/06/2015	1	0%	0																													
			349	95%																														

Today's Date	08/05/2015
Start Date	01/12/2014
End Date	08/06/2015
Total Man Days	349
Duration	187

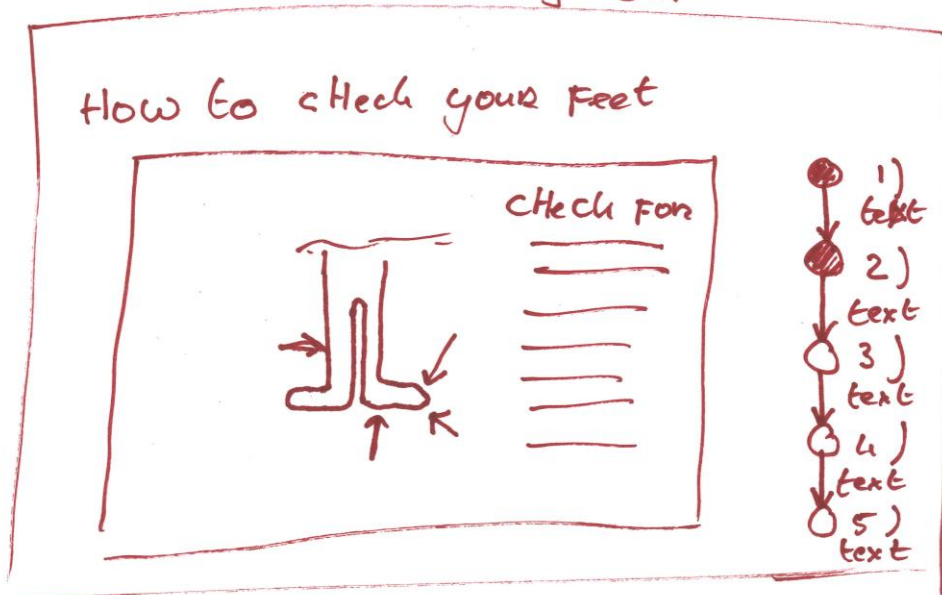
Appendix 5 - Form study prototypes

Participant 1) Low-level - ideas.

- * Short video's
- * mobile App → Easy blocks of text
→ videos.
- * maybe a step-by-step instruction?



