Effect evaluation of DiasNet, The Digital Hospital, Vendsyssel Hospital, Frederikshavn, Denmark

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Prepared by the Aarhus School of Business, DK, October 2003

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Preface

This report contains an evaluation of the effectiveness of DiasNet (DIAS = Diabetes Insulin Advisory System), a computerised diabetes technology system that is a subproject of the project entitled, "The Digital Hospital" at Vendsyssel Hospital in the Danish town of Frederikshavn, North Jutland. In October 2002, Frederikshavn-Skagen Hospital merged with Hjørring Hospital to become Vendsyssel Hospital. However, in our report we shall refer to Vendsyssel Hospital, Frederikshavn only (hereinafter referred to as *Vendsyssel Hospital)*. The Digital Hospital is a project under the auspices of the Digital North Denmark (*DND))*. The Aarhus School of Business (*ASB)* has prepared an effect evaluation of the implementation of the system piloted by patients and staff at Vendsyssel Hospital. ASB has monitored the implementation process throughout a year.

First and foremost, many thanks to the three patients who kindly agreed to participate in the project and share their experiences and observations with us in relation to DiasNet. The identity of the patients in question is undisclosed, and as a result we cannot thank them by name. We would like to thank the diabetes team of the medical outpatients' clinic for their participation in this project. Consultant Doctor Kurt Clemmesen, Diabetes Nurse Dorthe Bach Andersen, Diabetes Nurse Britta Nedergård, Medical Secretary Mette Birkjær and Dietitian Birthe Grønfeldt comprise the diabetes team. It was not always easy to combine a busy clinical working day with development work, but the drive and readiness to embrace change on the part of the team was reflected in the process and made it possible to carry through the evaluation.

Also thank you to the project group appointed in connection with the implementation of DiasNet. Project Manager Bettina Vindbænk, Implementation Consultant, IT-HEALTH, County of North Jutland, contributed with assistance in regard to the planning and practical implementation of the project.

We have enjoyed a valuable co-operation with Ph.D. student Egil Boisen with Aalborg University (*AU*). Thank you for many good discussions and input to our inquiry.

Finally, we offer our sincere thanks to Associate Professor Ole K. Hejlesen. Ole K. Hejlesen is heading the development of DiasNet, and we hope that this report may provide some input to his further work in this respect.

We would like to thank The Digital Hospital, Aalborg University and The Aarhus School of Business whom have financed the translation of this report.

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Chapter 1 - Introduction

1.1 Introduction

From 1 January 2002 until 31 December 2003, Vendsyssel Hospital is piloting the project entitled, "The Digital Hospital" under the auspices of the Digital North Denmark. This "Digital Hospital" is to be achieved by a massive IT effort, including system integration and increased data accessibility, in one single hospital. The purpose of The Digital Hospital is as follows:

To increase citizen satisfaction with the healthcare sector by:

- *enhancing the transparency in healthcare administration to patients*
- *supporting the patients in a new and more active role (the competent patient)*
- *ensuring a better patient care process*
- *contributing to a more cohesive healthcare system*

by means of a more effective exploitation of the options available in The Digital Hospital.[1].

According to the project description, the pre-requisite for enhanced administrative transparency and patient empowerment is providing the patients with easy and user-friendly access to information concerning the hospital and their own condition and treatment. To this end, the project of The Digital Hospital includes a series of digital aids, including the diabetes advisory system of DiasNet. The objective of the DiasNet subproject is to develop IT based solutions that to a larger extent than previous systems involve diabetics in disease self-management. This is also to promote a better understanding of the disease as well as a more effective treatment of the disease and its complications[2]

The development project, DiasNet, is a so-called "Decision Support System". Associate Professor Ole K. Hejlesen, Department of Health Science and Technology, Aalborg University (*AU*), Denmark, is currently developing the system in collaboration with several international scientists. The Aarhus School of Business (*ASB*), also in Denmark, has been assigned with the effect evaluation of four IT solutions as part of The Digital Hospital, including the diabetes advisory system.

[1] Project description for The Digital Hospital 2002-2003. Page 5.
[2] Project description for The Digital Hospital 2002-2003. Page 27.

1.2 Objectives of the effect evaluation

The focus of the effect evaluation is twofold, viz. on:

1. ***The consequences experienced by the members of the diabetes team when diabetic patients use DiasNet.***
   - ***Are there any changes in the tasks and duties of the team as a result?***
   - ***Which challenges face the team as a result?***

2. ***Patient observations and experiences with DiasNet in view of their coping with a chronic disease such as diabetes.***

ASB monitored the day-to-day clinical work at the outpatients' clinic and noted the nature of tasks and duties the diabetes team performs in relation to diabetic patients. In addition to this, we conducted interviews with 3 different diabetic patients before and after their consulting DiasNet, just as we studied the daily routines of the patients at close hand and gained an insight into their use of DiasNet as a diabetic management tool.

1.3 DiasNet project group

In connection with the implementation of DiasNet a project group was appointed, comprising clinicians, implementation consultants, a researcher from AU and the evaluation team from ASB. Appendix 12 provides a list of the members of this project group. The objective of the project group was to create a forum for planning and for addressing problem issues in regard to the implementation of DiasNet in practice.

1.4 DiasNet and monitoring research

In connection with the Digital North Denmark, Aalborg University has also launched monitoring research efforts, which do not constitute an actual project evaluation, but rather focus on the retrieval and dissemination of information as well as adopting a national and international perspective. The monitoring research programme has focused on the DiasNet project in a Ph.D. study conducted by Egil Boisen, student with the Department of Health Science and Technology, Aalborg University (cf. Appendix 13). The emphasis of the study is on the description of how the patients interface with DiasNet and use the system in terms of disease management, including also the focus on enhancing patient self-care skills. The DiasNet system is implemented as a learning tool for the patients and not merely a Decision Support System. With this emphasis the primary concern is on medical technology assessment and evaluation, albeit hopefully also facilitating the integration of the diagnostic method as a part of medical practices, just as the study is to provide input to the further development of the system, e.g. by means of addressing problem issues concerning user-friendliness.

ASB and the Ph.D. study have collaborated closely in order to pool as well as share data and experience alike. The projects in question were divided into two separate projects because

Aalborg University wanted to maintain a minimum invasive strategy in the monitoring research efforts, partly to protect the patients, partly to ensure that the project adheres as closely as possible to actual medical practice.

1.5 The evaluation report at a glance

Following an introductory outline of the overall objective of evaluating the effectiveness of DiasNet, **Chapter 2** provides a brief description of the diabetic disorder, and gives an introduction to the general objectives for diabetic care in Denmark until year 2010 as stated by the Danish National Board of Health.

Chapter 3 is an introduction to DiasNet. What kind of IT system is it? How do health professionals and patients use it in practice? How has the system been implemented in practice?

In **Chapter 4** we expand upon the methodological considerations in our approach to the effect evaluation of DiasNet. We have chosen the case study as the underlying method. In continuation of the case study we adopt a narrative approach in the inquiry into patient observations and experiences with DiasNet.

Chapter 5 gives an introduction to the medical outpatients' clinic at Vendsyssel Hospital. We describe the context of our inquiries, viz.: Which tasks and duties do the individual professional groups in the diabetes team perform? How frequent are patient reviews? Similarly, the chapter includes an elaboration of the type of data collection techniques applied to gain a fundamental grasp of the day-to-day routines and clinical work at the clinic.

Chapter 6 contains the findings of the study of how the diabetes team has made practical use of DiasNet. On the basis of interviews with the diabetes team we analyse these held up against a theoretical frame of reference, i.e. the theory pertaining to the "Learning Organisation" and the concept of competence. A summary closes this chapter.

Chapter 7 introduces the three patients that participated in the development project. After an individual patient presentation, we leave each patient to give a personal account of his observations and experiences when using DiasNet in practice. Also this chapter is closed by a summary.

Chapter 8 contains a conclusion, including the identification of the unique and typical characteristics of the case study. We compare how the health professionals and the patients experience DiasNet in practice.

Chapter 9 renders reflections in relation to the use of the case study method.

Finally, appendices explaining the applied observation and interview guides are enclosed.

Chapter 2 - Diabetes – treatment, development and objectives

2.1 Introduction

What is diabetes? Which are possible diabetic complications? This chapter intends to answer these questions. The purpose of this chapter is not to provide a comprehensive guide to the diabetic disorder but to give the reader a summary introduction to the disease, including its symptoms and treatment. Then follows a presentation of objectives for the diabetic care in Denmark and of their actual implementation on a local basis in the County of North Jutland.

2.2 What is diabetes?

Diabetes Mellitus is commonly referred to as diabetes. Diabetes is a disease that is characterised by poor glucose metabolism, either on account of the body's failure to produce insulin or on account of a reduced effect of the insulin produced.

Insulin is a hormone that is produced in the beta cells of the pancreas. Insulin is necessary in order to transport glucose from the bloodstream into the cells. Total absence of insulin deprives the cells of energy. If a person does not produce insulin, he develops insulin dependent diabetes, and insulin needs to be injected daily subcutaneously. Insulin cannot be administered in tablet form as it is broken down in the intestines[3].

There are two main types of diabetes[4]:

1. **Insulin dependent diabetes (type 1 diabetes, juvenile onset diabetes)**. This type of diabetes is characterised by the pancreas producing no insulin at all or hardly any. As a result, the diabetic patient needs to inject insulin on a daily basis to prevent acid poisoning, which is lethal if not treated. The disease is often diagnosed in people around 30 years of age, but may also develop in later years. Today, approx. 25,000 people suffer from type 1 diabetes in Denmark.[5]

2. **Non insulin dependent diabetes (type 2 diabetes, adult onset diabetes)**. This type of diabetes is characterised by the pancreas producing insufficient insulin, and the sensitivity to insulin by the cells of the body is reduced. The disease is treated by diet and exercise, often combined with tablets. An increasing number of type 2 diabetic patients now receive insulin treatment. Today, approx. 100,000-150,000 people suffer from type 2 diabetes in Denmark.[6]

The diabetic patients participating in the DiasNet project at hand all suffer from insulin dependent (type 1) diabetes.

[3] Danish National Board of Health: "Diabetesbehandling i Danmark – fremtidig organisering" ("A Statement of Treatment of Diabetes)". 1994. Page 105.
[4] Ibid. Pages 27-29.
[5] http://www.sst.dk/borgerinfo/sygdomme/sukkersyge.aspx?lang=da (updated 19/8 2003)
[6] Danish National Board of Health. Danish Center for Evaluation and Health Technology Assessment: Type II-diabetes. "Medicinsk teknologivurdering af screening, diagnostik og behandling. MTV 2003; 5(1). 105-150 ("Type 2 Diabetes. Health Technology Assessment of screening, diagnosis and treatment").

2.3 Insulin dependent diabetes – type 1

The symptoms of new onset type 1 diabetes often appear in the course of just a couple of weeks in children and young adults. Sometimes the onset of the symptoms is dramatic, resulting in acid poisoning (diabetic ketoacidosis). In adults the symptoms are often more insidious and gradually become stronger in the course of some months. Classic symptoms are excessive thirst, increased fluid intake, frequent urination, weight loss, fatigue and blurred vision. A constant concern of diabetic patients is their blood glucose (blood sugar) level. Below follows an explanation of the terms hypoglycaemia and hyperglycaemia:

Hypoglycaemia ("hypo"): Means that the blood sugar level is too low. A frequent complication related to insulin treatment, but may also occur in connection with treatment in tablet form. The symptoms of hypoglycaemia are: sweatiness, muscular twitching, hunger, fatigue, lack of concentration, dizziness, blurred vision (seeing "spots") and rapid heartbeat. This condition must be treated immediately by the intake of fast acting sugar foods. A further drop in blood sugar would result in loss of conscience until the state of unconsciousness, possibly accompanied by seizures. This condition is referred to as insulin shock and requires external assistance in the form of an injection with glucose or glucagon.[7]

Hyperglycaemia ("hyper"): Means that the blood sugar level is too high. Patients are not always able to feel when their blood sugar level is elevated and may in fact get accustomed to this condition. A patient may experience the following symptoms in connection with hyperglycaemia: fatigue, dryness of mouth, thirst and excessive urination.

2.4 Diabetic complications

Type 1 diabetes may change the metabolism profoundly. As a result, there is a considerable risk of developing complications in the kidneys, eyes, cardiac-vascular system, etc. In Denmark 25-30% of all insulin dependent diabetics will develop a chronic kidney disease[8].

Diabetes is also linked to an increased risk of the arteries hardening (atherosclerosis)[9]. Blood clots in the brain may occur 2-4 times more frequently in diabetics than in non-diabetics, and cardiac infarct 3-5 times as frequently.

Ulcers on the feet constitute another complication that diabetic patients are prone to, often owing to an impaired or non-existent sense of touch in the feet [10] and atherosclerosis, which reduces the blood supply to the patient's legs. Surgical amputations are performed approx. 10 times more frequently in diabetics than in non-diabetics of the same gender and age[11].

[7] Danish National Board of Health: "Diabetesbehandling i Danmark – fremtidig organisering".1994. Page 105.
[8] Ibid. Page 31.
[9] Danish National Board of Health: "Diabetesbehandling i Danmark – fremtidig organisering". 1994. Pages 27 and 103.
[10] Inflammation of nerve endings; also referred to as diabetic neuropathy.
[11] Ibid. Page 31.

2.5 Treatment

The overall principle of diabetic care is to gain the best possible control with blood sugar levels in order to prevent diabetic complications. At the same time it is important to sustain a high quality of life for the individual patient by avoiding a high frequency of hypoglycaemia. The above-mentioned complications of diabetes are seen as a direct result of prolonged hyperglycaemia. The treatment of type 1 diabetes requires the administration of one or multiple insulin injections every day. As part of a day-to-day routine the diabetic patients check their blood sugar levels, although it is up to the individual patient when and how often it is done.

Patients who are diagnosed with type 1 diabetes receive individual education concerning the progress of the disease, human physiology, insulin treatment, diabetic diet and diabetic complications.

As the DiasNet project is yet another step forward in the development of diabetic care in Denmark, the following paragraph is intended to give a brief account of previous measures so far:

2.6 Development of diabetic care in Denmark

In 1981, a task force under the Danish National Board of Health submitted a report on diabetic screening and care in Denmark. The report recommended the establishment of diabetic outpatients' clinics in all counties. However, in the course of the 1980s it became obvious that the counties were very inhomogeneous[12]. As a result, the National Board of Health set up a new task force in the early 1990s, which produced a memorandum in 1994 entitled, "A Statement of Treatment of Diabetes" [13].

This report outlines the objectives of the future treatment of diabetes in Denmark:

> ***"The overall objective of the future diabetic care is to safeguard the diabetic patient's quality of life and normal life expectancy"[14]***

[12] County of North Jutland: "Diabetesbehandling i Nordjyllands Amt - status, mål og midler" ("Diabetic care in the County of North Jutland – current situation, objectives and means"). May 1997. Page 6.
[13] Original title: "Diabetesbehandlingen i Danmark – fremtidig organisering". The task force comprised a broad range of specialists and various professional groups within diabetic care, economists, etc. The task force was asked to consider and describe how to improve ways to identify and treat diabetes mellitus and its complications, including suggestions as to how to improve the co-operation between general practitioners, specialist practitioners, hospitals and specialist wards, to the effect that the patients would feel that they encounter a cohesive healthcare system. The task force was to define qualitative goals and make practical recommendations in order to ensure and improve the quality of diabetic patient care in the years ahead until 2010.
[14] Danish National Board of Health:" Diabetesbehandlingen i Danmark – fremtidig organisering". 1994. Page 42. *Our translation*.

According to the statement this is to be achieved by:

- Preventive measures against diabetic late complications or related disorders
- Securing the qualified treatment of diabetic symptoms and complications
- Strengthening the diabetic patient's own resources to encourage self-management skills and awareness of own responsibility in the treatment with a minimum dependency on the healthcare team.
- Safeguarding continuity in the relationship between the diabetic patient and the healthcare team.

The statement mainly calls for the intensified treatment and monitoring of all diabetics, and the promotion of patient self-management skills to safeguard the diabetic patients' quality of life. In concrete terms, this means the relief from troublesome symptoms caused by diabetes, along with the prevention and alleviation of diabetes related complications. The new element in the stated objectives was the targeting of both type 1 (insulin treated) and type 2 (non-insulin treated) diabetic patients.

Furthermore, the emphasis is on the need for a better organisation of diabetic care in order to achieve this goal. Also, the statement calls for a closer co-operation between the primary and secondary healthcare services to the effect that part of the consistent monitoring efforts may be placed in the primary sector. The working relationship between the diabetic outpatients' clinic and the primary sector should be strengthened and improved. Thus it is recommended that the monitoring of insulin dependent diabetics be first and foremost performed by the diabetic outpatients' clinics, whereas the monitoring of non-insulin dependent diabetics is primarily the responsibility of the GPs. The National Board of Health has identified the following objectives for diabetic care in Denmark for the period until 2010.

2.7 Statement by the National Board of Health[15]

The bullets below reflect the objectives of diabetic care in Denmark before 2010:

- 50% reduced rate of new onset blindness.
- 70% reduced rate of diabetes related, dialysis dependent kidney failure.
- 30% reduced rate of major surgical amputations.
- 50% reduced rate of new amputations of other extremity.
- Approx. 50% reduced rate of newly developed foot ulcers.
- Reduction of the number of diabetics with thrombosis in the heart (myocardial infarction) and embolisms in the brain (apoplexy).
- Prevention (or slowing down) of serious symptomatic diabetic nerve damage.
- Elimination of the increased frequency of congenital deformities in the children of diabetic mothers.

[15]Opcit. Page 42.

The task force puts particular emphasis on the recommendation to pursue the objectives by means of intensifying the educational programmes aimed at diabetic patients and their families, promoting increased home monitoring of blood sugar levels, improving the organisation of diabetic outpatients' clinics as well as the co-operation between the primary and the secondary healthcare sectors. Furthermore, the 1994 statement argues in favour of making it key to diabetic treatment that the diabetic patient becomes an expert in his own right and at his individual level. The health professionals are to solidify the knowledge of the diabetic patient and empower him to cope with the disease, thus acting as *tutors* in support of the diabetic patient's self-management skills. The diabetics should, on the basis of the individually tailored goals and the results of the home monitoring of blood and urine, be able to make adjustments in the disease management in co-operation with the healthcare team[16]. Although this poses a considerable challenge to the individual diabetic patient, the task force is aware of this dilemma and states, "This is why educational programmes and practical guidance by health professionals are essential if the diabetic patient is to assume this kind of responsibility[17] "

The task force recommends the appointment of a basic diabetes team representing various professional groups – medical doctor(s), nurse(s), podiatrist (foot care specialist), dietitian(s), social worker(s), psychologist(s) – to guide, assist, instruct and treat diabetic patients. No one therapeutic professional group has the sufficient comprehensive platform of theoretical and practical knowledge to offer advice and treatment concerning the multitude of problems that may arise in the course of diabetic patient care, thus a group of therapists is called for – a diabetes team. In this context, the idea of establishing a diabetes team at the diabetic outpatients' clinic in the hospital sector or in general was conceived. To ensure that the intentions of the National Board of Health are followed up, every county is advised to appoint a county community advisory committee on diabetes.

2.8 Diabetes advisory committee in the County of North Jutland

On the basis of the memorandum prepared by the National Board of Health, the health committee of North Jutland in 1995 decided to establish a county[18] community advisory committee[19] on diabetes. The committee is to monitor diabetic care in North Jutland and suggest ways of improvement. This is to be achieved by continuously enhancing the quality of treatment and by ensuring a clear division of labour and improved integration of the treatment options in the entire healthcare system.[20]

[16]Opcit. Pages 45-47.
[17]Opcit. Page 47. *Our translation*.
[18] The Committee is set up to comprise both users and healthcare sector representatives involved in diabetic care and treatment.
[19] County of North Jutland: "Diabetesbehandling i Nordjyllands Amt - status, mål og midler". May 1997. Page 6.
[20] In addition, the Committee has the following tasks: *Monitoring existing and suggesting new educational programmes aimed at patients and their families. *Imparting knowledge about disease prevention and health promotion in the diabetic area. *Instigating the establishmed of user groups at local diabetes clinics. *Suggestions in regard to the further and supplementary training of health professionals.

In May 1997 the County Community Advisory Committee on Diabetes (in Danish: Det amtslige Diabetesudvalg) published the report entitled, "Diabetic care in North Jutland – current situation, objectives and means" (*our translation*, original title: "Diabetesbehandling i Nordjylland – status, mål og midler"). This report proposes a 5-year plan, the concrete contents of which are recommendations of an improved organisation of diabetic care in the County of North Jutland. In the opinion of the committee the plan would help reduce diabetic late complications. There are in excess of 12,000 diabetic patients in the county, and according to a National Board of Health estimate the annual cost of treating diabetic complications amounts to DKK 250,000 – 500,000 million. In light of the committee's recommendations, the County of North Jutland has introduced e.g. eye screening for diabetic patients.

It could be argued that the DiasNet project helps to make the general objectives of diabetic care in Denmark more specific, but it may also be viewed as an invitation to diabetic patients to become better at self-care.

In the following chapter we shall introduce the DiasNet system. What is it able to do? And how has it been implemented?

Chapter 3 – Introduction and implementation of DiasNet

3.1 Introduction

This chapter will start with an introduction to DiasNet by means of answering the following questions: What is the functionality of DiasNet? How is it used in practice by hospital staff and patients? What are the patients taught at the diabetes school? Finally follows a brief description of the implementation of the system. However, before turning to the description of DiasNet, below follows a summary account of the data collection techniques applied.

3.2 Data collection techniques

In order to get acquainted with DiasNet we attended an introduction course to the system provided by Associate Professor Ole K. Hejlesen, AU, at a diabetes project group meeting and we reviewed articles on DiasNet.

Qualitative interview

We interviewed Associate Professor Ole K. Hejlesen to learn about the functionality of DiasNet as well as the visions behind it. The interview guide is enclosed as Appendix 2.

Observation

We attended patient education sessions at the diabetes school. Appendix 8 is a survey of the aspects we focused on in connection with our observation. We recorded our observations and subsequently used them in the analysis of our data.

3.3 Description of the diabetes advisory system

DiasNet is a web-based IT system in aid of improving the self-management skills of diabetic patients. In an interview[21], Associate Professor Ole K. Hejlesen, AU, explains that the system has been undergoing constant development throughout a decade - and still is. In charge of the system development is an international research team, including researchers from Aalborg University in Denmark and the Royal Bournemouth Hospital in England. In the course of this ten-year period, the Royal Bournemouth Hospital has already provided theoretical and subsequent hands-on training to more than 400 patients.

DiasNet on the Internet

DiasNet is a so-called "Decision Support System", which aims at giving patients, medical doctors and other healthcare staff a better picture of the individual patient's diabetic condition. This means that DiasNet makes adjustment suggestions as to the insulin regimen of the patient in question. On this basis, the patient, the nurses and the medical doctor jointly decide whether or not to make adjustments to the current treatment plan. DiasNet is located on a web site on the Internet where the individual patients are able to log on and enter their specific data, which may subsequently be reviewed by the diabetes team at the hospital, who may thus

[21] Interview on 1 September 2002

monitor the blood sugar values of the patients in question without necessarily requiring their presence at the clinic.

DiasNet operates with a model of human glucose metabolism and on the basis of the patient's intake of food and insulin as well as actual blood sugar measurements it predicts which glucose concentrations he should in fact have according to the mathematical model[22] applied by the system. Nevertheless, at present the system does not make allowances for the impact of factors such as e.g. stress, physical exercise, alcohol and fever.

The expected outcome of the system is the prevention of a high frequency of hypoglycaemia and hyperglycaemia in diabetic patients, who thus become more adept at controlling the occasional episodes that are bound to occur[23]. This is required in order to achieve a generally improved diabetes control, including a reduction of late complications. Some of these expectations in regard to the system are tied to the fact that DiasNet operates with the theory of counter-regulation in diabetic care[24].

Counter-regulation

The theory of counter-regulation was discovered in e.g. tests where patients had blood sugar measuring devices surgically implanted under the skin. In this connection it transpired that DiasNet generally simulates the blood sugar values very well, except in a time span of 10-25 hours following episodes of hypoglycaemia when the computer calculates the blood sugar values at a level of up to 5-10 mmol/L lower than actual values. This leads on to a concept that is of crucial importance in the use of DiasNet, viz. counter-regulation[25]. According to theory, counter-regulation is the body's natural reaction to hypoglycaemia, even if neither registered, nor measured. In theory the body will thus about 6 hours after hypoglycaemia initiate a counter-regulation to the effect of elevated blood sugar levels, which seem inexplicable without the concept of counter-regulation. This high blood sugar concentration may then last for up to 18 hours.

If the blood sugar level is unacceptably high in a patient, DiasNet may be able to pinpoint whether this could be due to a previous episode of hypoglycaemia. If this is the case, the solution is not the administration of more insulin to prevent the high blood sugar concentration. In stead, a smaller dosage of insulin should be administered to avoid hypoglycaemia, which triggers the elevated blood sugar levels 6 hours later. Having now explained some of the ideas behind DiasNet, we shall turn to a description of the practical application of DiasNet at Vendsysssel Hospital.

[22] www.diasnet.dk
[23] www.diasnet.dk
[24] www.diasnet.dk
[25] www.diasnet.dk

3.4 Introducing patients to DiasNet

The introduction of DiasNet will cause major changes in the way diabetes is controlled both by clinical staff and patients. The figure below shows how DiasNet affects various aspects:

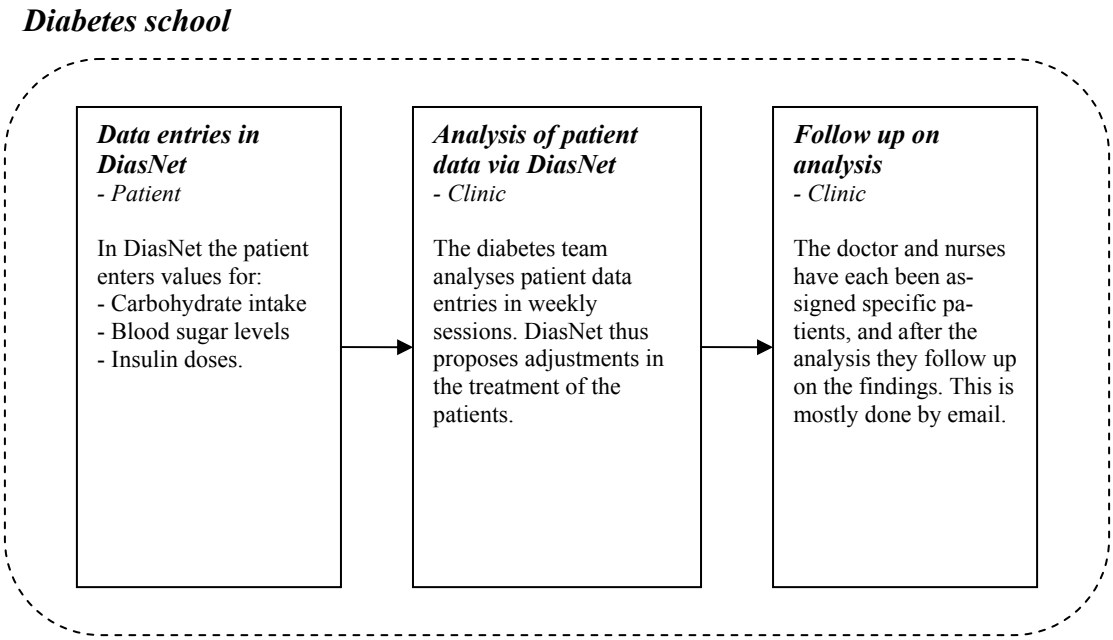


Figure 3.1: Structure of the diabetes school.

The patient will test his blood sugar and record the intake of insulin and carbohydrates, all values to be entered into the system. This procedure is repeated over a 3-day period.

When the patient has completed his data entries, the diabetes team at the outpatients' clinic will meet to analyse the data of the patient in question, and in all probability DiasNet will propose options to improve his treatment plan. The diabetes team will discuss the options and then contact the patient, either by email or telephone. Alternatively, the patient may be called in for a routine check at the outpatients' clinic if this is deemed necessary by the diabetes team in light of the present information available on the patient in question.

The above-mentioned approach reflects a model and summary account of the practical uses of DiasNet. The individual elements of the model will be specified in greater detail below so as to give an idea of what it is DiasNet can do and how. In addition to the day-to-day practice outlined above, the patients are invited to attend an introductory course, called the diabetes school. Here all 3 elements will be thoroughly dealt with in the course of 4 afternoon sessions in order to give the patient a good grasp of the programme before running it. Below please find a brief introduction to the programme and the ideas behind this diabetes school. Subsequently, we turn to an in-depth description of the day-to-day use of DiasNet.

3.5 The diabetes school

In order to instruct patients in the use of DiasNet the hospital invites them to attend an introductory training programme, called the diabetes school. In the course of the 4 afternoon sessions the programme is scheduled to last, the patients are introduced to DiasNet and are also supplied with up-to-date information on the subject of diabetes.

At the diabetes school at Vendsyssel Hospital the specific disease-related education led by a dietitian, diabetes nurses and a medical doctor put particular emphasis on the effect that carbohydrates, exercise and the patient's emotional state have on the diabetic condition. Furthermore, the medical doctor explained the condition of diabetic ketoacidosis – where prolonged seriously elevated blood sugar concentrations may lead to "acid poisoning" of the blood. As a rule, no more than 8-10 patients attend the diabetes group session. However, only 3 patients attended the session we sat in on.

This training programme was intended to support the specific system-related introduction to DiasNet. As it turned out, the diabetes school allowed the patients considerable time to learn how to enter their data in the system and how to analyse these data in a group session.

The syllabus of the diabetes school reads as follows:[26]:

1st session	2nd session	3rd session	4th session
12.30 - 12.45 Introduction of staff and patients Practical information – programme content 12.45 - 13.45 Introduction to DiasNet 13.45 - 14.15 Coffee break 14.15 - 15.15 Patient specific data on blood sugar values, carbohydrate and insulin intake are entered in DiasNet 15.15 - 15.30 Break 15.30 - 16.00 Group review of DiasNet with completed datasets 16.00 - 16.15 Evaluation of today's session	12.30 - 13.45 Patient specific data on blood sugar values, carbohydrate and insulin intake are entered in DiasNet 13.45 - 14.15 Coffee break 14.15 - 15.15 Dietary information 15.15 - 15.30 Break 15.30 - 16.15 Review of values measured by patients	12.30 - 13.45 Patient specific data on blood sugar values, carbohydrate and insulin intake are entered in DiasNet 13.45 - 14.15 Coffee break 14.15 - 15.15 The causes of lower blood sugar levels The effect of physical exercise on blood sugar Ketoacidosis /disease 15.15 - 15.30 Break 15.30 - 16.15 Review of values measured by patients	12.30 - 13.30 How is diabetic control influenced by the patient's emotional state? 13.45 - 14.15 Coffee break 14.15 - 14.45 Group discussion of profiles 15.00 - 15.45 Group discussion and evaluation

Figure 3.2: Programme of the diabetes school.

[26]www.diasnet.dk

So as to be able to cover all 3 elements in one session at the diabetes school, viz. data entry, analysis of entered values and follow-up on the analysis, the patients were after the initial session asked to keep a diary for 3 days and nights to be used in the second education session, making it possible to discuss the actual use of DiasNet in class. The patients thus recorded their intake of carbohydrates and insulin, and also wrote down the results of the blood sugar tests performed in connection with every meal as well as in the morning and before bed.

In the second afternoon session at the diabetes school the patients were asked to enter the registered data that they would be entering on their computer at home on a daily basis, and in the second half of this session the diabetes team would join the patients in a group evaluation of the patient data in question by means of DiasNet. At the diabetes school, the subsequent consultation with the patients will of course take place immediately. This was also the case in this instance and as a result a few patients had their insulin dose adjusted already at this stage.

The third and fourth sessions at the diabetes school followed the same pattern, except that the patients prior to these sessions had already made data entries in the system from home so as to check the performance of the DiasNet application on their individual personal computers. These 4 education sessions at the diabetes school combined with the comprehensive analyses and reviews of the individual datasets made the patients feel very confident about the system.

The more technical aspect of data entries and evaluation will be specified below in the description of the daily use of the system.

3.6 Data entries in DiasNet – by the patient

The patient himself picks a 3-day period that reflects his typical everyday routines in terms of sleep, exercise, food intake, etc., so as to prepare the required profile including 3 days and nights of patient regimen data. Over the 3 days and nights in question, the patient will then complete the form illustrated below with intakes of carbohydrate, insulin doses and blood sugar values so that these data may subsequently be entered in DiasNet. The forms are handed out at the diabetes school. The figure below shows a typical completed form.

Time	**Meal**	**Blood sugar**	**Insulin**	**Carbohydrates**
Time/Hour.	*Description of meals and snacks.*	*Measured blood sugar value (mmol/L).*	*Units insulin S (short acting) and L (long acting).*	*Total carbohydrate content in meals.*
Early morning 645/700	½ slice of rye bread with cheese	14.2	S_3 / L_8	10g
Late morning 945		14.7	S__	
Lunch time 1230	1 slice of rye bread + salad	17.1	S_6	20g
Afternoon 1530	Roll	8.7	S_3	35g
Evening meal 1730/1800	Potatoes + turkey + gravy	12.7	S_4 / L10	40g
Late evening 2030	Chocolate	4.6	S__	20g
Night 2230		8.3	S__	
Time	**Meal**	**Blood sugar**	**Insulin**	**Carbohydrates**
Early morning 700	½ slice of rye bread with cheese	18.5	S_6 / L_8	10g
Late morning 945		12.7	S_4	
Lunch time 1130	1 slice of rye bread + 3 sweets	15.3	S__	30g
Afternoon 1515	Chocolate ”snow-ball”	5.7	S__	14g
Evening meal 1730	Vegetables, ris-soles and rye bread	7.2	S_4 / L10	40g
Late evening 2015	½ cheese roll	5.1	S_8	40g
Night 2245		4.8	S__	
Time	**Meal**	**Blood sugar**	**Insulin**	**Carbohydrates**
Early morning 700	½ slice of rye bread with cheese	18.5	S_6 / L_8	10g
Late morning 1000		18.5	S_6	
Lunch time 1300	1 slice of rye bread + greens	9.3	S_4	20g
Afternoon 1600	?	5.5	S__	8g
Evening meal 1730	Pasta salad + bread	8.9	S_4 / L10	40g
Late evening 20	Ice cream + bread	9.9	S_2	45g
Night 2315		13.8	S_2	

Figure 3.3: 3-day profile of diabetic patient.

Upon expiry of the 3-day diary period the patients log into DiasNet on the web site www.diasnet.dk by means of designated user name and password. This prompts the screen layout depicted below, which constitutes the main window for patient actions and entries.

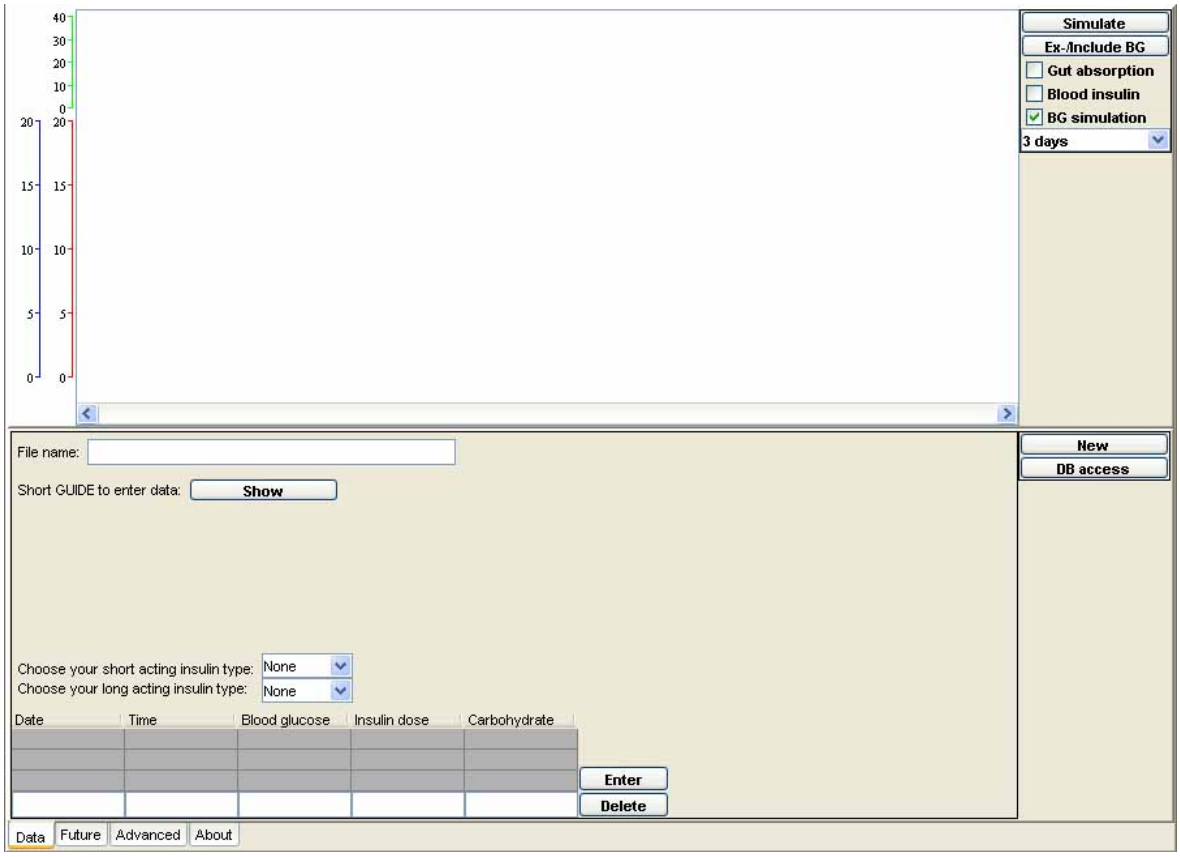
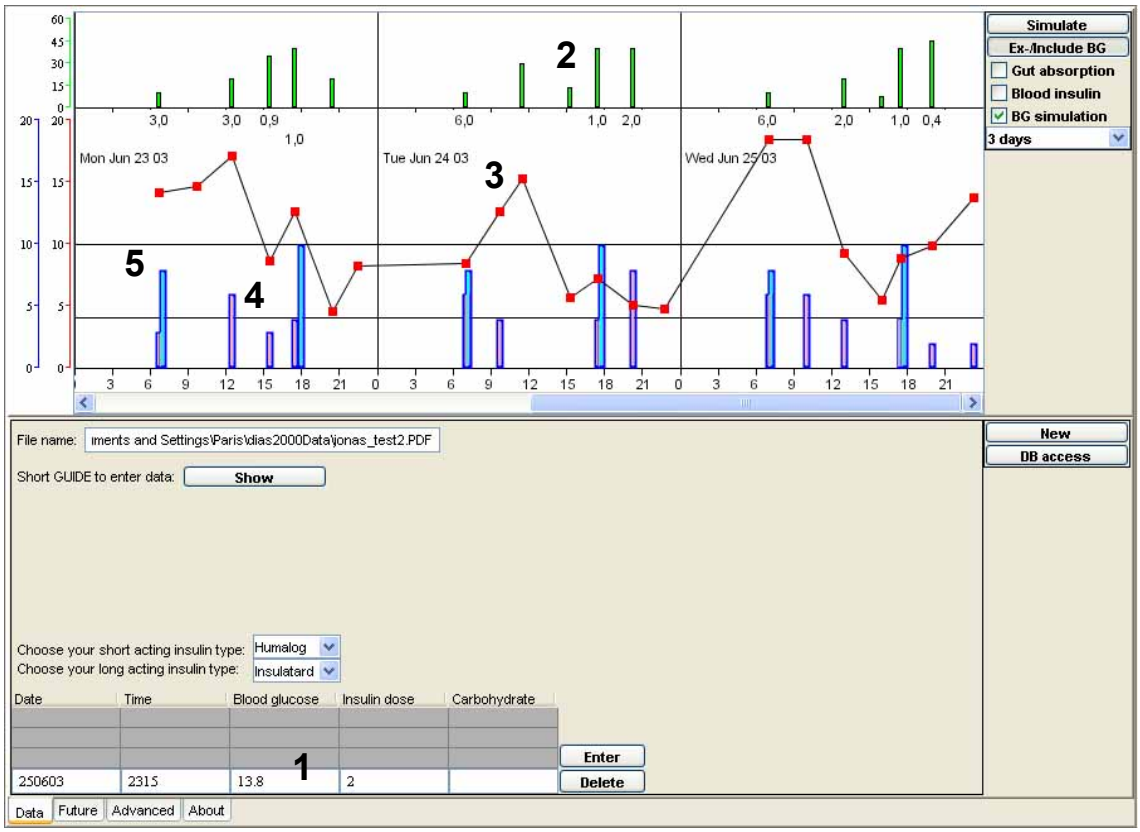