Step-by-step



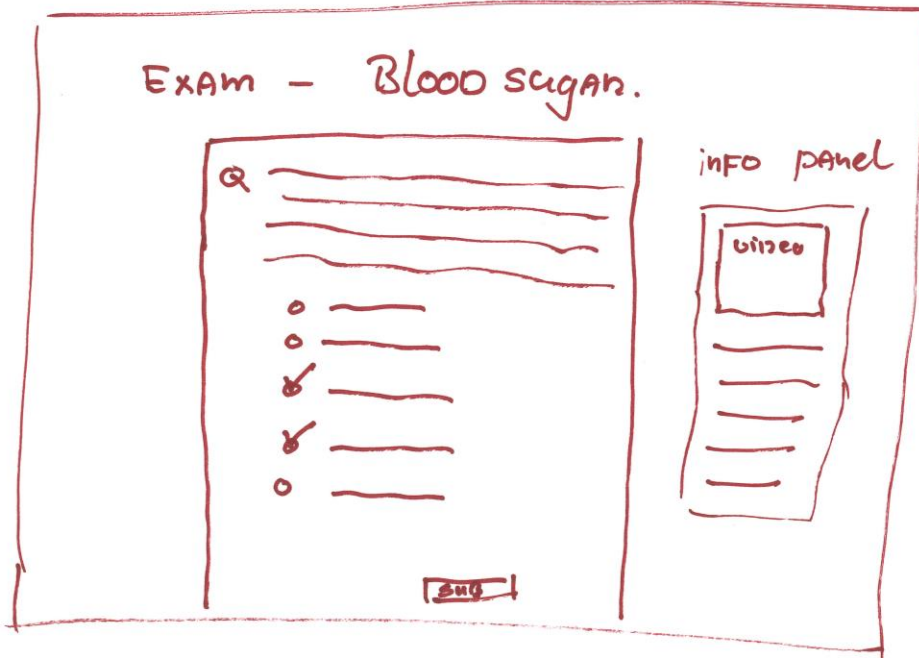
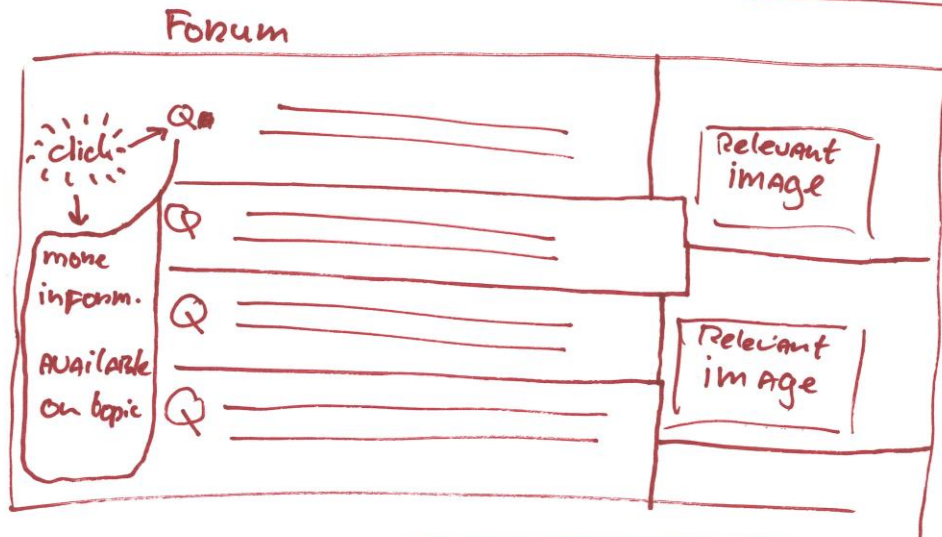
* participant 2 - low_level_idea.

→ video's with some text

→ Forum to Ask others

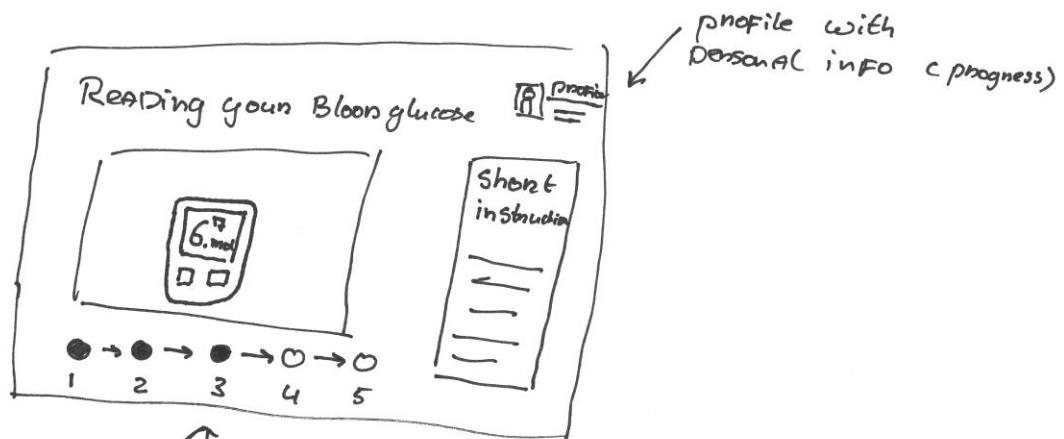
→ mobile app.

→ A test to Assess knowledge.