Figure 3.4: User interface with empty DiasNet.

In this section the patient may enter his recorded data. In the window situated in the bottom half of the screen layout, the diary entries from the form above on the patient's intake of carbohydrates and/or insulin, and/or blood sugar test results are copied into the system by the hour. The data values are displayed by the hour, both as an entry in the table in the bottom half of the screen and graphically in the top half of the screen.



1. Data entries
2. Carbohydrates
3. Blood sugar values
4. Short-acting insulin
5. Long-acting insulin

Figure 3.5: Screen layout with data entries in bottom half of screen and connected data in top half.

Upon entering data in the field marked ”1”, the input will be graphically displayed in the top half of the programme. The bars numbered “2” display the patient data on carbohydrate content in the meals consumed each day, the dots marked “3” visualise the blood sugar values measured and then entered into the system by the patient. The bars marked “4” indicate the time of day and the dose of short-acting insulin, and the bars marked “5” indicate injections of long-acting insulin.

This graphical display in the top half of the screen now constitutes the basis for the analysis that DiasNet will generate and the staff at the diabetic outpatients’ clinic will review. We shall describe this procedure below.

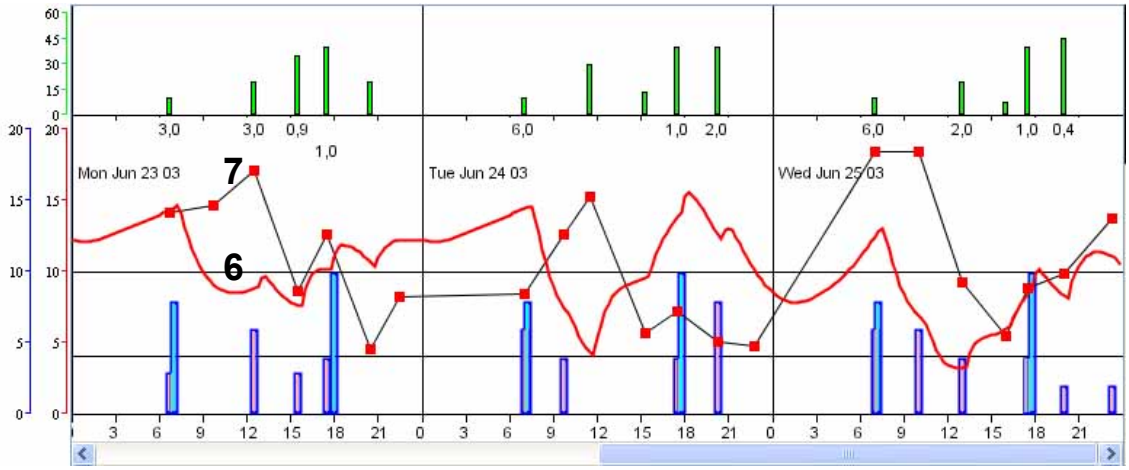
3.7 Analysis of patient data via DiasNet – by the clinic

By means of DiasNet a better visualisation of the blood sugar values recorded over the 3-day period is thus made available both to the diabetes team and the patient. On the basis of this visualisation DiasNet may subsequently generate its analysis.

Once the patient has entered his 3-day profile in DiasNet, the next step is a review by the clinicians. At Vendsyssel Hospital this took place in weekly joint sessions attended by the nurses and the doctor in order to evaluate the previous week's data entries. Every patient was given a specific contact with the team of diabetes nurses and the doctor throughout the programme. After the weekly session, every patient would be notified, usually by email, by their individual contact concerning possible insulin dose adjustments or increases in the frequency of home glucose testing.

Firstly, the data will be reviewed for episodes of the above-mentioned counter-regulation and on this basis the data will be "adjusted" so that they are ready for DiasNet to use in the so-called simulation in order to provide guidelines for insulin dose adjustments.

In the dataset used in this report we describe a case of counter-regulation on the basis of the figure below.



6. The blood sugar value predicted by DiasNet
7. Actual blood sugar value tested by patient

Figure 3.6: DiasNet indicates counter-regulation.

The red curve marked "6" shows the blood sugar prediction generated by DiasNet. As illustrated by the figure, the blood sugar predictions generated by the system are close to the actually measured values ("7") in some intervals, and in others they differ quite considerably. In general, however, it seems safe to say that even a rather wide gap between the levels indicated

by the curves marked “6” and “7” does not change the fact that they are very unanimous in their indications of a rise or fall in blood sugar levels.

On the last day of the simulation it appears that the patient has performed tests (“7” in the figure above) that show values, which are considerably higher than the DiasNet predictions (“6”). According to the counter-regulation theory this could indicate an episode of nocturnal hypoglycaemia, which has caused a strong increase in blood sugar concentrations for a period of 12-18 hours.

As mentioned, the data that are a result of counter-regulation will be “cleansed” from the dataset and the simulation may now begin.

Simulation in DiasNet

As now only the input remains that is believed to reflect the way in which the patient responds to carbohydrates and insulin respectively, the simulation by means of DiasNet may be initiated. In the simulation section DiasNet displays the recommended insulin regimen for the day in question.

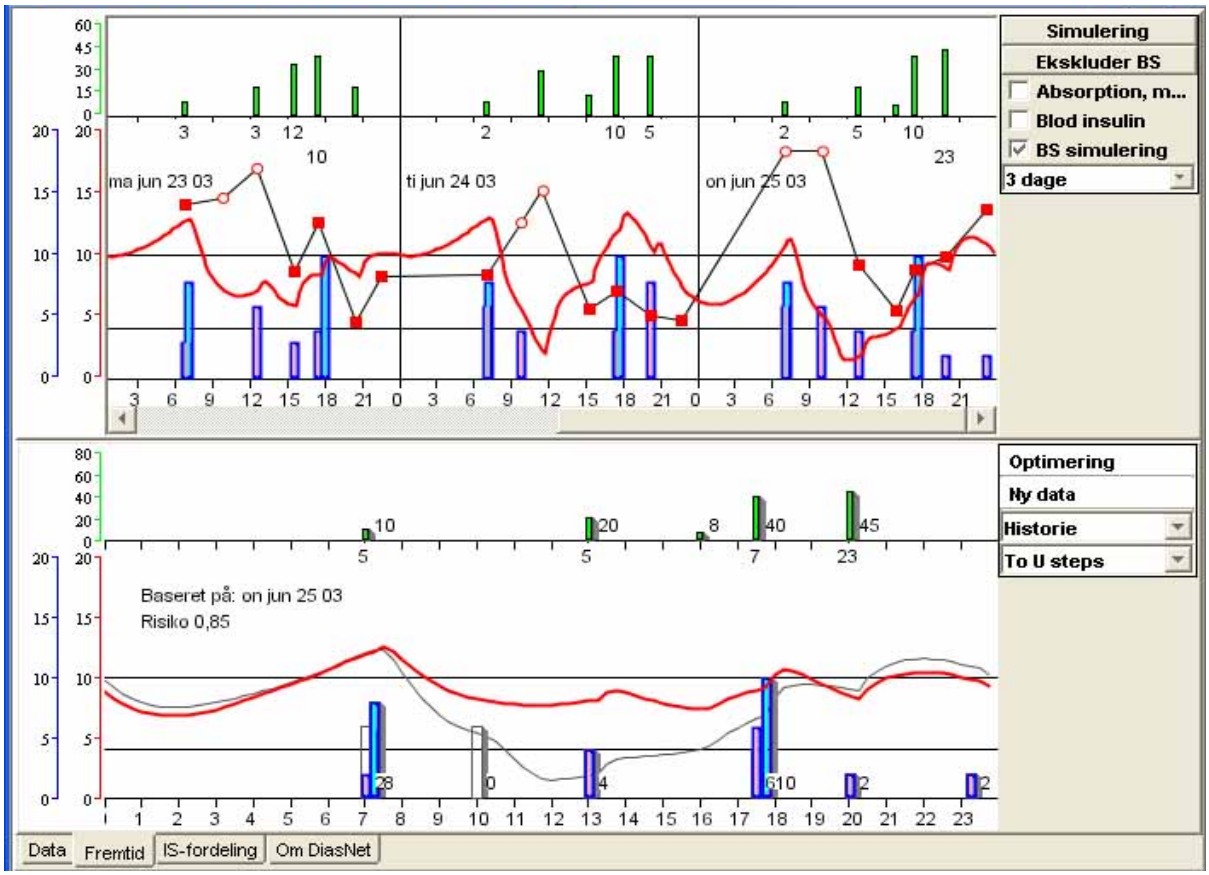


Figure 3.7: Example and simulation of a patient’s intake of carbohydrates and insulin as well as blood sugar test figures.

In the scenario illustrated above, we have chosen to analyse the third day of the 3-day profile, i.e. the day on the right in the top half of the screen. *Please note that this screen dump does not exist in an English version, hence this Danish version.* As the simulation now shows, DiasNet suggests that the patient on this specific day, with this specific carbohydrate intake, could well have reduced his morning insulin dose from 6 to 2 units, altogether omitted the 6 units injected at 10.00 a.m. and increased the evening insulin from 4 to 6 units.

This analysis alone does not justify a change in the patient's insulin dose, but if a pattern emerges in the analysis of several days over a longer period of time, it will definitely be a change of regimen worth considering.

DiasNet has provided a good graphical tool for the visualisation of episodes of counter-regulation. This helps to improve the patient's ability to prevent the episodes of hypoglycaemia that occur 12-18 hours before the elevated blood sugar concentration sets in, and the treatment may be aimed at these episodes of hypoglycaemia. This is preferable to treating the elevated blood sugar levels with insulin, which is often the case today.

3.8 Follow up on analysis – by the clinic

When the diabetes team has completed the above-mentioned analysis of patient specific data, one of 3 possible follow-up options is selected. The patients receive feedback by email. If major adjustments are required, the patient is summoned for consultation at the clinic. If the patient specific data are satisfactory, there is no reason to waste resources on a clinical review and the patient may thus not necessarily be contacted again until the renewed entry of a 3-day profile via DiasNet, which will again be analysed by the diabetes team.

The following chapter describes the methodological approach employed in this project.

Chapter 4 – The case study as underlying research method

4.1 Introduction

The purpose of this chapter is to outline the overall methodological considerations on which the effect evaluation of DiasNet is founded. The steering group[27] of The Digital Hospital decided that the focus of the DiasNet effect evaluation should encompass the following two main fields of study:

1. ***The consequences experienced by the members of the diabetes team when diabetic patients use DiasNet.***
    - ***Are there any changes in the tasks and duties of the team as a result?***
    - ***Which challenges face the team as a result?***

2. ***Patient observations and experiences with DiasNet in view of their coping with a chronic disease such as diabetes.***

In this chapter we argue in favour of our choice of methodological approach, and in Chapters 6 and 7 we give an introduction to the data collection techniques applied, along with an analysis of the collected data.

4.2 The case study

We have chosen the case study as the overall methodological frame of reference in our study of how health professionals and patients use the DiasNet application. A case study[28]:

- Is an empirical study of contemporary phenomena.
- Is set within the subjects' real-life context – i.e. requires the investigator to get close to other people on their terms.
- Does not always encounter clearly evident boundaries between phenomenon and context.
- Requires, on the other hand, that the investigator seeks to include as many data sources as possible.

When adopting the case study method we choose to view people and society in relation to a concrete context.

[27] The steering group is comprised of County Health Director Jesper Christensen, IT Manager Frank Petersen, Project Manager Mette Mullerup, Project Manager Bjarne Lykkemark, Rambøl, Hospital Director Ingeborg Thuesgård, Vendsyssel Hospital, Departmental Manager Karl Henrik Lauersen, Vendsyssel Hospital, Stig Kjær Andersen, V-chi, Aalborg University, Associate Professor Povl Erik Rostgård Andersen, Aarhus School of Business.

[28] Maaløe, Erik: "Case-studier af og om mennesker i organisationer". Akademisk Forlag. 1999. Page 58.

The case study is founded on the scientific theory of phenomenology, in other words "to understand". *"Understanding"* may verify a specific interpretation as a valid possibility, but there may also be other reasons. People do not respond unambiguously to the same influences, and as a result we need to apply methods that can reveal what the actions of people in fact mean to them.[29] Thus, the case study calls for presence and empathy, including both observation and conversation/dialogue. We will return to a specification of the concrete data collection techniques used.

A corner stone in the traditional phenomenological theory of science is the ability to perceive otherwise unrecognised behavioural patterns in other people by means of contemplation and reflection[30]. The disadvantage of this tradition is the risk of losing ones way. This is where the question of validity enters the equation. In our capacity as evaluators, we will by our mere presence influence the people we observe or talk with. We therefore need to be aware of our affect on the people we interact with, e.g. as observers. When planning our case study we therefore gave priority to making it an integral part of the data collection process to validate our collected data with the diabetes team and the patients. Did we, as evaluators, understand this and that correctly and in a correct context?

4.2.1 What is our pre-understanding?

Prior to initiating the data collection and analysis process, we need to be aware of our own view of the world and humanity, as this is a key element in a case study. Who are we, and what baggage do we bring to the study, and why do we choose to do the things we do? In other words, what is our pre-understanding? Already when selecting the case study approach as the general methodological strategy we stick to a phenomenological world outlook. We want to nurture a comprehensive understanding of mankind, and want to view man both as a societal individual, a group individual and a unique individual all at once. We are inspired by a system theory that draws on hermeneutical cognition[31] in so far that the individual human being may be argued to depend on a system.

We, the two research assistants who have been responsible for most of the data collection and analysis work for this report, each have an educational background that facilitates our approach to viewing a hospital in terms of activity theory, human resources, patients, etc. One of us is studying to become a Master of Science (Business Informatics); the other holds a Master's degree in Public Administration and is also a registered nurse. In our data analysis we are therefore not adopting an atheoretical approach, but of course draw on the theory apparatus and concepts we have become familiar with. Similarly, in our opinion a practical experience of the healthcare sector is crucial in order to understand the context in the case study, viz. the medical outpatients' clinic at Vendsyssel Hospital.

[29] Ibid. Page 65.
[30] Ibid. Page 66.
[31] Hammerlin, Yngve et al.: "Menneskesynet i teorier om mennesket". Klim. 1999. Pages 188-189.

In relation to the application of a computer programme such as DiasNet we have no frame of reference to draw on. Nevertheless, our expectations are that DiasNet – which is part of the current trend in the healthcare sector – will inspire patients to take increased responsibility for their own disease management.

4.3 Generalisability of the case study

One of the recurring discussions in relation to the case study approach centres on its generalisability. Works of reference on the case study formulate guidelines of how to optimise the basis for generalisation by strategic case selection. We will not venture further into this discussion here, but merely point out that the medical outpatients' clinic at Vendsyssel Hospital, as far as the scope of the case study is concerned, is to be perceived as a field of research. The primary objective of the effect evaluation of DiasNet is oriented towards development and practice. To the extent that we find it possible, we single out the typical features of our case study (cf. Chapter 8). We do not view generalisability as a criterion for success in regard to the effect evaluation, because we start from the assumption that the problems that exist concerning the generalisability of our case study perhaps to a larger extent reflect a feature of real life rather than the case study as research method.

4.3.1 Analytical generalisation

Case studies are used to test the validity of existing hypotheses or point to new ones. Cases may be a challenge to use or may challenge the existing theory in a particular field or lay the foundations of a new one. A game where practice and theory, reciprocal testing, deduction and induction unfold together with and against each other within the given circumstances.[32]
As mentioned, the effect evaluation of DiasNet falls into two parts, and in the inquiry into the tasks and duties of the diabetes team related to DiasNet we apply a theoretical frame of reference - the reason for this being that health professionals and hospitals interact in a common organisational and institutional context. As a result, we try to infer typical characteristics of this part of the study. As evaluators it is therefore important to distance us in the integration of data in relation to theory in order to prevent the process from becoming theoretically self-fulfilling. Below we explain how we intend to study the personal observations and experiences of the patients.

4.3.2 Narrative inquiry into patient observations and experiences

In continuation of the case study and the underlying concepts we have chosen to model the inquiry into patient observations and experiences with DiasNet according to a narrative approach[33]. Narrativity as genre is used in a great many scientific disciplines, but springs from the humanities, i.e. linguistics and literary studies[34]. Narrativity is in this context used to solicit patient observations and experiences with DiasNet.

[32] Maaløe, Erik: "Case-studier af og om mennesker i organisationer". Akademisk Forlag. 1999. Page 72.
[33] Riessman, Kohler Catherine: "Analysis of personal narratives". Handbook of Interview Research. Sage Publications. 2002. Page 695.
[34] Pedersen, Anne Reff: "Den udfoldende praksis". Roskilde Universitets Forlag. 2000. Page 45.

The advantage of narrative analysis is the possibility of portraying patient observations and experiences by means of first-person accounts. The disadvantage of narrative analysis is the fact that the reader is not informed in advance of what we as evaluators believe to be of specific interest in the narratives. Needless to say, our search for stories in the transcribed interviews is coloured by our pre-understanding.

On the other hand, the inquiry into patient observations and experiences with DiasNet is thus – as opposed to the inquiry into the interviews conducted with the hospital staff – analysed on the basis of a theoretical frame of reference. We let the patients tell their own personal stories and apply no theory under the pretence that we know why the individual patient experiences the way he does. In other words, we pass on the stories told by the patients.

Our aim is not to generalise, but to give an account of the patients' life-styles and diabetes management by means of DiasNet.

In Chapter 7 we explain our considerations in connection with the patient selection process.

4.4 The case study as a process

The case study constituted a process and as a result we divided it into multiple stages in relation to our inquiry and data collection. Firstly, we aimed to get an understanding of the day-to-day routines of the medical outpatients' clinic. Secondly, we concentrated on gaining a better insight into the tasks and duties the individual professional groups in the diabetes team perform in relation to the diabetic patients. At the same time we wanted to get to know the diabetic patients and their ways of coping with diabetes (before participating in the DiasNet project). Thirdly, we followed – as observers – the diabetes team and patients in the process of getting introduced to DiasNet. Finally, we conducted interviews with the diabetes team and patients to pinpoint what the hospital staff and patients have gained by participating in the DiasNet project.

In the following chapter we give a description of the medical outpatients' clinic and the diabetes team of Vendsyssel Hospital.

Chapter 5 – Introduction to the medical outpatients' clinic and the diabetes team

5.1 Introduction

The purpose of this chapter is to provide a description of the case context, viz. the medical outpatients' clinic at Vendsyssel Hospital. As mentioned in the Preface, in the autumn of 2002 the two local Danish hospitals of Frederikshavn-Skagen Hospital and Hjørring Hospital merged into Vendsyssel Hospital. As a result of the hospital merger the healthcare team was downsized.

As evaluators – given the case study as underlying method – we feel that it is important for us to have a basic understanding of tasks and duties performed by the diabetes team in relation to the diabetic patients, the way diabetes consultations are conducted, etc. We give a brief account of the case context and the data collection techniques that we used in order to acquire this knowledge. This is followed by an introduction to the medical outpatients' clinic and the diabetes team. So as to enable us to identify possible changes in the tasks and duties owing to the application of DiasNet in the diabetic care it was necessary to get a "picture" of which tasks the individual professional groups perform in relation to the diabetic patients when not applying DiasNet.

5.2 Data collection techniques

We started our data collection before the actual development project was launched so that we had a basic understanding of the characteristics, correlations/contexts, phenomena, etc. of our case. The initial data collection took place in September 2002. At that point, the hospital staff had only seen a less sophisticated version of DiasNet in use during a study trip to England.

We used the following techniques:

Observation

To acquire a basic understanding of the case context, our first step was to observe the everyday routines at the clinic. How are clinical reviews of the diabetic patients conducted? What are the tasks and duties performed by the nurse, the secretary, the medical doctor and the dietitian? How are the tasks and duties divided between the professional groups, etc.? We enclose appendices to describe the observation guides we used. We spent two days at the clinic – days when primarily diabetic patients came in for reviews. We were also participant-observers in the diabetes school for type 2 patients to study the course of the training programme, listen to the questions asked by the patients, etc. We took observation notes in connection with the observation. The observation guide is enclosed in Appendix 3.

Documentary material
In addition to our observations, we reviewed material prepared partly by the ward, partly at the hospital, on diabetes, functional descriptions for diabetes nurses, overall objectives, service target objectives, etc. We deemed this review essential to acquire a comprehensive understanding of the case context.

Qualitative interviews
The purpose of conducting interviews was to identify the diabetic patient related tasks and duties that the individual professional groups perform (when not applying an IT programme). We interviewed two diabetes nurses, a consultant doctor, a medical secretary and a dietitian. The individual interviews lasted an hour and were conducted on the basis of semi-structured interview guides (cf. Appendix 5). The interviews were tape-recorded and transcribed to facilitate data management. Quotations included below have been translated into English for the purpose of this report.

Interviews with informants
Finally, we interviewed a representative of the hospital's medical management.

5.3 Medical outpatients' clinic M1

M1 comprises s medical day ward and an outpatients' clinic. The ward has 4 consultant doctors attached to it, specialising in pulmonary diseases, endocrinology, neurology and gastroenterology respectively. The appointed consultants work according to a regular rotation schedule. In total, approx. 4,500 consultations take place here on an annual basis.[35] The ward is staffed with a ward sister, 4 nurses, 2 medical secretaries, 1 medical secretary trainee and 1 cleaner. It also takes on student nurses.

The ward handles the following functions[36]:

- Pre-admission and examination centre, which admits scheduled, referred patients for the purpose of assessment and treatment.

- Sub acute admission and visitation to reduce the number of acute admissions of patients requiring non-acute treatment in the evening and night hours.

- Admission of not fully assessed/treated patients from the inpatient wards for the purpose of completing treatment and/or patients who require a review frequency that cannot be accommodated by the outpatients' clinic.

- Nursing staff consultations with diabetic patients all weekdays.

[35] Sønderby, Anette: "Afsnitsprofil M1". Frederikshavn-Skagen Hospital 2001. Page 6.
[36] Ibid. Page 9.

- Diabetic patients consult their own GP every three, six or twelve months. The interval between clinical reviews varies from patient to patient.

For use by the medical ward various tests are run. As at August 2003 the medical outpatients' clinic had 288 patients under treatment.

5.3.1 The digital outpatients' clinic

The project of The Digital Hospital was launched in January 2002. From the date of project start IT courses were offered to all members of staff to guarantee a basic level of IT qualifications in the team.

As far as the outpatients' clinic was concerned this involved the implementation of digital dictation, electronic patient files (EPF), a booking system and the DiasNet application. As the first step, digital dictation was introduced in the spring of 2002, then followed EPF in June 2002, the DiasNet project in January 2003 and the booking system in May 2003.

5.3.2 Diabetic patients

The clinic has 233 outpatients with type 1 diabetes[37] attached to it. On all weekdays time is allocated to diabetic patients who come in for regular reviews every 3 or 6 months and for an annual review. The interval between clinical reviews varies from patient to patient. Patients with new-onset diabetes follow a set clinical monitoring schedule.

5.4 Diabetes team

The diabetes team at the medical outpatients' clinic includes a consultant doctor, two nurses, two dietitians, a podiatrist, a medical secretary and a social worker. In terms of composition, the diabetes team at Vendsyssel Hospital complies with the recommendations made by the National Board of Health in 1994 (cf. Chapter 2).

[37] According to the patient registration system as at August 2003.

A central issue is how the visions and objectives for diabetic care and treatment are put into practice at the medical outpatients' clinic at Vendsyssel Hospital. The health professionals quote the visions and objectives to be as follows:

Visions and objectives for diabetic care and treatment

- "That the chronically ill patient leads a tolerable everyday life and is not depressed by being a diabetic. To set the diabetic free."[38] (consultant doctor).
- "We have worked towards pure nursing care consultations to the effect that they only meet the doctor once or twice a year." [39] (diabetes nurse I).
- "Change their life-styles so that they get a good life."[40] (diabetes nurse II).
- "I make a big point out of making some recommendations that come close to the normal routines of the person in question. So that the patient experiences that they hardly change things. In this way, chances are that the changes become permanent".[41] (dietitian).

Below we describe the concrete tasks and duties the individual professional groups in the diabetes team perform in relation to diabetic patients. We want to point out that the diabetes team does not deal with diabetic patients 37 hours a week. The team members are part of the entire staff at the medical outpatients' clinic, which as described above is involved with patient care within several branches of medicine. One consultant doctor, two nurses, a dietitian and a medical secretary piloted the DiasNet development project. Hence these professional groups are represented in our data collection.

Medical doctor[42]

The medical doctor who is part of the diabetes team is a specialist in internal medicine with sub specialty in endocrinology. He primarily sees diabetic patients for clinical reviews 2 days a week at Vendsyssel Hospital. The doctor's work consists of ward rounds on the medical ward, medical supervision on other wards, administrative work, teaching and research. After ward rounds the doctor holds an afternoon clinic for diabetic patients (due to a shortage of doctors). In relation to diabetic patients, the doctor has the following tasks and duties:

[38] Interview 5D on 25 September 2002
[39] Interview 3D on 2 September 2002
[40] Ibid.
[41] Interview 6D on 1 September 2002
[42] Interview 5D on 29 September 2002

Tasks and duties related to diabetic patients

- Overall responsibility in regard to the compliance with National Board of Health recommendations and similar in relation to diabetic care.
- Making recommendations and guidelines available to diabetic patients and staff at the outpatients' clinic.
- Patient-related tasks and duties:
    - Monitoring of clinical data (blood sugar values, BP, pulse, kidney count, cholesterol, etc.).
    - Ensuring that eye specialist, podiatrist and others have assessed the patients.
    - Ensuring that the patients have been instructed in regard to e.g. diet, handling tools (syringes, needles, blood sugar measurement devices, etc.).
    - Ensuring that the patients receive counselling and guidance in diabetic medicine and its adverse effects.

Diabetes nurses
Two nurses are included in the diabetes team.

Nurse I[43]
Has been a nurse since 1976, and has broad experience within diabetic care and treatment. Has worked at the medical outpatients' clinic for 9 years.

Nurse II
Finished nurse's training in 1988. Has worked with diabetic patients for a number of years. Has worked at the medical outpatients' clinic for a year.

A functional description was prepared in regard to the diabetes nurses at the medical outpatients' clinic in 1998, cf. the appendix section. The nurse is the co-ordinator in relation to the diabetes team and has an advisory, consultative and educational function in relation to diabetics and health professionals. [44]Appendix 4 contains a functional description for the position of diabetes nurse.

[43]Interview 3D on 2 September 2002
[44] Functional description for the position of diabetes nurse at medical outpatients' clinic, Frederikshavn-Skagen Hospital. September 1998

Through interview sessions with the diabetes nurses it was explained to us in greater detail what a nursing care consultation involves – including also which tasks and duties a diabetes nurse performs when seeing a diabetic patient at the clinic.

Tasks and duties related to diabetic patients[45]

- Nursing care consultations
  - ”Our most essential duty is teaching diabetic patients how to live with their diabetes – to cope with their disease”.
  - The individual patient needs serve as starting point (e.g. whether it is a new-onset Type 1 or Type 2).
  - Diabetic patient education:
    - E.g.: diet, blood sugar values, treatment, exercise, etc.
  - ”And we spend some time instructing the patients how to check blood sugar concentrations or take insulin”.
  - ”There is a lot to consider when monitoring blood sugar, the blood sugar values are not always what they seem, you know”.
  - Prevention of late complications
    - ”Going along with their individual life-styles”
      - ”We have an ongoing dialogue with the patients”.

[45] Interviews 3D on 2 September 2002 and 4D on 2 September 2002

Dietitian

Graduated in 1983. Has broad experience as a dietitian, e.g. from working with the Danish Diabetes Association. Has worked at Vendsyssel Hospital since 1993. There are two dietitians attached to the hospital, and both are part of the diabetes team. In addition to being attached to the diabetes team, the dietitian performs dietetic functions (healthy eating and dietary advice to patients, staff, etc.) in the entire hospital.

Tasks and duties related to diabetic patients[46]

- Patient contact is initiated on the basis of referral.
    - "...I meet the person in question at the level he is at in the diabetic training programme, because they need to have a basic knowledge before we start. From this starting point I structure the educational sessions".
    - Is based on the needs of the individual patient – and involves his family.
        - "..Try to go through every minute of their everyday routines in regard to food...".
        - Filling in a checklist (about everyday routines, food habits, special considerations, etc.), which is used in individual patient consultations.
    - Healthy eating and dietary advice to diabetic patients and staff.

Medical secretary

Has been a secretary since 1988, and has worked as a secretary with diabetic care at the medical outpatients' clinic since April 2000. In this connection it deserves mention that the secretary performs additional functions besides the tasks and duties related to diabetic patients.

Tasks and duties related to diabetic patients [47]

- Summoning diabetic patients for screening (once a year).
- Summoning patients to the diabetes school.
- Retrieving and filling in patient files after consultation.
    - "My function is to get out the patient files and type in whatever may be dictated to me and then put back the files".
- Receiving patients at the reception desk.
- Answering telephone inquiries about opening hours, etc.

[46] Interview 6D on 1 September 2002
[47] Interview 2D on 2 September 2002

In the following chapter we provide an up-to-the-minute or “snapshot” account of what the diabetes team has gained so far from being part of the DiasNet project. In Chapter 7 we describe the patient observations and experiences.

Chapter 6 – The diabetes team and DiasNet – inquiry into tasks and competencies

6.1 Introduction

In this chapter we want to give a ”snapshot” account of the benefits that the diabetes team has gained from working with DiasNet. The objective of the effect evaluation is to study:

> ***The consequences experienced by the members of the diabetes team when diabetic patients use DiasNet:***
> - ***Are there any changes in the tasks and duties of the team as a result?***
> - ***Which challenges face the team as a result?***

We want to emphasise that the evaluation takes place at a very early stage of the implementation process. At the point in time when we collect data, DiasNet has been up and running from mid-January to June 2003. At the diabetes school, the diabetes team has trained 11 patients, who have participated in the entire project. The implementation of DiasNet has represented a development process on the part of staff and patients alike, and the following status account will thus reflect a “snapshot”. We are under the clear impression that most difficulties related to the initial implementation phase of DiasNet had been overcome by June 2003.

Further to our hermeneutical approach – by means of the case study method – we chose to build the analysis around quotations from the interview sessions, documentary material as well as observations. In addition to this, we employed the analytical tools acquired on the basis of the theoretical frame of reference, to the effect that we also view the context from a theoretical perspective.

The chapter is structured in such a way as to commence with a brief introduction to the theoretical framework, followed by a description of the data collection techniques we have used as well as analysis of the collected data, and the chapter is closed with a sub-summary. As we are conducting a case study, we want to point out that we have neither the ability nor the intention to generalise “what any diabetes team may gain from working with DiasNet”. However, we can say something about the experiences and benefits that the diabetes team at Vendsyssel Hospital gained from working with DiasNet in practice for 6 months.

6.2 Theoretical framework

We have chosen to include Peter Senge’s classic theory on the “Learning Organisation” and competence development theory. We have chosen to include these theories because the DiasNet project is a development project, the objective of which is practical experience. As a result, in our analysis of the collected data we find it interesting to see things through “spectacles” that focus on individual and organisational learning for the members of the diabetes

team. In the first place, the theory on the "Learning Organisation" is introduced, then the theory on the concept of competence.

6.2.1 The "Learning Organisation"

The "Learning Organisation" may be defined as follows:

"Organisations where people continually expand their capacity to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free, and where people are continually learning how to learn together"[48]

In his book entitled "The Fifth Discipline", Peter Senge lists 5 disciplines that determine whether an organisation can learn. This is done on the basic understanding that people do not resist change, they resist being changed[49]! Senge thus feels that the basis for organisational learning is in place, provided the guidelines in the 5 disciplines are met. And this readiness to learn and try something new is exactly what we believe is demanded of the participants in a project such as DiasNet.

The 5 disciplines defined by Peter Senge are "Building Shared Vision", "Mental Models", "Personal Mastery", "Team Learning (Dialogue)" and "Systems Thinking". The "Shared Vision" springs from the individual and is not dictated from the top down. If a "Shared Vision" exists, people do not learn because they have to, but because they want to. The feeling of obligation and thus the commitment to the task, the objective and each other will be soaring high.

"Mental models" are deeply rooted assumptions and generalisations, which colour our world outlook. The purpose of "Mental Models" is to improve the individual's ability to see and form his own mental models, and thus both possibilities and limitations, so that the models are not static but develop in accordance with the situation in which the individual finds himself.

The "Personal Mastery" discipline is a process that acknowledges that you work with mental models and as a result are no expert on all issues – that you have strong and weak points, and that you may benefit from other members of the organisation because they work with other mental models than yourself. By means of "Personal Mastery" you may thus identify and clarify personal visions.

The concept of "Team Learning" is founded on dialogue and therefore gives true collective thinking and shared vision. "Team Learning" implies that the members of an organisation have the time and inclination to listen so as to learn how to think and analyse as one collective

[48] Senge, Peter:"The Fifth Discipline", Currency Doubleday. Page 3.
[49] Ibid. Page 138.

whole (on the basis of their individual ”Personal Mastery”) and not as the individuals they are. The ability to listen and to make use of each other's strong and weak points also ensures that the members of the organisation do not stand with clearly separated personal mental models, which would otherwise be the case. Once this discipline functions impeccably, the organisation will feel that it is able to accomplish more collectively as a whole than it would have done if the individuals were separate.

”Systems Thinking” is an overall discipline that links the other disciplines and makes it possible to understand them as a unified whole. “Systems Thinking” implies that you view a given situation as a whole with the tasks, interested parties and players there may be and that you act in accordance with the “Team Learning” mentality and react to this overall picture of the situation that “Systems Thinking” provides.

After a summary introduction to the ideas behind the “Learning Organisation” we will introduce the concept of competence.

6.2.2 Competence

Competence may be defined as follows:

Competence is the individual's capacity to use his qualifications and skills in a concrete work-related context. Competence is thus person-linked and context-related.[50]

Competence is not merely a question of the knowledge, the skills and the attitudes displayed by the professional individual, but equally important a question of which values, motives and professional potentials that underlie staff actions, as well as the ability to take responsibility and make a professional assessment, independently and competently. Competence implies that a person or an organisation possesses some qualifications that are applicable or necessary in relation to the surrounding milieu. Put differently, “Competence is the ability to do what you have to do”.

The Danish Competence Council (Kompetencerådet), set up by The House of Mandag Morgen, has defined four key competencies[51]:

- **Learning competence,** defined as the ability to acquire knowledge and transform it.

- **Change competence**, defined as the ability to take initiatives to move both mentally and physically, and to switch roles.

[50] Danish Competence Council (Kompetencerådet) Report 1999. ”Danmarks nationale kompetenceregnskab”. Mandag Morgen. Strategisk Forum. *We have translated this quotation into English*.
[51] Ibid and ”Kompetenceprofil for Sygeplejersker, der arbejder med diabetes mellitus”. November 2002.

- **Relation competence**, defined as the ability to handle cultural diversity and to form networks.

- **Meaning competence**, defined as the ability to see, create and exchange meaning, both as individuals and collectively. This can only be achieved if the individual is aware of his own identity and focus.

The four competencies are interrelated, and possession and development of one competence is thus pre-requisite to the development of the others.

Qualifications imply a certain ability or knowledge, whereas competence implies that you have the required ability and knowledge. It makes good sense to talk about individual and organisational competence, and the process – as e.g. the implementation of DiasNet – by which the individual and organisational competence is acquired or developed, represents individual and organisational learning.