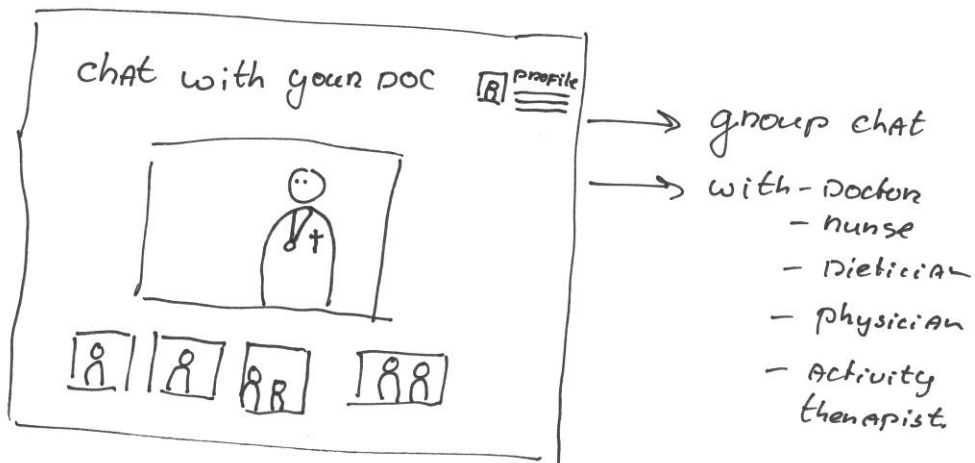


Deelnemer 3.

- * website profile
- * instructions on performing Blood glucose.
- * A chat with the doctor / nurse / Dietician
- * videos instead of text !!!



step by step instructions



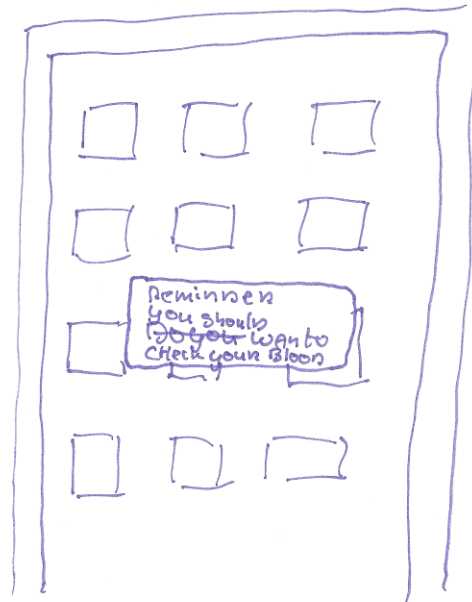
Participant 4.

- * web- Application.
- * mobile Application
- * Reminders on ipad or Android.
- * connection with several doctors → physician
→ nutritionist
- * Easy to use (videos + pictures)
- * not too much text.



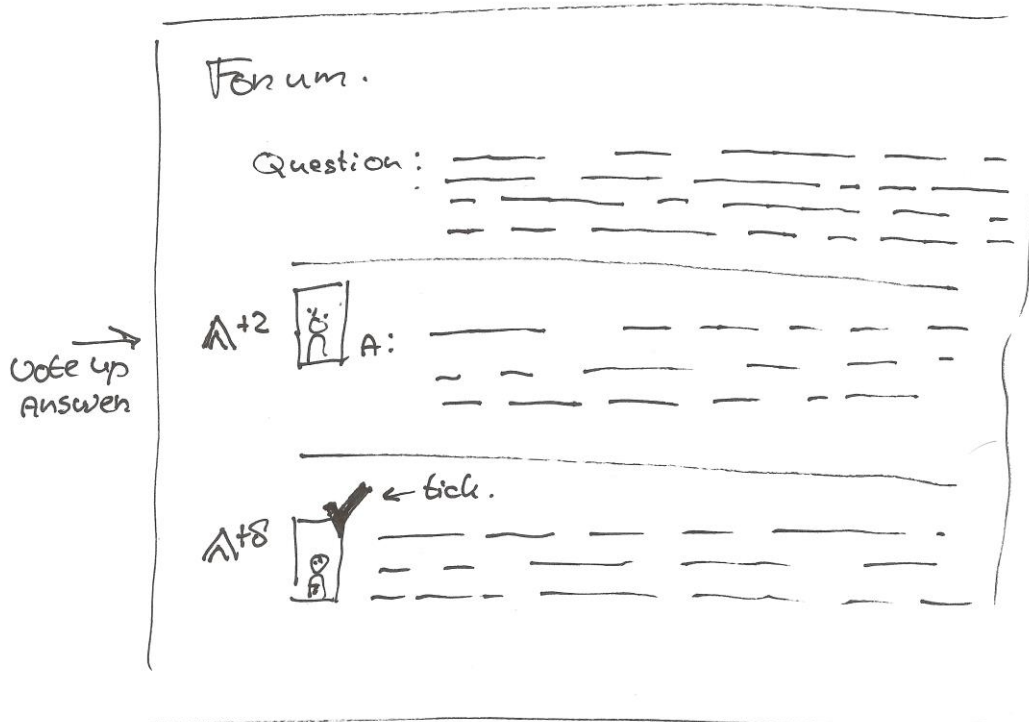
mobile Application
Should show the
exact same
thing in the exact
same way as the
web Application
(Bootstrapping)