Concepts such as learning and competence are closely connected, and we therefore find their use as analytical tools justified in relation to our case study of the diabetes team and their practical experiences with DiasNet.

6.3 Data collection techniques

We have used the following techniques:

Qualitative interviews

The purpose of interviewing the members of the diabetes team individually was to identify possible new tasks and duties in connection with the use of DiasNet in diabetic care. We conducted interviews with two diabetes nurses, a consultant doctor, a medical secretary and a dietitian. The individual interviews lasted an hour and were conducted on the basis of semi-structured interview guides, cf. Appendix 6. The interviews were tape-recorded and transcribed to facilitate data management. Quotations included below have been translated into English for the purpose of this report.

Focus group interview

The purpose of the focus group interview was partly to validate the individual interviews, partly to investigate how the diabetes team as a whole experienced DiasNet in relation to shared tasks and competencies. The focus group interview lasted an hour. The interview guide is enclosed as Appendix 7. Also the focus group interview was tape-recorded and transcribed to facilitate data management. Quotations included below have been translated into English for the purpose of this report.

In addition to data collected in the qualitative interviews and the focus group interview, we included our observation notes, etc. Thus, we conducted a methodological triangulation in order to validate data continuously by this means.

6.4 The diabetes team and DiasNet – a ”snapshot” impression

We commence by outlining some of the general impressions and observations made during data collection: Data that immediately fit into the scope of the analysis, and which may serve the reader as an illustration of some aspects in the context and real-life world that characterise the medical outpatients' clinic and the diabetes team as well as constitute part of the "frame" in which to view the "snapshot".

When entering Vendsyssel Hospital you are immediately struck by the physical surroundings that clearly signal that this is a new, up-to-date and patient-friendly hospital. The impression we were given was clearly one of an outpatients' clinic where the patient is the centre of attention for the staff. The spirit of the place is friendly and accommodating, although also modest in the face of the services that are actually provided to the patients. Maybe it is because we are in this particular region of Denmark!

The question is how the staff members experience the clinic as a workplace. Many of them have worked on the ward for a number of years. When we first visited the ward in September 2002, we sensed a wait-and-see attitude in relation to the project of The Digital Hospital. The staff found it difficult to relate to the implications the project would have for them, but thought that it would be an exciting challenge.

By spring 2003 The Digital Hospital had become a more tangible concept, as the clinic had had EPF implemented, DiasNet was up and running and the booking system was being implemented. At this point we met a team that was frustrated in the efforts to fit everything into a tight work schedule. The medical outpatients' clinic is a busy workplace characterised by a good sense of humour, drive and a healthy scepticism towards new measures.

6.5 The diabetes team – as a learning team

When viewing the diabetes team in terms of the ”Learning Organisation” theory, we get the impression of a team that is ready for change and motivated for learning. They make a "strong team", professionally and socially. Prior to project start even, the team was in step in terms of visions and goals in diabetic care, and the individual professional groups in the team know each other's functions. This was an excellent starting point for the project. The DiasNet project has represented a learning process for the diabetes team. We expand on this below.

Being in step

Initially, it was essential to study how the diabetes team perceives itself as a team. To quote the diabetes team, the interdisciplinary co-operation is as follows:

> *"We have an interdisciplinary co-operation, which is probably superior to that of most places in the country. There is an open discussion and debate in the interdisciplinary team and in the clinic in general."*[52] *(consultant doctor).*

> *"It is difficult to gather the members of the diabetes team. We have plenty of issues to address… but in our experience it has been very good to meet."*[53] *(diabetes nurse I).*

> *"Our co-operation is excellent – we are in a small place where we know each other."*[54] *(dietitian).*

The diabetes team at Vendsyssel Hospital is characterised by candour and respect for each other's different abilities and aptitudes. They make good use of the fact that they work at a minor hospital with a close-knit working environment where they are close to each other's competencies. The team arranges interdisciplinary conferences. They exploit the process related to team learning to complement their individual strong and weak points, and they are more than willing to enter into a debate as they have common goals and know the people standing next to them to pursue these goals.

> *"We have an open discussion and debate...that's something I take for granted…Why, it's that very team concept that I like, the fact that we are indeed a group to run things."*[55] *(consultant doctor).*

On account of the close co-operation described above, a certain team spirit prevails in the small diabetes team that leaves you in no doubt as to whether they rally around their project.

> *"But what I'm saying right now I'm dead certain that the others think too, I don't doubt that at all… the better we understand each other's backgrounds and stuff like that, the better we can communicate and work together."*[56] *(consultant doctor).*

We have learnt something

In the course of our data collection we got the clear impression that the members of the diabetes team had been somewhat curious about and interested in joining the DiasNet project, both on an individual and on a group basis. We think that this may be explained on the grounds

[52] Interview 5D on 25 September 2002
[53] Interview 3D on 2 September 2002
[54] Interview 6D on 1 September 2002
[55] Interview 14D on 13 June 2003
[56] Ibid.

that this is an IT system that directly involves patients in the treatment, which makes good sense in the eyes of the staff. Also, the DiasNet project got off to a good start because it was first introduced in connection with a study trip to England. No doubt, this has also had a positive effect on the motivation to getting acquainted with the system, and it has been a good basis for implementing the system in practice.

> *"As diabetes team we've had a common project, and that's been instructive."*[57] *(consultant doctor).*

We had the impression that the IT skills of the staff – before the DiasNet project – ranged right from the elementary level to a more advanced level. Through interviews our observations were confirmed: That all members of the diabetes team – irrespective of preliminary IT skills – had found it easy to get familiar with the functionality of DiasNet. The staff members were instructed in the use of DiasNet in two afternoon sessions.

> *"I think that it's easy to get a quick grasp of the way of thinking. I also feel that this applies to our users – you see, they do not possess the background information that we have."*[58] *(diabetes nurse I).*

> *"I think that I'm a right "shark" at it… I find it easy to learn how to use the system."*[59] *(diabetes nurse II).*

As previously mentioned, the implementation of DiasNet took place alongside EPF and a booking system. This has caused the staff some frustration, and has at times meant that the DiasNet project did not receive full attention. Initially, the staff agreed to meet every Thursday to discuss the blood sugar values entered by the patients. The purpose of the Thursday sessions was "Team Learning". In a focus group interview with the diabetes team, however, the team "confesses" to not having been good at sticking to this weekly appointment. By means of observation we received the impression that "Team Learning" to a higher extent took place in an informal setting instead.

Enhanced professional competence of the nurses

In addition to the above analysis founded on the notions of learning, we found it natural to include the concept of competence to assess whether learning prompted a development of the above-mentioned key competencies. DiasNet opens up the possibility of "Team Learning", which is of vital importance for the use, complementation and further development of individual competencies, as well as getting closer to each other as human beings (cf. 6.2.2). The project work is therefore given high priority in the diabetes team. The doctor explains:

[57] Interview 14D on 13 June 2003
[58] Ibid.
[59] Interview 13D on 11 June 2003

"And the reason why I want to include the nurses in it, is that if they are part of scientific projects, then they'll get hooked."[60] *(consultant doctor).*

An obvious result of the DiasNet project has been the enhanced competence of the diabetes nurses in relation to diabetic patients and the prescription of insulin. Diabetes nurses have considerable experience with diabetic care and are happy about the enhanced competence. Nevertheless, the nurses point out that the precondition of enhanced competence is written guidelines. At present these are still pending in the DiasNet project. The nurses especially encountered problems when they had queries and it was not possible to consult the doctor who is part of the project, on account of holidays, etc. Other ward doctors were not familiar with DiasNet, and as a result the nurses had to wait until it was possible to consult the doctor attached to the project.

On the issue of surrendering competence to the nurses, the consultant doctor claims:

"Why, I've done that. I don't feel that I have surrendered anything, I feel that I've given them something."[61] *(consultant doctor).*
"...Then it needs to be described, doesn't it, so that we have this competence, don't you see?!? And then there is also the question of a raise, 'cause we are in fact doing the doctor's work".[62] *(diabetes nurse II).*

In connection with the DiasNet project the medical secretary was assigned with updating a project web site. The secretary found this to be an exciting challenge.

Additional changes on account of DiasNet
Having analysed the collected data from a theoretical point of view, we want to point out other areas that attracted our attention in connection with the data collection. In Chapter 5 we described the tasks and duties that the various professional groups perform in relation to diabetic patients. After 5 months' practical experience the staff members feel that the most significant change is working at the computer screen. The practical application of DiasNet has altered the ordinary problem issues related to diabetes. We elaborate this point below.

Reduced insulin requirements
This study has not aimed to report in concrete terms on the consequences that DiasNet has had for the patients and the management of their diabetes. Given the focus of this study it is thus not possible to say anything about the implications for the patients' insulin requirements.

[60] Interview 14D on 13 June 2003
[61] Ibid.
[62] Interview 13D on 11 June 2003

However, through the staff interviews we learnt that the insulin doses of several patients have been dramatically reduced, which has come as a surprise to the staff.

> *" ... The thing that most impresses me is that the "machine" has identified some patients that are given far too much insulin."*[63] *(consultant doctor).*

Closer follow up with the diabetic patients

When adjustments are made in the patients' insulin regimen, the staff members know from experience that the individual patient requires closer monitoring. The diabetes nurses state that they have better possibilities than the doctors of following up closely with the patients. The doctor thinks that the enhanced competence of the nurses is a good thing, and he suggests that this be taken into consideration in the future development process.

Diabetic counselling increased focus on carbohydrates

As outlined in Chapter 3, patients are also required to enter the carbohydrate content of their food when they enter their blood sugar values. The dietitian thinks that the "healthy eating" element became more prominent once the patients started using DiasNet. Dietary counselling used to focus on fat content and meal patterns as well as on fast acting carbohydrates. This was formerly the approach to achieving good diabetic control. On the basis of the DiasNet project, nurses and dietitian are of the opinion that the principles of counselling have changed with DiasNet. The former principles still apply, but it becomes increasingly important to give priority to the patient instruction in carbohydrate counting. According to the staff they have already started to focus more on carbohydrates in the instruction of diabetic patients outside the project.

Electronic communications between staff and patient

It is certain that DiasNet has resulted in a new way of staff-patient communications. The patients are offered a service that has not been available before and have "just about" had a nurse or doctor at their personal disposal on-line. The staff members are of the opinion that the electronic patient communications offer many advantages. It is possible to communicate irrespective of time and place. Through DiasNet the patient and staff may together view the graphical display of the blood sugar profiles. According to the staff, the system provides a good overview, but if they need to ask the patient a question, they miss his physical presence.

> *"It makes me feel rather uncomfortable that my assessment of a patient's biochemistry takes place on a computer screen, without the patient sitting next to me."*[64] *(consultant doctor).*

[63] Interview 14D on 13 June 2003
[64] Interview 14D on 13 June 2003

Email communications with the patients have predominantly been handled by the nurses and the doctor, and have primarily involved insulin adjustment. The diabetes nurses explain that they have summoned in patients in case there were major problems to discuss.

> *"It's difficult to discuss diet and exercise over the Internet. Time and again, when we have the patient next to us, also other issues related to the patient's diabetes crop up".*[65] *(consultant doctor).*

The medical secretary feels that email communications have facilitated a more direct and swifter patient contact.

Setting aside computer time

The nurses feel that it is hard to justify work at the computer screen. Clinical work is "legitimate", but screen work is yet to become an integral part of a new working culture.

> *"Nobody sees what we're actually doing at work if we're just sitting at the screen."*[66] *(diabetes nurse I).*

Furthermore, the nurses point out that the day-to-day planning of work at the clinic does not allocate time for computer work, e.g. responding to emails from patients participating in the DiasNet project.

Where to document?

The focus group interview identified a central and new concern, which emerged in regard to the possibility of patient email communications. Health professionals have a legal obligation to provide documentation for their actions and prescriptions. The diabetes team clearly expressed the need for new specifications for electronic documentation in nursing as the changed working conditions mean changed procedures and routines, whereby a centralised documentation centre is not viable. A set of guidelines is called for to govern the documentation procedure in the event of email communications between staff and patient.

> *"I don't delete my emails in order to be able to defend my actions."* [67] *(diabetes nurse II).*

Points of development

It is a development process that has been initiated. And judging from our "snapshot", it is obvious that the individual members of staff are very keen on continuing the process and gather more practical experience with DiasNet. Although some "teething problems" have

[65] Interview 12D on 11 June 2003
[66] Interview 12D on 11 June 2003
[67] Interview 13D on 11 June 2003

been overcome, the staff members give us the impression that the use of the IT programme may have transformed completely in a year or so. The present basis of experience is slender. Nevertheless, even at this stage they believe that patients who agree to pilot the DiasNet project in future may well be exempt from the compulsory 3-monthly clinical review, etc. and that diabetes nurses may possibly have PC workstations installed at home.

6.6 Summary

The objective of the effect evaluation was to study:

> ***The consequences experienced by the members of the diabetes team when diabetic patients use DiasNet:***
> - ***Are there any changes in the tasks and duties of the team as a result?***
> - ***Which challenges face the team as a result?***

Having provided a ”snapshot” impression of the consequences of DiasNet as experienced by the diabetes team, we summarise our findings in the table below:

Diabetes team	Changes in tasks and duties as a result of diabetic patients using DiasNet
Medical doctor	• A more direct patient contact – but the physical presence of the patient is missing • Ability to communicate with the patent irrespective of time and place • Enhanced knowledge about counter-regulation • The carbohydrate counting focus has gained prominence, but is not a new invention • A closer patient follow-up programme is required
Nurses	• Close monitoring of patients whose insulin doses are adjusted • Better visualisation of blood sugar profiles • New means of patient communications • Enhanced competence of the nurses (e.g. insulin prescriptions) • An increased number of work tasks • More time at the computer screen • Counselling increased focus on carbohydrates in the event of elevated blood sugar levels • New working culture (it is all-right and ”legitimate” to spend time on screen work) • Documentation of treatment • New working procedures and routines
Secretary	• More direct and swift patient communications • A higher number of IT related tasks (web site) • Secretary more visible to the patients • Stronger impression of being part of the diabetes team
Dietitian	• ”The “healthy eating” element has become more prominent” • Carbohydrates have become the focus of attention – revision of counselling practices • “We (nurse, doctor and patients) spend more time talking about carbohydrates” • Food has become a matter of more pronounced interest to all parties

In our study we also focused on an inquiry as to whether the above-mentioned key competencies were included by the professional groups in the diabetes team. Before project start we

encountered a diabetes team that was highly motivated for learning and innovation, but also met DiasNet with a healthy dose of scepticism. This was a good starting point for the project. Whether or not all four key competencies have been "shaken" we cannot say. DiasNet has **only** been used in practice for 6 months. The team has pointed out to us that they have not given the system their full attention due to the simultaneous implementation of other IT systems as well as a busy clinical workday. There is no doubt, however, that this has been a learning process for the team, who is ready and willing to continue working with DiasNet.

Chapter 7 – Diabetic patients' observations and experiences with DiasNet

7.1 Introduction

The purpose of this chapter is to study:

> ***Patient observations and experiences with DiasNet in view of their coping with a chronic disease such as diabetes.***

In continuation of the case study we have – as mentioned in Chapter 4 – chosen to apply a narrative approach to this part of the evaluation. Before presenting the patients' stories, we want to describe the criteria for patient selection and introduce our data collection techniques.

We want to point out that the identity of the patients is to remain undisclosed, and they have thus been given fictitious names to avoid recognition.

7.2 Patient selection

How did we select the three patients for our study? Before selection we had identified some criteria that the patients should comply with, viz. they should:

- Be dissimilar
- Be willing to learn something new
- Have the required resources to get acquainted with the new system
- Be prepared to give interviews
- Have type 1 diabetes
- Differ in terms of gender, age and occupation

The selection criteria were communicated to the diabetes team, who then made a shortlist of possible candidates. It turned out that it was impossible to meet all criteria, even the aim to have both men and women represented. The result was that three different men with diabetes agreed to pilot the project.

7.3 Data collection techniques

We have applied methodological triangulation in order to validate our data, and below we introduce the data collection techniques we have used.

7.3.1 Observation

In connection with the patients' introduction to DiasNet the diabetes school (cf. Chapter 3) conducted four successive Monday afternoon sessions. We were participant observers at all sessions. The purpose of observation was to acquire a basic understanding of DiasNet, and to experience the system in use between staff and patient. What issues were included in the patient training programme? Which questions did the patients ask? How was the interaction be-

tween the diabetes team and the patients, etc.? We prepared observation notes, which are available to ASB only. These notes were used in the ongoing data analysis process. Appendix 8 contains the observation guide.

7.3.2 Diaries

In connection with the diabetes school the patients were asked to keep a diary (cf. Appendix 11) during the DiasNet project period. The diaries were intended primarily as a tool to share the thoughts, considerations and experiences of the individual patients in the course of the project. The patients were requested to make the diary entries on their own PC in a word-processing programme. It was never the intention that the patients should make daily entries, but only when they felt that they had something on their mind, had experienced something new in relation to their diabetes, or when they felt that they had been through a difficult situation. Finally, the diary entries were meant to be included in the general data collection and analysis.

The patients were positive about contributing, and at midway-evaluation we received diary entries from two of the patients. However, the patients complained that it was too time-consuming to keep a diary and it was therefore agreed to discontinue the activity.

7.3.3 Qualitative interviews

We conducted two rounds of patient interviews. Before the patients had seen DiasNet in practice, we conducted qualitative patient interviews. The purpose of this preliminary round of interviews was:

- To get acquainted with the patients.
- To acquire knowledge of how the patients are coping with diabetes in everyday life.
- To map the IT skills of the patients.
- To identify the patients' expectations in regard to DiasNet.

The interviews were conducted on the basis of semi-structured interview guides (cf. Appendix 9), and lasted 1.5 hours each. The interviews were transcribed to facilitate data management.

7.3.4 Narrative interviews

When the patients had been using DiasNet for six months, we conducted our round of narrative interviews. The purpose of these interviews was:

- "Capturing" the patients' account of the way they experience their everyday life when using DiasNet as a diabetic management tool.
- Studying how patients learn disease management by means of DiasNet.
- Bringing into focus the implications of DiasNet for the individual patient's diabetes and quality of life (physical, mental and social dimensions).

The narrative interviews lasted 1.5 hours each and were transcribed. We used open interview guides (cf. Appendix 10), and thus let the patients set the ”agenda” for what they thought essential to impart to us.

The narrative interviews were not intended for analysis in relation to a theoretical frame of reference. Rather, we encouraged the patients to ”speak their minds” in terms of observations and experiences. But no story without a storyteller, no matter which kind of story, and no matter which media in which it is told. As a result, we chose to interview the patients on the basis of very open interview guides, letting the patients control what to include in their personal narrative of experiences and observations with DiasNet.

Our role – as evaluators – is to pass on these patient experiences and observations. In the presentation of the stories we seek similarities, connecting aspects and dissimilarities in order to differentiate and compare the three patients' personal narratives. Needless to say, in our capacity as ”storytellers” we have favoured some stories over others. In this respect, our pre-understanding (cf. Chapter 4) has guided our story selection.

7.4 Observations and experiences of diabetic patients with DiasNet

First, we will introduce the individual patients who have participated in the project. The introduction is based on data collected in the preliminary round of qualitative interviews. After introduction – through the narrative interview approach – follow the individual patients' accounts of how they have experienced DiasNet as part of their everyday lives. We will include quotations from the individual interviews to make these accounts more vivid. For the purpose of this report, we have translated the patient quotations into English.

7.4.1 Introduction of Per[68]

Per is 57 years old and has suffered from type 1 diabetes since 1972. Per used to work as a driver, but due to his impaired vision he was forced to change occupation, and today he works as a technician.

Getting diabetes

Per was 25 years old when he was diagnosed with diabetes. He had just become a husband and a father. He explains how difficult it was to get the diagnosis:

> *”...I had no idea of what it was…. It was tough, and I recall that I wasn't admitted to hospital. That was the big mistake they made. 'Cause you have to learn what it's all about…I didn't feel like going into hospital, 'cause I had a job to do”.*

[68] Interview 10D on 28 February 2003

Per adds that after six months he could not hold it together any longer. He was admitted to hospital and learnt about diabetes. He was constantly hungry during the first couple of years of his diabetes:

> *"It was incredible what you'd find in my lunch box. There was near-raw leek, no it was boiled leek – just to get something down me. I'd be away for 14 or 15 hours. Bread was weighed out then… It wasn't much we were allowed then. It was a strict diet".*

Complications

Per has previously undergone balloon angioplasty and two bypass operations. He has had herpes on his left eye for 27 years. He moans:

> *" And it keeps breaking out all the time. Sometimes, why 12 to 15 times a year at least. I've hardly any vision left on my left eye".*

Per explains that he has good vision on his right eye and is therefore still able to drive a car.

Diabetes and family

Per is married with three grown children. His wife is a catering officer. The rest of the family has always eaten the same food as Per. His wife does the cooking and the family has benefited from the fact that she is accustomed to dietary considerations at work, and at the same time she has always been interested in diabetes. Per's wife knows him so well that she knows when his blood sugar level is too low.

> *"Well, I can't feel it, only when it's really low. I think my wife's able to feel it before I do. It happens quite often that she goes, "Hey, you need to test your blood sugar, don't you"".*

Work and diabetes

Per worked for a firm of haulage contractors for many years, and he felt that he had a hard time at work.

> *"Now, I haven't changed work a lot, 'cause I didn't want them to think that I couldn't manage … I always felt that I had to put in 50% more at work than the others, so they wouldn't think that I was sick".*

When Per turned 38, he could not cope any more, "mentally". He worked extensive hours and spent a lot of time away from the family. The family decided to move to another town and start a new life.

"We had to try something else. And mentally I was very wild. And I believe that had something to do with the diabetes ... a feeling of inadequacy ... I even had a guilty conscience when I had to ask for time off to see the doctor".

The family relocated and Per got a new job. Now he no longer felt that it was a problem to see the doctor during work hours, because his workplace took a more sympathetic view of the need for the clinical monitoring of his diabetes. Today, Per still has the same job and is content. A technician's job is very varied work, although it may also be very physically demanding at times. Per works both day shifts and evening shifts in his current job.

Managing diabetes

Per realises that he is not always managing his diabetes as well as he could. He knows that he is more attentive of the disease when he is due for a review:

"It does me good to have my ears pulled every now and again. I can feel that I take better care of myself 14 days before and 14 days after my check-up."

His blood sugar can drop to a very low level before he notices it, and especially in situations when he is under pressure it may drop to an extreme low level. When he knows there is a stressful late shift ahead at work, he injects a little less insulin.

"When you've had diabetes for as long as I have, then you're fully capable of making your own adjustments".

For a number of years, Per has visited the medical outpatients' clinic for reviews. He tells us that he checks his blood sugar 2 or 3 times a day. Also, he always does a test before driving his car, exactly because he finds it difficult to sense the warning signs of a hypo. Per feels that living with diabetes is easier nowadays, given all the technical aids available.

Physical exercise

Per goes swimming at the public swimming baths, but has otherwise never taken regular exercise.

Per and IT

Per uses a computer at work to receive and send emails only. Per has great expectations in regard to DiasNet and is very keen to support projects that may help improve diabetic patient care.

Having introduced Per, we will now let Per give a personal account of his observations and experiences with DiasNet. Except for linking the narratives together with a few words, we will allow them to speak for themselves.

7.4.2 Experiences and stories told by Per[69]

Per has been highly motivated for joining the project. He has been aware of his rather poor IT skills, but was not discouraged from participating in the project. When we met Per for an interview six months after project start, his immediate reaction was one of happiness to have piloted the project. He had just been admitted to another hospital for eye surgery. He reports:

I couldn't use my laptop at the other hospital

> *"I'd brought my laptop, but they didn't have Internet access down there. I was a bit upset by that. I'd have liked to show them the [DiasNet] programme down there, 'cause they do have computers. The staff had no idea what so ever there was something by that name. But it was an eye ward, so I told them a bit about my participation in this project. I also told them that I was so happy to be part of it. But I wonder why… I didn't get to talk to anyone who knew about it. I told them that I believed it was better for me to get regulated when returning to my own hospital. The staff on the eye ward wanted to call a diabetes specialist to regulate my diabetes. And there was no way he could do that in two days anyway. No way. It would be far better for me to come home and write it all down, make data entries on the computer and then talk it over with the staff here [at [Vendsyssel Hospital, Frederikshavn]. And that's what I've done. My diabetes is now OK again!"*

At our meeting with Per he was clearly disappointed to have been unable to use DiasNet at the other hospital. It is part of the story that Per in connection with the eye operation had received hormone treatment, which had caused an imbalance in his blood sugar values. It was therefore necessary for Per to get help to gain renewed control of his blood sugar values. Per turned to the medical outpatients' clinic and in co-operation with a diabetes nurse his diabetes was quickly regulated. Per firmly believes that the reason why the control of his diabetes was re-established so quickly was that DiasNet made it easy for the nurse to get a general overview of his blood sugar values, and on this basis she was able to offer advice and counselling in regard to an insulin dose adjustment.

The new facility that enables patients and the diabetes team to communicate by way of emails has made Per feel safer than before. As mentioned in Chapter 3, each of the patients had been assigned a specific contact to whom they could send emails, but all professional groups in the diabetes team may be approached.

[69] Interview 19D on 11 August 2003

I feel safe being able to email the hospital

> *"I've been incredibly happy to be able to send mails. I use it like when there's something I'm a bit uncertain about, and then I send a message to the doctor if he'd take a look at it. Then I get a reply back. I think that it's really good this system, and I feel very safe using it. You see, it's easier for me to get a picture of my blood sugar values for three or four days. 'Cause then you'd probably need a little less here and a little more there – that's how I use the system a lot. I feel safe being able to email the hospital just like that. It's much easier in the sense that I can just write something or other in the mail, and then they can go in and see how my blood sugar levels are. I feel that they're sitting opposite me when I'm sitting at my screen at home. You see, I transmit it to them, and they review it, so that's a fine rapport. I actually feel that I'm close to them when I have them this way. You'd think that with a computer it could become all impersonal in some ways? I don't feel that's the case at all, and not at all the way we communicate together, "Hello Per", is the doctor's greeting, it's really nice and easy-going, so I appreciate that."*

Besides a feeling of greater safety, Per explains that he has become better acquainted with the entire diabetes team.

I've become confident about the entire diabetes team

> *"I've grown so fond of [the diabetes team], 'cause I've had the chance to get to know them. I've always been one to find it a bit awkward with new people. I'm usually always a bit on my guard and sceptical, but I haven't been like that in this place. Now, I only knew one of the nurses in advance, so I trusted her. I didn't trust anyone else. After getting to know them all, I've become just as confident about them, and that's great. I'm probably what you'd call a difficult patient".*

In Chapter 3 we described how patients and staff make practical use of DiasNet. At the diabetes school the patients and the diabetes team have agreed on home glucose testing three days a week. The test results are to be entered into DiasNet, and once a week the staff will review the data and report back to the patients. However, the question remains which concrete implications the use of DiasNet has had for Per?

I feel better – now that I can control my diabetes

> *"Actually, I feel fine – both physically and mentally I also feel better. Whether this is thanks to some of my clean conscience in regard to control and managing, I don't know. Actually, I've had a really good summer. I believe that the true perspective of this programme is that you're able to cope much better on your own. It's become easier, but*

again it's got something to do with self-control. It's hard to say what happens to us. I for my part really don't like to see figures that look lousy. I'd hate to do without the programme, 'cause I'm happy to be part of this. I feel that I'm able to control my diabetes. The future lies in this way of doing things. Why all these constant reviews, if it can be done this way and at the same time help people to achieve improved blood sugar. I'm very positive about it".

On his perception of enhanced self-control Per claims:

I've become my own watchdog

"I probably give it a bit more thought. I'm not as sloppy as I used to be. I try to get some reasonable figures, and that's also best for me too. But it's not enough, 'cause in the past I just wanted to have some reasonable figures before I was going for check-up. Then the doctor was pleased, but you see it's also quite nice to feel fit for your own sake and not just for his sake. I reckon that's the way many diabetics have been reasoning. I keep checking up on it a lot, and especially right now, I have to, 'cause I'm on [hormone] medication. But I feel that I've improved the control of my blood sugar values. At this point I'm able to go in and make a minor change, and I know almost immediately what's wrong. It's probably a bit hard to explain, but I've become my own watchdog. In the past, when going for check-ups, I was careful during the three weeks before the review – now it had to be sorted out. And I think many people are doing just like that".

As outlined in the chapter on DiasNet, the patient is required to enter the carbohydrate content of every meal or snack. That means that the patients need to refocus on their diets. Per experienced this change of focus as follows:

I regulate the blood sugar by diet

"I regulate the blood sugar when I've tested it so as to avoid major fluctuations. 'Cause you're able to feel that almost right away. But it's just as much by diet as by insulin. If the blood sugar has reached a level of some 10-12 mmol/L, and you eat something wrong, then it soars, of course. Then we eat some more greens that day so that I can keep it down there. I can't help it, I can actually regulate almost as much through what I eat, if I just have the backbone to do it. It's easier to take some more insulin and then eat some good food. But the effect is really better [by diet]."

Per tells us about some of his experiences:

I use DiasNet for half an hour every evening

> *"I still test my blood sugar values at work every single day, but it's something I've been doing in recent years, 'cause I'm unable to sense my blood sugar level. I mostly use DiasNet from home. I've hardly got time for it at work. I use the system for half an hour every evening. I always do home glucose tests three times a week. Morning, noon, evening and night, and I keep a record. For the rest of the week I also test my blood sugar levels, but without writing them down. Through force of habit I test my blood sugar when I'm about to eat. I test my blood sugar often, and it's become a habit, so it doesn't bother me. But usually I don't test my blood sugar some 8-10 times a day seven days a week – like I do at the moment. And the level is indeed also tolerably good right now. Perhaps a bit too low. 'Cause when my blood sugar level was elevated, I often grew tired, I felt that, and when it fluctuated, I was irritable too, if it fluctuated a lot. I feel better when it's at a tolerably good level."*

Not only Per uses DiasNet. Per's wife is also interested in the system.

I appreciate the fact that my wife also uses the system

> *"My wife thinks that it's reassuring that my blood sugar is at a lower level. I've often experienced considerable fluctuations. In fact, she often comes and takes a look at DiasNet on the screen. She's able to see the advantages of the system now. She's probably going through the same as I did at first, that she can't really understand it. But she's always been really into my diabetes and been an enormous help. It's just as well that she can't hear me right now, 'cause I don't want her to hear all these compliments. My wife has been so very helpful – I think that you may easily get sick and tired of it all. But I for one am very happy that I have become part of this".*

There is no doubt that Per has learnt many new lessons with DiasNet in relation to his diabetes. But how did he like using DiasNet? As previously mentioned, Per hardly made use of IT facilities prior to this project.

It took some time to get to know the system

> *"It took me a long time to get started on the PC. You see, I didn't have the programme for the first couple of months. That meant that I lagged behind a bit right from the start. But I do believe that I've caught up now. I've mostly relied on myself and found out things for myself. And I've been talking to a diabetes nurse. That's the way it is when us old fogies join in".*

Per goes on to state:

Now we use the Internet

> *"And now we also send emails to friends and acquaintances every now and again. It's not a great deal, but perhaps once a week. Incidentally, my wife's also started to use it a bit. When there's something she wants to see on the Internet, then she also connects to it – I've taught her that. And she never used to be particularly keen on it before".*

The patients have been instructed in the practical use of DiasNet at the diabetes school. In this context it was possible to practice using the system in the way that they - from the first session on – were asked to enter their own blood sugar values. Per comments as follows:

I needed more training

> *"Well, I've learnt what to do by now, but I could probably have done with some more training. But it's also because men of my year are not so familiar with programmes and PCs. 'Cause young people really pick up much faster on that kind of thing. Had I only been ten years older, then I'd have needed much more training. But I've used it quite a lot at work, but the programmes we have there are some easy ones. As far as the diabetes school is concerned, it's done me good to be reminded of the essentials of treating diabetes through insulin and diet – especially diet. Well, and about this diet thing, you need to have somebody pull your ears once in a while. Simulation programmes I would like to use a bit more. I've tried to use it, and it's actually correct what insulin doses it then predicts that you should have. It also corresponds to my impression of it".*

Per has gathered considerable experience with DiasNet. And on the issue of his future use of DiasNet as a tool he claims:

DiasNet is the future

> *"I believe the future lies in providing newly diagnosed diabetics with this option of diabetic control. Had I been 20 years old and had just developed diabetes, then I really think that my life with diabetes had been made easier. It's got something to do with learning to understand [DiasNet and counter-regulation], and to my mind that's something you learn a great deal from, even though I've had it for so many years. And it's also very useful to me. You may well set up oceans of educational programmes, but I don't think that will get people interested to the same extent. In this way you yourself are involved and close to it, and I reckon that's much better. And I also think that people with new onset diabetes as the very first step should try to take a look at the programme so they can see what happens to their blood sugar. That would be terrific for them".*

Below we will introduce Jens.

7.4.3 Introduction of Jens[70]

Jens is 45 years old and has had type 1 diabetes since 1991. For many years he has been working in an IT department, which he has helped build from nothing, and despite his young age he has celebrated his 25th anniversary at work.

Jens was admitted a few hours after his GP made the diagnosis. The first couple of days he spent reading and learning as much as possible about diabetes, and when he somehow realised that this disease was a chronic disease, he focused a great deal on the things that were no longer possible as a result, but as he also realised that this was a life-long condition, he was, in step with new knowledge and experience, able to turn this attitude into something more positive, as diabetes is "the healthiest disease in the world", and he quickly acknowledged his share of responsibility for his diabetic care.

> *"Today I can't see any limitations I can't live with, but of course your planning has to take into account your diabetes at all times, making sure that you have insulin, food and measurement tools available, but gradually that just happens automatically."*

For the first couple of years, Jens indeed lived "by the book"; constantly testing his blood sugar and adhering to a strict diet with meticulously portioned meals. Bearing in mind that this was a learning phase, many things still seemed a nuisance, e.g. restaurant visits, or having dinner at the homes of friends and relatives.

Getting diabetes

> *"Today I don't feel that's a problem. When I go to a restaurant, I just inject through my clothes, when the food is served."*

> *"What I find most annoying about having diabetes today is that I have to go to the GP and the police station to have my driver's license renewed every 2 years."*

Diabetic complications

Jens has developed no complications on account of his diabetes, but also admits that he has made sure to make regular visits to a podiatrist, eye specialist, etc.

[70] Interview 9D on 3 February 2003

Diabetes and family
Jens is married with two daughters. He characterises his family as very understanding and patient in regard to the fact that he has diabetes.

> *"As I'm the one doing the cooking at home, the change of diet was very easy."*

Work and diabetes
Working in an IT department may sometimes be stressful. Jens likes his job and thinks that his workplace shows great flexibility in view of the fact that he has diabetes.

> *"…I'm so lucky that my boss' wife is also a diabetic. And we talk about diabetes a lot, and exchange experiences… When I'm going for a hospital check-up I'm free to go just like that, everybody understands, even my colleagues."*

Managing diabetes
Jens accepted his disease early on, but will not let diabetes run his life. He believes that his diabetes is reasonably well controlled, albeit he points out the following problems:

> *"At the clinical reviews most of it has looked fine, but it's caused us some trouble to lower the long-term blood sugar. It's higher than we'd like it to be. And a couple of years ago, my cholesterol count started going the wrong direction… My blood sugar is nearly always high in the morning, no matter what the test has shown the evening before… In this respect I can profit from DiasNet by gaining control of my blood sugar at night".*

At times he has failed to do daily blood sugar tests, because he was not confident that they rendered a true picture, and instead he attached greater importance to the long-term blood sugar levels. He thinks that it is difficult to regulate his blood sugar when he is under pressure. Often when he gets the warning signs of a hypo, he makes sure to get something to eat. He is careful to space out his meals, but sometimes it is somewhat inconsistent with work.

When Jens' blood sugar levels have been elevated for 2 or 3 successive days, he turns rather nearsighted.

> *"And then I know the score… I've been living "too good a life", and then it's back to testing by the book for 3 or 4 days, until my vision returns to normal. That's a fine indicator to have."*

Physical exercise
Jens does not exercise regularly. He goes swimming once a week and takes the family dog for daily walks.

Jens and IT

By virtue of his job in an IT department Jens is an old hand at IT, and he warmly welcomes the DiasNet project. On a previous occasion he tried to get some line of communication started with the doctor at the clinic, but as he only had a private email address at that point and also had a full workload, nothing ever really came of it. Jens has great expectations in regard to the DiasNet project.

7.4.4 Experiences and stories told by Jens[71]

Our meeting with Jens for the purpose of hearing about his observations and experiences with DiasNet was characterised by his immediate positive attitude. Having used the system even for a very short time only, Jens had already witnessed results, as it was suggested at the diabetes school that he should try to reduce his insulin dose. Jens gives the following account:

My insulin dose is almost diminished by one half

> *"I was on 32 units of long-acting insulin, when we started, and now I'm on 18 units. So that's almost diminishing it by one half. And I was on 28 units or so of short-acting insulin a day, and now I'm down to about 12 to 14 units. So that's a lot, but it's also because I eat less now when everything goes on record, but I feel fine. Of course, it can be a bit of a bother to do so many glucose tests a day. I really feel good, and I think it's OK. It's a nuisance to have to do tests three days in a row. My head's like this that once I get started on these tests, then I begin to live accordingly, really deliberately like. That's why I think it can be somewhat a strain, but anyhow… I do the tests three days a week without fail".*

Jens has been reduced significantly in insulin, and compared to his appearance at our first meeting we can tell that he has lost considerable weight. About his weight loss he explains:

I've lost 12-14 kg – and now I exercise regularly

> *"I've lost a lot of weight. I've lost something in the neighbourhood of 12-14 kilos, and of course I've been well pleased with that. But now we are getting to the point when I'd prefer it to stop. You don't want to end up a stick insect either. That has of course also helped weaken the insulin seizures. But there are also other things that have made an impression on me – especially Richard gave me some inspiration to exercise a bit more. Actually, I used to think that I was getting my fair share of exercise, but as a matter of fact I've changed my routines and now exercise regularly three times a week and go for a short run in the woods. I can feel the effect immediately after such a run, so in the evening I can suddenly allow myself a bit more. Then I have to eat a little extra, or else I lose more weight."*

[71] Interview 18D on 11 August 2003

In short, Jens has started to exercise on a more regular basis, and has been inspired by Richard, whom he met at the diabetes school. Jens continues:

> *"I feel very privileged to have participated in the DiasNet project. And I feel that we've gotten to know [the other patients and the staff] better."*

However, the question is how Jens has experienced using DiasNet as part of his everyday life?