Reminders on
Home screen. not
friendly ramping
Reminders, But
telling patients they
should check their
Blood glucose.



Participant 5.

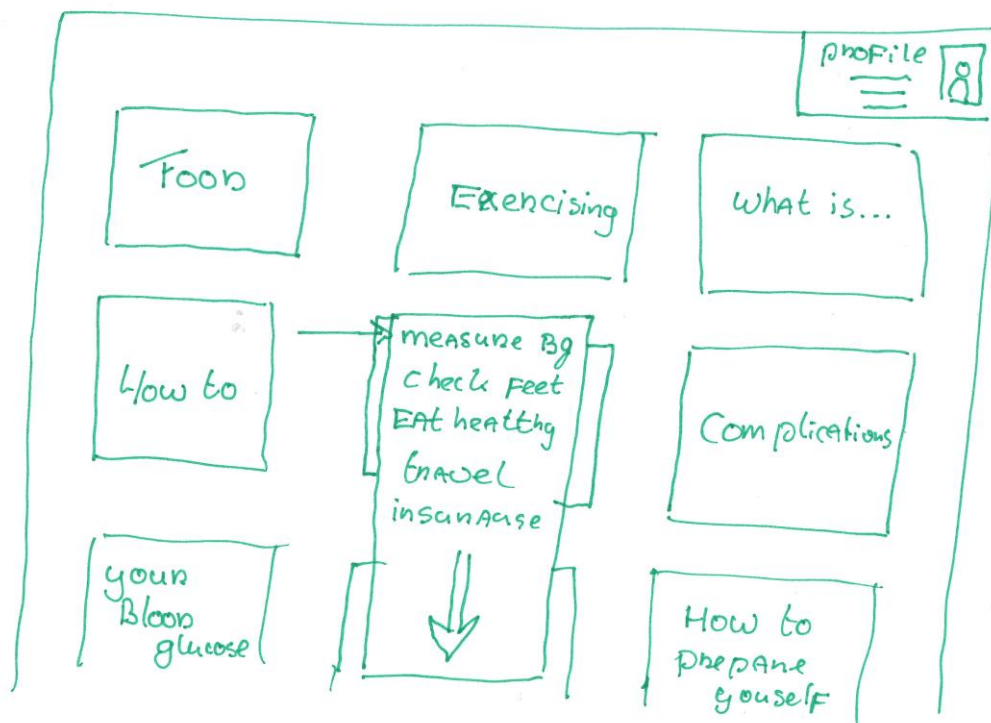
- EASY interface.
- Reference links to car centrolen.
- choosing your topics, some know more than others.
- Forum
- Verified Doctors in the Forum.
- Visibility of who is verified (maybe with an tick. symbol).



Participant 6.