I lead two separate lives

> *"Obviously, it can be tough with all this focus on diabetes, but you see it's on the basis of the reported data that we may improve the insulin treatment. But I'm inclined to think that the pattern remains more or less the same week after week. So right now I feel a bit like I lead two separate lives. The three days with focus on blood sugar figures and carbohydrates, and then the four days when you live a more ordinary life. And those four days; Well, I might as well be honest and confess that you're in no way likely to be tempted or anything when you only allow yourself to live within such a narrow margin. If you start to open up a little…why, then there're the weekends, you eat all differently then. On weekdays I usually have half a slice of rye bread in the morning. I wouldn't dream of starting my day like that during weekends when it's my time off. The weekend pattern is slightly different. But that's no good either; I should perhaps try to test during weekends. I sometimes do some tests to check things out".*

Due to the safety risk Jens is not allowed to install DiasNet on his home computer, as it connects to the computer network of his workplace. As a result, he always runs DiasNet at work.

I'm not able to view DiasNet at home

> *"I'm not able to use DiasNet from home, 'cause I'm online with the PC network at work, so I have to resort to a bag of tricks at work to circumvent our Firewall in order to access DiasNet. It means that there's little time left for anything but data entries in DiasNet, and then only a few simulations. I usually check the graphics and then I send an email."*

On account of the technical difficulties Jens explains that he has not had the opportunity to experiment with DiasNet. Still, he has tried to use the simulation function of the programme (cf. Chapter 3). But he has not tried to make his own insulin dose adjustments. Jens complains that he continues to have problems with his nocturnal blood sugar.

I still don't know for sure if I have hypos at night

> *"Actually, I don't know for sure if I have hypos every night, but there are signs to that effect. On the rare occasions that I've done a test at night, my blood sugar level had dropped compared to the value measured before bed. In the morning it's gone up again. I've tried to go to bed with results ranging from 3.5 to 11 or 12 mmol/L. I can't handle to do 2 tests a night 3 days in a row – I'm a sound sleeper."*

Jens carries on talking about DiasNet and the necessity of planning the home glucose testing:

It's a nuisance to do these frequent blood sugar tests

> *"Everyday life is different – more of a nuisance on the days when I test my blood sugar. 'Cause besides concentrating on work I also have to concentrate on tests, what I eat and test results. I can't help reacting. So I have to do some planning, or else I miss out on too many tests".*

Even if Jens thinks that it may at times be inconvenient to test his blood sugar, he explains that he was raised to always be the active part.

On the option of ongoing email communications with the staff Jens states:

I've established a closer relationship with the staff and get a quicker response

> *"I'm a middle-of-the-road sort of guy, and I think that applies to the tests too. I think that's my nature. I know deep down that this is every three months, and I'm just as interested in getting it down, 'cause I'd be terribly upset if I should for instance get some of the complications, such as blindness or something with the kidneys. Of course that scares me. You have to try to do the best you can, so that you won't have to say, "You should have done this and that then"... But it's because you make an agreement that from now on you do it three days in a row. When we did it in the little book, we weren't in contact with the hospital until three months later. So, in principle, we could really live it up for two and a half months and then, the last 14 days, we could just put something together to show at the clinic. That's probably also the reason why people call it a telltale. [With DiasNet] it happens weekly, and you get a response on the things you adjust upwards or downwards, 'cause it's been over a long period of time when we've reached this and that by minor adjustments, and we haven't finished yet. Last week in the mornings we tried to reduce the insulin a little despite high blood sugar values. That's what I like about it, that you get an immediate response. Traditionally, you come to the clinic having been away for three months, and you're rather excited to see how the long-term blood sugar is. You nod and agree that it doesn't look too good, and then*

it's back to your normal routine for 3 months before you focus on it again. So it goes without saying that it makes a difference".

Jens tells us that when sending emails to the staff he always includes a brief commentary offering his explanation as to why the blood sugar values are what they are. In connection with DiasNet carbohydrate counting is demanded of the patients in the course of the day. How does Jens experience this?

Carbohydrate counting is easy - it gives you a little freedom

"Why, that's how I feel, it's somehow become easier. In the past they were really into this system of portioning everything, and then all of sudden they started saying that even when we eat all the good things, then it also makes a difference if it's fast or slow. It was starting to get a bit complicated then. You become rather tired of having to give it so much thought. But when we in fact only look at the carbohydrate content – then it doesn't matter if it's ice cream or four slices of rye bread, I find that easy. And when at the same time you're able to find out that if you eat so and so many carbohydrates, then you have to take this as well. Well, that also gives you a little freedom, when you're in a strange place then you'll have to take a guess and then take insulin accordingly".

In Chapter 3 we described how DiasNet was introduced to the patients. Jens is of the opinion that it was a good idea to start with the diabetes school, because it helped brush up his general knowledge about diabetes. He says:

DiasNet cannot stand alone

"In my opinion it was a good idea for us to start with four days at the diabetes school. First of all, we got better acquainted; at the same time our knowledge of diabetes was brought up to date. About this idea of starting with the computer programme – it must never stand alone. The entire diabetes team was involved with small lectures on various diabetic issues, and Ole from the university gave a good introduction to DiasNet. Twelve years ago, when I was here at the same hospital, you learnt how to portion your meals. It's true that one tries to keep up with all the new trends and developments, but it was really good to go through it again… I think I wouldn't dare to do a lot of stuff of my own accord."

Having used DiasNet for six months, Jens describes the system as follows:

I see DiasNet as a reporting system

> *"I still see it as a reporting system, and I spend a couple of minutes trying to see what does it actually look like? Do the graphs follow each other nicely? And as long as they do, it's actually OK. Should I do what the computer suggests, then I'd have to do them every day, take something up, when I go down, then try to go in there and see what [the programme] has predicted. If you've taken insulin five times a day, for instance, 'cause you want to reduce it, then it also makes suggestions that nearly always correspond with 5 times a day. I've not been able to make any use of that. It's helped me a bit, I stick to the long-acting insulin, and then I've always been able to do the simulation. And then I can see, okay, this is where it thinks I should take some more, in fact at an hour when I don't eat so much."*

After Jens has gathered some experience with the system, he finds the clinical reviews every 3 months superfluous:

Do away with the 3-monthly clinical reviews

> *"I'd like to give something in return 'cause the doctors spend a little time on us on a regular basis. Those 3-monthly reviews, those we could maybe cut down to just one visit where we actually take stock. I think that would be absolutely sensible, that would free some time for the staff also – sometimes you feel that [3-monthly reviews] are a bit ridiculous. I have to wave goodbye to almost an hour and a half every time I have to come here, just for a 5-minute chat. And often we get to talk at cross-purposes. I'm weighed a little, and all the stuff you could easily do yourself ... But if we're able to do our bit, by electronic means, to get a better day-to-day tool, and save doctor and nurse resources to boot, then everybody wins".*

On his project participation Jens says:

New focus on diabetes has paid off

> *"It's been incredibly exciting to be part of such a project, 'cause you've been given something tangible, and I feel much better".*

Jens's final remark is as follows:

All diabetics should be offered this facility

> *"But I hope that all diabetics will be offered this facility – imagine the perspectives! On the other hand, I realise, of course, that some will pass it up, primarily because of the electronic medium."*

Below follows an introduction of Richard.

7.4.5 Introduction of Richard[72]

Richard is 51 years old and has suffered from type 1 diabetes since 1977. His daily job is with a football club as manager. He used to be an athlete in the top class.

Getting diabetes

Richard developed diabetes at the age of 25. He did not find it difficult to come to terms with the fact that he had become a diabetic.

> *"Obviously – I had to get up in the morning and take insulin … but I don't feel that it was a burden to have diabetes… I don't think about it."*

At one point he found it rather difficult to satisfy his hunger, as his diet was very strict and Richard was a very active athlete still.

> *"I felt hungry all the time… It's become somewhat easier since the short-acting insulin became available."*

Complications

Richard has developed no complications and in his own opinion his diabetes has always been very well controlled.

Diabetes and family

Richard is married with two grown sons. Richard tells us that his wife has been behind him all the way. The whole family has eaten the same food. Although his wife sometimes bakes an ordinary cake, cakes and sweets do not tempt Richard at all.

> *"And that's why I'm so fortunate to have a wife, who… well, she's just been so great about all this".*

Diabetes and work

Prior to his job at the football club, Richard worked at a shipyard. His former job could be physically demanding, just like his current job – e.g. Richard is responsible for marking foot-

[72] Interview 8D on 28 February 2003

ball fields several times a week and easily walks 6 or 7 km each time. His current work means that he works both days and evenings, but with a high degree of freedom. He plans his own work routines and is therefore spared the problems of fitting hospital visits into his work schedule. Richard likes his job.

Managing diabetes
Richard made no changes in his life-style after he was diagnosed with diabetes. However, in connection with his football some changes had to be made.

> *"When I played a match back then, I would eat 2 or 3 lumps of sugar. But today I take less insulin, and then perhaps 8-9-10 lumps of sugar ... but I've managed to sort that out. It's fine now."*

Richard only started to come in for reviews at the medical outpatients' clinic four years ago. He had gone into insulin shock and had been admitted to hospital. Following his admission he started to visit the clinic regularly:

> *"If I had some physical work, I would be low on carbohydrates for a very long time afterwards. My wife had to wake me up several times at night… but fortunately I've sorted that out by going to the clinic".*

According to Richard, his current problem is with his nocturnal blood sugar. He checks his blood sugar before bed and before going out to mark fields.

> *"If you go out in the fields by yourself, then it's no good if your blood sugar is too low".*

Physical exercise
He used to play football in the top league, but now it is down to a weekly match on Saturdays.

As mentioned previously, Richard gets a great deal of exercise in connection with his daily work.

Richard and IT
At the clubhouse Richard controls the clubhouse heating and electricity by means of a PC. In addition, he plays patience and accesses the football club's homepage. He does not use IT in his everyday life, and he does nothing to hide his lack of interest in IT. His family has a computer at the house, and his wife uses it to find recipes on the Internet and on the web site of the diabetes association.

7.4.6 Experiences and stories told by Richard[73]

At project start Richard had no expectations in regard to DiasNet, but – being local – he was nevertheless excited about getting introduced to the system. Already at the very first session at the diabetes school his insulin dose was reduced. At the second training session he announced that he felt really great. This rubbed off on the other diabetic patients to the effect that Richard helped imbue the class with some ”sporting spirit”. When meeting Richard after he had gathered some experience with the system, we were told that his insulin had been reduced further, and that he felt fine. However, it had taken some time for the technical side of things to be sorted out, so that he had been a little delayed in getting started on the system. That is, Richard was not able to use the system until May. On the issue of using DiasNet Richard says:

I’ve made data entries twice

> *”Within the latest five or six weeks I’ve transmitted blood sugar values twice… I wrote when [my contact] went on holiday…Well, there are a number of things…. You sometimes get uncertain about things, and I know, of course, that I may just phone the clinic. Well, the possibility exists. I’m optimistic, I believe it’ll improve”.*

In regard to managing his diabetes by means of DiasNet Richard explains:

After all, I’m the one in charge

> *”Well, it’s all very good and dandy, I can watch and know how it’ll react, but after all, I’m the one in charge, but that’s fine by me. I can try to see how it changes by eating some more and taking some less insulin or some more insulin”.*

In Richard’s opinion, DiasNet, as opposed to the traditional 3-monthly reviews, helps him monitor his blood sugar values more closely.

DiasNet enables better control

> *”In the past, you see, you went to your own GP and had your blood sugar tested or to the clinic every 3 months. That way you have to keep yourself in order, and that’s of course all very fine. But then the day after, then you don’t have to at all, and then you’re back to square one. Previously I was the one to keep an eye on myself”.*

[73] Interview 17D on 12 August 2003

As explained in Chapter 3, the theory behind DiasNet is based on counter-regulation. Richard believes that his understanding of this concept has improved:

I've got a better understanding of counter-regulations

> *"Yes, but also with the effect of insulin… if it's been either too high or too low, then counter-regulations set in. I've got a better understanding of this now".*

In connection with his nocturnal low blood sugar Richard has not used DiasNet to get an overview of his blood sugar values. Nevertheless, he claims:

The tool helps me feel better

> *"Yes. I believe that with this tool I feel better."*

As mentioned, Richard has a physically demanding job. And when using DiasNet he finds that the system has its shortcomings. He says:

The programme does not allow for physical activity

> *"Well, it's a really great system and all. I also think that when you can [do simulations] like that, then the physical [dimension] is not taken into account. You have to learn to make reservations in this respect. I find that when I've done some hard physical work, then [the system] is way off".*

Richard's final remark is that he intends to make some more use of the system.

I need to practice some more

> *"I made an entry last Sunday, and then I'd suddenly forgotten something, and had to start from the beginning again. But that's got something to do with "practice makes perfect" and all that. But I'm OK with it, really".*

7.5 Conclusive remarks

The purpose of the effect evaluation in relation to the patient perspective was to study:

> ***Patient observations and experiences with DiasNet in view of their coping with a chronic disease such as diabetes.***

At this point, we want to summarise what the patients feel they have gained from their project participation. Subsequently, Chapter 8 contains a conclusion where we compare the findings

of Chapters 7 and 8 and single out the unique and typical characteristics of this case study of DiasNet, the diabetes team and patients.

In our first round of patient interviews we were given the impression that the three candidates were very dissimilar, which was also our stated target in the patient selection process. All three had had diabetes for more than 12 years, and were working in totally different lines of business. Before the patients embarked on the project, they felt that they had ”a good grip” of their diabetes. Common to them all was a good base of support and understanding, both at home and work, in regard to their diabetes. Although at project start, the IT qualifications of the patients differed considerably, this held none of them back when they threw themselves at DiasNet. In the table below we have summarised the patients’ experiences with DiasNet:

Diabetic patient	Patient experiences with DiasNet
Per	• Greater well-being • Diminished insulin dose • Unable to run DiasNet at another hospital • Feels safe about emailing to the diabetes team • Enhanced trust and closer contact with the diabetes team • Improved diabetes self-management – experiences better self-control • Increased awareness of carbohydrates in regard to blood sugar regulation • Makes extensive use of IT, e.g. the Internet • Enhanced knowledge of blood sugar values • DiasNet is a good tool • Learnt from the other patients
Jens	• Greater well-being • Insulin dose diminished by one half • Weight loss of 12-14 kg. • Learnt from the other diabetes school attendants • Closer contact with the diabetes team • Emails facilitate quicker responses from the staff • ”Leads two lives” – when testing blood sugar for DiasNet and when not • Better knowledge of counter-regulation, diet, etc. • Improved insight into the correlations between diet, exercise and blood sugar values • Carbohydrate counting provides certain freedom • 3-monthly reviews unnecessary • Improved diabetes control • Got to know the other patients and was inspired by them
Richard	• Greater well-being • Diminished insulin dose • Better knowledge of counter-regulations • Improved diabetes control • DiasNet has difficulties “handling” physical activity • Emails provide better rapport with diabetes team

In co-operation with the diabetes team all three patients have had their insulin regimen adjusted. As only three patients have piloted this development project, however, it is impossible to make any valid deductions in terms of insulin adjustments in connection with DiasNet.

The possibility of communicating with the staff by way of email was a positive experience to the patients. They feel that they know the staff better, and that the rapport with the diabetes team has become more personal.

The three patients perceive that the system and the diabetes school training programme have empowered them to better disease self-management. In other words, DiasNet helps to make the patient feel more responsible in regard to his disease, because his knowledge of it is enhanced.

The patients think that it was easy to get acquainted with the system, although two of the patients would have liked additional instruction in the use of the system. None of the three patients have used the simulation function.

In the opinion of the patients carbohydrate counting is easy. Two of the patients declare that they to an increasing extent regulate their blood sugar by diet as opposed to insulin, which they were quicker to resort to in the past. One patient feels that it gives a greater sense of freedom, e.g. when going out, because carbohydrate counting is uncomplicated.

The patients suggest that provided DiasNet is used, they can do without the 3-monthly clinical reviews, thereby saving staff resources.

All three patients agree that DiasNet is the future, despite its limitations, e.g. the failure to allow for physical activity.

Chapter 8 - Conclusion

In conclusion we single out unique and typical characteristics related to this case study of how the diabetes team and diabetic patients have made practical use of DiasNet. The purpose of the effect evaluation was an inquiry into:

1. ***The consequences experienced by the members of the diabetes team when diabetic patients use DiasNet.***
   - ***Are there any changes in the tasks and duties of the team as a result?***
   - ***Which challenges face the team as a result?***

2. ***Patient observations and experiences with DiasNet in view of their coping with a chronic disease such as diabetes.***

Generalisation is not the intended purpose of the effect evaluation of DiasNet, as the study offers only limited data material and concerns a development process. Instead, we want to outline some development characteristics and provide a "snapshot" of the effects that 6 months' use of the system has had.

Below we single out some unique and typical characteristics. Unique characteristics we define as development traits specific to the patients and the diabetes team at Vendsyssel Hospital. Typical characteristics we define as more general development traits, which may apply to the diabetes teams of other Danish hospitals (cf. Chapter 3). The table below lists the characteristics unique and typical for diabetic patients and the diabetes team in connection with the implementation and use of DiasNet.

	Unique characteristics	Typical characteristics
Diabetic patients	• Greater well-being • Diminished insulin dose • Feeling of safety in the dialogue with the hospital by email • Increased IT competence • Weight loss • Better knowledge of counter-regulation • Improved insight into the correlations between diet, exercise and blood sugar values • Carbohydrate counting provides certain freedom • DiasNet easy to use in practice	• Increased confidence and more personal rapport with the diabetes team • Improved diabetes self-management – experiencing better self-control • Increased awareness of carbohydrates in regard to blood sugar regulation • Emails facilitate quicker responses from the staff • 3-monthly reviews unnecessary • Mutual learning among the patients attending the diabetes school
Diabetes team	• Enhanced knowledge of counter-regulation • Increased number of work tasks • New work culture (screen work needs to be recognised as part of "legitimate" work routines) • New routines and procedures • Stronger team identity in regard to learning in the diabetes team • DiasNet is user-friendly	• Emails facilitate a patient / diabetes team dialogue irrespective of time and place • Revised diabetes counselling practice with focus on carbohydrates • Enhanced competence to the nurses in regard to insulin dose adjustment • Specification of electronic documentation practice required • Improved visualisation of blood sugar profiles • Closer follow up with diabetic patients • Food has become a matter of more pronounced interest to all parties

Having summed up the DiasNet implementation characteristics that are unique and typical for both patients and diabetes team, we give a brief account of what we deem to be of particular interest in regard to the typical characteristics.

As far as the patients are concerned, we find it remarkable that the patients experienced feelings of greater confidence and a more personal rapport with the staff. In our opinion, this may be explained by the fact that they attended the diabetes school and in this way became better acquainted with the staff than they would when coming in for regular clinical reviews.