- 1) Ability to create profile
 - 2) A user forum, with a Q&A section
 - 3) Shortcuts to special topics
 - 4) Ability to print-out things
 - 5) A mobile app
 - 6) Videos with powerful messages.
-

Front page Design:



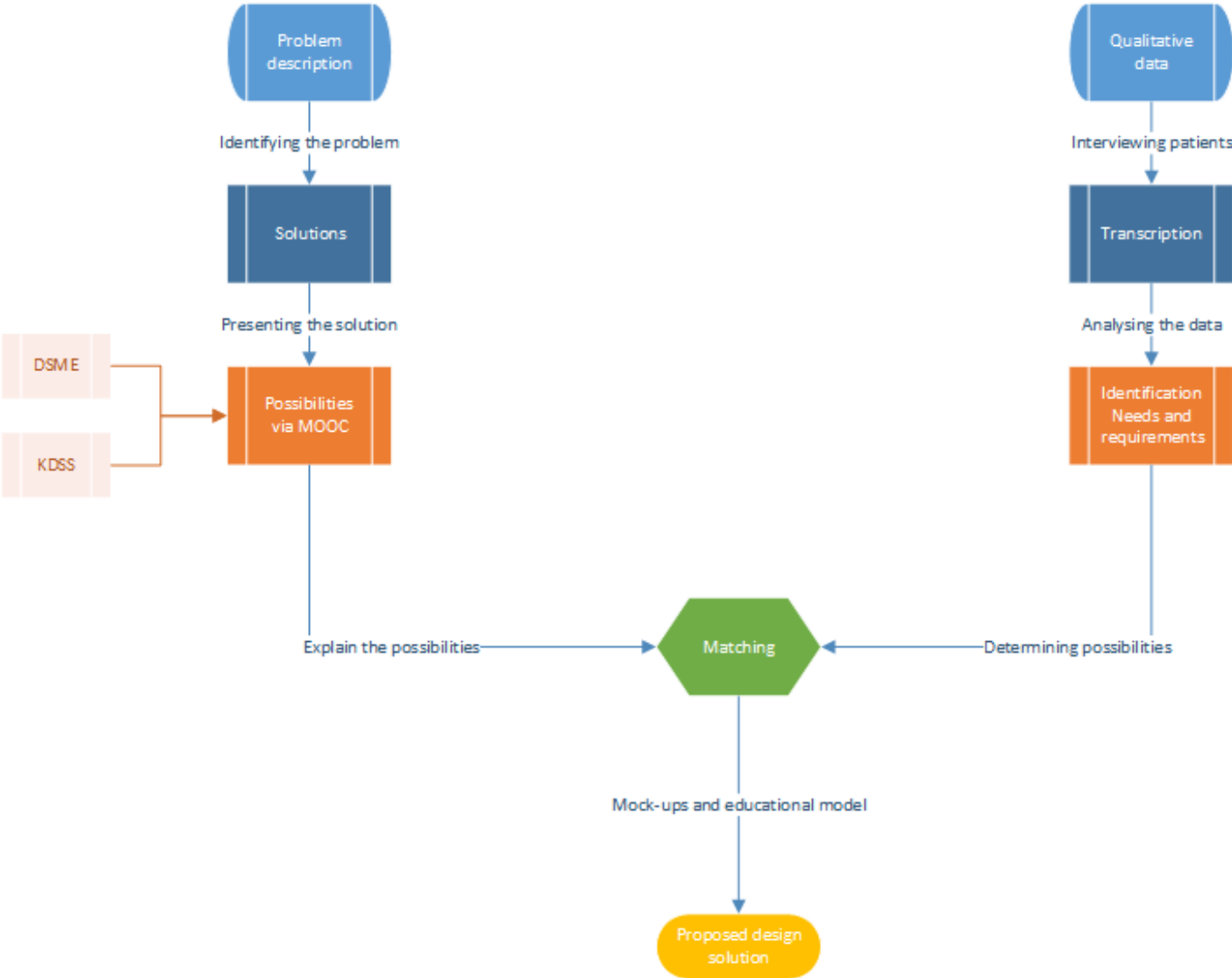
Appendix 6 - DSME topics presented to patients

DSME (Diabetes Self-management education)				
Disease and treatment process	Incorporate nutritional management into lifestyle	Incorporate physical activity into lifestyle	Using medications safely	Monitoring blood glucose, interpreting and using results
The definition of diabetes	The effects of food on glucose monitoring	The effects of exercise on blood glucose levels, specifically, exercise types and durations	Action and effects of diabetes medications on paper	Recommended blood glucose targets and personal targets
Types of diabetes	Methods for meal planning and preparation	How to address barriers to physical activity, specifically, physical, environmental, psychological, and time limitations	Types of diabetes medications used to treat diabetes	Self-monitoring blood glucose equipment choice(s)
Options for treating diabetes	Sources of carbohydrates, proteins and fats	How to develop an appropriate activity plan that balances food and medication with the level of activity	Potential side effects	Selection, timing and frequency of testing
	How to make healthy food choices		Appropriate timing and frequency of medication administration	Target values, interpretation, how to use the results
			Effect(s) of missed and/or delayed doses	Regularly check blood pressure, urine ketones, and weight as appropriate
			Instructed how to prepare medication for injection, giving an injection	
			How to store and travel with medications	

DSME (Diabetes Self-management education)

Prevention, detection, and treatment of acute complications	<i>Prevention, detection and treatment of chronic complications</i>	<i>Developing strategies to address psychosocial issues</i>	<i>Develop strategies to promote health/change behaviour</i>
Symptoms of hyperglycaemia or hypoglycaemia	Natural course of diabetes (progression, need for future (additional) medication)	Diabetic is assessed for the type of support needed (networks)	The ABC of diabetes - A1C - Blood Pressure - Cholesterol (and suggested goals)
How to treat low blood sugar	Relationship of blood glucose to the long-term complications	Psychosocial issues that may occur with diabetes and their treatments	Appropriate screenings needed to reduce risks
Actions for lowering high blood glucose levels	Standards of care, therapeutic goals, preventative care to decrease risks		How to schedule and personally plan for screenings
	Smoking cessation		
	Performing food inspections, monitor blood pressure, measure blood glucose		
	Maintain personal care records		

Appendix 7 - Data analysis approach



Appendix 8 - Patient information leaflet



Improving self-care management among type 2 diabetic patients

By introducing an online educational portal

Information for participants

This is a study on the integration of an online educational platform with a focus on MOOC (*Massive Open Online Courses*) for type 2 diabetes patients. The study is part of a research that is investigating whether it is possible to provide patients with information via a “Decisions Support system” (DS) that is custom tailored to their needs. This might increase self-care management and improve patient education among type 2 diabetics. The study focusses on understanding the needs of patients in education via an online platform. By performing discussions with patients, we can identify different scenarios, used in the development of a new educational model for diabetics.

About the participants

Participation in this study is completely on voluntary basis. Patients have been selected between the age of 30 to 55 years old, diagnosed with type 2 diabetes recently and proficient in the English language. The reason why we chose for this group is because several studies have shown that this age-group is noticeably active in finding answers to their questions via the internet. Of course, if the participant wants to withdraw from the study, this will be possible at any given time by informing the interviewer.

About the participation

Each participant will have a discussion that will take about 30 to 60 minutes. During this discussion, a number of questions will be asked related to your illness and the education you (*wished you had*) received. Depending on your answers, follow-up questions might be asked to get more clarification on your needs in that particular situation. A voice-recorder will be used to record the session. After the study has been finished, patients can receive a copy of the outcomes by leaving their email address with the interviewer.

Is there any risk of discomfort or inconvenience?

The questions are not aiming on any personal situations, but are designed in such a way so that we can understand what the information needs are for patients in everyday situations. Therefore, questions will be very general and related to topics like: working out, nutrition, blood glucose, handling a hypo- / hyperglycaemia etc. The participant can always skip questions they don't want to answer.

How will my participation help?

By providing us with better understanding of what the needs are in terms of primary information and education towards diabetics, future diabetic patients could be provided with a solid understanding of the importance of self-assessment and taking well-educated decisions using distance education in the comfort of their own home. In the long run this could also prevent patients from getting severely ill.

What about my privacy?

The study will be completely anonymous. This means that the information will not contain any names or information relating back to the participant. The participants can decide at any moment to withdraw from the study by contacting the interviewer via bastiaan.franssen@stud.ki.se