The 4-week patient training programme at the diabetes school is a new initiative in diabetic care in Denmark. There is no doubt that both patients and the diabetes team benefited from this initiative. The patients declared that they learnt a great deal from each other, especially in connection with the group review of their individual blood sugar values.

The fact that the functionality of DiasNet centres on the patients' entry of the carbohydrate content of their meals has triggered a greater awareness on the part of the patients in regard to blood sugar regulation by means of carbohydrates. We find it interesting that the patients point out that carbohydrate counting gives them a greater sense of "freedom"!

DiasNet is a tool well suited to giving the patients an understanding and insight into their own disease, so as to promote increased disease self-management. This is in line with the ideas behind The Digital Hospital to support the patients in a new and more active role, viz. "the competent patient".

Also, we find it interesting that the DiasNet project has contributed to the diabetes team revising their counselling practice by focusing on carbohydrates. In this connection we wonder whether this is old knowledge that has now resurfaced again?

DiasNet has caused changes in the tasks and duties performed by all professional groups in the diabetes team. In this context the enhanced competence of the nurses in regard to insulin dose adjustment deserves special mention. This constitutes one of the most significant functional changes caused by DiasNet.

The possibility of communicating by way of email was a positive experience to the patients and staff alike. However, it is essential to provide guidelines for the diabetes team handling documentation of diabetic care and treatment when emails are the hub of communication.

The Digital Hospital project has been running over a 2-year period and as previously mentioned has involved the ongoing implementation of various IT systems (cf. Chapter 5). The members of staff clearly indicate that this period has been instructive, albeit at times too intense. As a result, the team members have not always given the DiasNet project their full attention and by their own admission they have not always been good at keeping up the practice of weekly sessions to give the patients feedback on their data entries. The patients have also voiced dissatisfaction with the feedback from the diabetes team. Nonetheless, both parties consider this to be a temporary problem.

Before project start the diabetes team was comprised of members who knew each other well, and this project has undoubtedly strengthened their team spirit. We had hoped to be able to identify the use of new competencies, but in this instance we were too ambitious on behalf of the diabetes team. An inquiry into this perspective will be more interesting in 12 months' time.

As an IT system DiasNet has been easy to learn how to use for both patients and staff. Both parties agree that it is a development process, and that there is hope that the project may continue in future so that practice may be improved to the effect that DiasNet to a higher extent – than today – is integrated in the work routines and procedures as well as the co-operation culture between patient and diabetes team and among the professional groups of the diabetes team.

At the time of writing it remains to be decided whether the DiasNet project is to continue once the project period of The Digital Hospital expires. Certainly, all parties are keen to learn and experience more with the system.

In the final chapter we render our reflections in regard to the case study approach as methodological foundation.

Chapter 9 – Reflections in regard to the case study approach

In this chapter we intend to give a short summary of our reflections concerning our choice of methodology. As methodological foundation we opted for the case study approach. In this connection we will also view the approach in relation to our role as evaluators. Our decision to use the case study approach was based on the premises of modest data material (interviews with three patients and the diabetes team) and that the project in question is a development project.

In retrospect, we can see that our role as external evaluators went through various stages of development in the course of the project. This will be elaborated in the following. At the initial stage, there was a clearly defined boundary between our role as external evaluators and the object of study – the DiasNet project. In this phase we perceived the respondents as "data suppliers". The selection and combination of data collection techniques in the initial phase proved rewarding for us in terms of quickly acquiring both knowledge and an impression of the context and real-life world that are the hub of the project: the medical outpatients' clinic, the diabetes team and patients.

The methodology benefits from the advantage that we – as researchers – have been close to our field of study. We won the confidence of the diabetes team and the patients, who then spoke more freely than could perhaps otherwise be expected. By our presence – also in social contexts, e.g. at coffee breaks – we displayed our interest in following the project closely, from the patients' point of view as well as from the staff's point of view. We gained valuable insights by spending time and acting within the organisation. We turned this knowledge into good account when preparing interview guides, getting an understanding of the context as well as when analysing the collected data.

However, at the same time it is essential to consider that when we as researchers desire closeness with the context we are studying, it also means that we to an unknown degree influence this same context. The invariable research question is therefore whether we study the reality we mean to study or whether we study a reality in which we ourselves act?

As far as our analysis of the diabetes team is concerned, we must admit that our theoretical background was rather too ambitious. The effect evaluation should not have been prepared at this early stage if the aim was to identify competencies. It could be interesting to re-evaluate in 12 months' time, provided the project continues!

The relatively short duration of the DiasNet project period caused us some concerns as to what the patients have in actual fact gained by using DiasNet. It is difficult to differentiate

between the real effects on account of DiasNet and the effects that may be explained "only" by the increased focus on the patients because they piloted this project!

As researchers we found it valuable to use the narrative approach, because we met very frank and outspoken patients who shared their thoughts, observations and experiences with us. The individual patients offered their personal narratives, which varied from patient to patient.

We have singled out characteristics unique and typical for both patients and diabetes team. It is important to bear in mind that we have taken a "snapshot" picture of a development process, and thus it must be assumed that the picture will change.

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Table of appendices

Appendix 1

August 2002

Guide to interview with ward sister, medical outpatients' clinic

1. Mutual introduction.
    - Education/training
    - Experience

2. What are the objectives of the care and treatment offered diabetic patients?
    - Which values do you find important?
    - What are your priorities?
    - How do you pursue your objectives in practice?
    - Do the objectives of nursing care and treatment differ in any way?

3. Current work routines and procedures in regard to diabetic care and treatment. How do you perceive this from a management viewpoint?

    - How do you assess the current procedures in regard to diabetic patients?
    - What procedures are good? What procedures should be improved?
    - In which areas do you expect the procedures to be affected by the DiasNet project?

4. Interdisciplinary co-operation – how do you see it?
    - Describe co-operation interface. Pros and cons.

5. Use of IT today.
    - How do you use IT today?
    - How do the members of staff use IT today?
    - What is the level of IT skills among the staff?
    - Have all of you attended courses offered by The Digital Hospital?
    - What are your expectations in regard to the diabetes project from a management viewpoint?

Appendix 2

October 2002

Guide to interview with researcher working with DiasNet

1. Mutual introduction.

2. How was DiasNet developed in terms of scientific research?

3. How did you – as a researcher – become interested in the area of diabetes?

4. How do you experience patient quality of care in relation to DiasNet?

5. What is your attitude towards the concept of ”the competent patient” and DiasNet?

6. In your opinion, how will the diabetes team react in regard to DiasNet in terms of:

    a. Getting to know the system
    b. IT, care and treatment
    c. Tasks and duties.

7. What are the visions behind DiasNet? When will it become a commercially available system for general use by diabetic patients?

Appendix 3

September 2002

Observation guide used at medical outpatients' clinic

Objectives

- Acquiring an understanding of the clinic as a workplace.
- Acquiring an insight into the normal day-to-day work at the clinic.
- Acquiring an insight into the work procedures and tasks performed by the diabetes team in relation to diabetic patients.
- Observing how the clinical review of diabetic patients is conducted.
- Acquiring an insight into how visions and objectives for diabetic care translate into practice.

Focus areas

1. What features are characteristic of the staff members at the clinic?
   - Professional groups
   - Work culture

2. Current work procedures and tasks in regard to diabetic patients.
   - Administrative/clinical
   - Clinical reviews
   - The contact of various professional groups with the diabetic patients
   - Guidance/counselling

3. Interaction between diabetic patient and diabetes team.

4. Visions and objectives for diabetic care and treatment.
   - Attitudes to care and treatment

5. Today's use of IT by the staff in the day-to-day work.
   - How is it applied today? To which type of duties?
   - IT competencies

Appendix 4

”FREDERIKSHAVN-SKAGEN HOSPITAL, Medical Ward
(Dated 10 Septemer 1998)

FUNCTIONAL DESCRIPTION
for
the position of diabetes nurse at medical outpatients' clinic
Frederikshavn-Skagen Hospital

Job description: **Diabetes nurse.**

Place of employment: **Medical Day-Ward/Outpatients' clinic.**

Organisational position: **The ward sister.**
(immediate superior)

Conditions of appointment: **Appointment on a group contract basis.**

Qualifications:

- **Trained nurse with Danish registration.**
- **Broad clinical experience within the area of medical health and nursing care.**
- **Minimum 6 years' experience in total.**
- **Specialised knowledge and expertise within the area of diabetic health/nursing care.**
- **Educational experience in regard to planning and running educational courses.**
- **The ability to work independently.**
- **The ability and readiness to enter into a professional and interdisciplinary co-operation.**
- **The ability and readiness to take additional educational courses within the field of diabetes.**
- **Knowledge of quality assurance and research work.**

Responsibilities and competence:
The diabetes nurse administers nursing care to diabetic patients and patient relatives who consult the Medical Outpatients' Clinic/Day Ward, in close collaboration with the other health professionals in the diabetes team.

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In regard to the team the nurse functions as coordinator. The diabetes nurse performs a counselling, advisory and educational function in regard to diabetics and health professionals internally at the Medical Ward and externally in the catchment area of the hospital. The diabetes nurse is committed to secondary and tertiary disease prevention activities related to the field of diabetes.

Other functions:
Participation in projects and surveys pertaining to diabetic health efforts.
Attendance at relevant professional meetings and courses, including the county community advisory committee on diabetes
Attendance at and running relevant professional and interdisciplinary conferences pertaining to diabetic health efforts.
Preparation of specifications and guidelines concerning diabetic health efforts.
Co-operation with diabetic user group, the Danish Diabetes Association and the internal hospital diabetes committee.
Participation in the training of student nurses/Social and Health Service assistant trainees and others on the ward.

Appendix 5

August 2002

Interview guide to qualitative interviews with members of the diabetes team

1. Mutual introduction
    - Education/training
    - Previous employment
    - Experience

2. Present tasks and duties
    - What would you describe as your most important tasks and duties related to the diabetic patients at the clinic?
    - What type of duties do you have in connection with diabetic patients visiting the clinic? (administration, guidance, clinical duties, etc.)
    - How do you assess staff resources in view of tasks and duties?

3. Interdisciplinary co-operation in regard to diabetic patients
    - How would you characterise the interdisciplinary co-operation?
    - What are the good points? What should be improved?

4. What are the visions and objectives for diabetic care and treatment?
    - Which values do you find important?
    - What are your priorities?
    - How do you pursue your objectives in practice?
    - Do the objectives of nursing care and treatment differ? If so, in what way?

5. IT today
    - How do you use IT today?
    - Have you attended courses offered by The Digital Hospital?
    - What are your expectations in regard to the diabetes advisory system?
    - In which ways do you expect it to affect your work?

Appendix 6

June 2003

Interview guide to qualitative interviews with members of the diabetes team

1. Is the enclosed description adequate in terms of your current tasks and duties in relation to diabetic patients?
    a. If not, what needs to be added?

2. How would you describe your tasks and duties in relation to diabetic patients who use DiasNet as a diabetic management tool?

    a. Are your tasks and duties the same?
    b. Have new tasks and duties developed? Please exemplify, if possible?
    c. Have any of your tasks and duties disappeared?
    d. Do you spend more time on some specific tasks and duties than others in your contact with the diabetic patients?

3. What are your experiences in regard to using DiasNet?
    a. What do you see as pros and cons?

4. Have your expectations in regard to DiasNet been met? Why? Why not?

5. Has DiasNet had any implications on the distribution of tasks and duties within the diabetes team?

    a. Do you see any new opportunities?
    b. Could the tasks and duties be distributed differently?

6. How do you use IT in general in your work today?

Appendix 7

June 2003

Interview guide to focus group interview with diabetes team

1. Have you as diabetes team been given new tasks and duties?

2. What is demanded of you as a result of these changed tasks and duties?

3. Has working with DiasNet meant that you have had to acquire new knowledge or use your knowledge/expertise in a new way?

4. In your experience, has your general approach and attitude to how you do your job changed? Please exemplify, if possible.

5. What significance has the DiasNet project had for the diabetes team in terms of:

    a. Co-operation
    b. Learning

Appendix 8

March 2003

Observation guide used at diabetes school

Objectives

- Monitoring the sessions at the diabetes school.
- Observing how the patients learn to use DiasNet.
- Monitoring how the staff and patients together learn to use DiasNet.
- Observing the patient interaction.

Focus areas

1. The diabetes school as a whole
    - Organisation of school (educational content and programme)
    - Organisation of teaching
    - Overall – the 4-day training programme

2. Patients and learning in regard to the use of DiasNet?
    - How does the individual patient learn?
    - How easy is it for the patients to approach DiasNet? (questions and comments)
    - How is the patient interaction?

3. Diabetes team, patients and DiasNet
    - How is the interaction?

Appendix 9

March 2003

Interview guide to qualitative patient interviews

Objectives

- ”Capturing” the patients’ account of the way they experience their everyday life when using DiasNet as a diabetic management tool.
- Studying how the patients learn disease management by means of DiasNet.
- Bringing into focus the implications of DiasNet for the individual patient’s diabetes and quality of life (physical, mental and social dimensions).

1. Mutual introduction.

2. How long have you had diabetes?
   - Do you suffer from any diabetic complications?

3. Would you please tell us what went through your mind when you were diagnosed with diabetes?
   - What did you find difficult?
   - What did you do in order to learn how to cope with the disease?

4. Would you please tell us how you cope with your diabetes today?
   - At home together with the family
   - At work
   - In your leisure time (in connection with activities such as sports, etc.)
   - What do you find difficult? What do you do when you have problems with your blood sugar?

5. Would you please tell us how you self-monitor your diabetes?

6. Would you please tell us how the review at the hospital is conducted?
   - What are the pros and cons of this way of diabetes monitoring?

7. What are your IT skills?
   - How do you use IT privately/at work?
   - What do you expect to gain from participating in the diabetes advisory system test?

Appendix 10

August 2003

Interview guide to narrative patient interviews

Objectives

- Acquiring factual information on
    a. Insulin requirement after DiasNet
    b. Clinical reviews
- Exploring and understanding the individual patient's observations and experiences with DiasNet.
- Hearing the patients' personal accounts of how they experience everyday life when using DiasNet as a diabetic management tool.

1. What is your insulin requirement today, compared to your requirement before starting to use DiasNet?

2. How frequently do you go to the clinic for reviews today?

3. Has DiasNet caused any changes in your day-to-day life? At work and at home? Please exemplify, if possible.

4. What experiences have you gathered about your diabetes by means of DiasNet?

5. What are your experiences with DiasNet?

6. What, in your opinion, do the members of your family/your colleagues think about you using DiasNet as at diabetic management tool?

7. What are your thoughts for the future if DiasNet is to become part of your everyday life?

Appendix 11

March 2003

Diary: Letter addressed to patients

Dear patient,
We would like to ask if you would be prepared to keep a diary in connection with your participation in the diabetes project.

The reason behind the diary is:

- that we would like to follow you, in terms of what thoughts, considerations and experiences you encounter when using the diabetes advisory system.
- that we would like to understand how you gain experience with your disease as time goes by.
- that we achieve a common tool on which to base our talks at the interview in September 2003.

Practical details
The diary is written on your own PC in a word-processing programme. ASB would like to receive the diary for review immediately prior to the September interview. You are not requested to make daily entries, only when you feel that you:

- have something on your mind
- have experienced something new in regard to your diabetes, or
- when you feel that you have been through a difficult situation.

Below please find some questions that may serve as inspiration:

1. What is it like to use the diabetes advisory system in day-to-day life?
2. Have I become any wiser about my disease lately? Please exemplify, if possible.
3. Have I had any aha-experiences?
4. Have I changed my life-style? (work, family, leisure time, etc.)
5. If you face a difficult situation with your diabetes – what do you do? Do you act differently than you would otherwise do?
6. Pros and cons of using the diabetes advisory system?

We hope that you want to share your thoughts and experiences with us. We would like to remind you that we are bound to observe patient confidentiality and your diary will thus be handled accordingly.

Kind regards

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Appendix 12

The diabetes project group:

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AU = Aalborg University
M1 = Medical Outpatients' Clinic, Vendsyssel Hospital, Frederikshavn.
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Appendix 13

Description of Ph.D. study by Egil Boisen (eb@hst.auc.dk) 'CID – Copability in Disease Management', 2002-5.

The project has three significant components, the 'substantial' part, the theoretically conceptual work and the operational part.

The substantial part of the project is 'disease management' within diabetic care of type 1 patients. The optimum insulin regulation requires in principle constant adjustment in regard to the factors that influence the blood sugar level, including especially carbohydrate intake, but also factors such as physical exercise, weather conditions, fever and alcohol. Thus the factors are intimately connected with the patient's life-style. Studies have shown that good results are achieved by conventional means through constant aggressive treatment. The considerable costs incurred by this, both financially and in terms of quality of life, make it attractive to seek new means. As a possible solution research is ongoing within the field of 'disease management' into ways of empowering the patients with enhanced competence in regard to self-regulation and maintaining a stable blood sugar balance. The empirical foundation of the project is the implementation and further development of a patient support system, DiasNet, by means of which the patients gain a better insight into the dynamics underlying diabetes and obtain direct advisory indications of how much insulin to take. The programme is developed and implemented by the project's subsidiary Ph.D. tutor, Ole K. Hejlesen, in collaboration with Vendsyssel Hospital, and since January 2003 11 patients have used the application – so far with very positive outcome.

The conceptual work of the project is concerned with making a methodological contribution to the evaluation of IT systems within the area of disease management: In addition to the classic evaluation terms of usability and utility, the concept of 'copability' is introduced, signifying how well a user – a patient, in this instance - copes with a new tool. This is motivated by a criticism of "classic" HCI and usability approaches as being inadequate in terms of context-orientation. The description of the way DiasNet is used will be based on activity theory (Vygotsky, Leont'ev, Engeström, Kaptilinin et al.), as a foundation for the conceptual work with the term of 'copability'. During the conceptual part of the project it will be interesting to define the concept of 'copability' on the basis of activity theory, in part on the basis of an adaptation of questions specifically related to the diabetes project. A concept of crucial importance in activity theory is "motive", the desire that elicits all actions, so to speak. In the course of the project it turned out that the diabetic patients' desire for diabetic self-care has been stimulated in the process. Through working with qualitative research interviews of diabetic patients' experiences in the course of the DiasNet project period an analytical model in support of a focused approach to patients' motives is to be specified. This is to be viewed in relation to the modern endeavours of the healthcare sector aimed at giving the patients increased responsibility for their own health, and it also needs to be viewed in relation to aspects of health psychology that determine these endeavours, including the patient's "readiness" and conditions, to handle this responsibility.

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A central issue is how DiasNet (including the design of the application and the way it is introduced to the patient) may contribute to the process towards enhanced diabetic self-care and motivate the necessary life-style changes on the part of the diabetic patient.

The operational part is intended to involve an intervention in the form of a wizard to guide the patients not only in the use of the programme, but also in integrating its use in their everyday lives as diabetics, just as the wizard should also help motivate the diabetic patients.

The Ph.D. project is related to DND as part of the monitoring research programme, which centres on the concept of 'learning' (the concept of the "Learning Region'). Project tutors are Ann Bygholm (Department of Communication) and Ole K. Hejlesen (Department of Health Science and Technology), both with Aalborg University. Project completion is expected in the summer of 2005.