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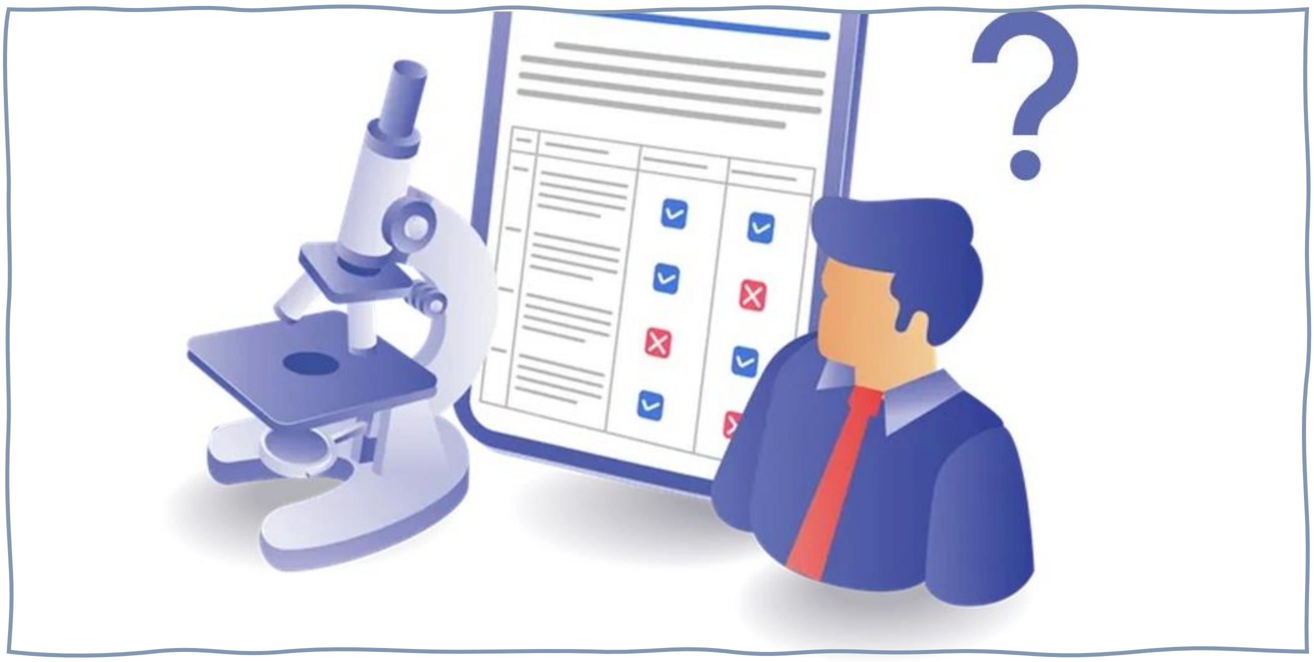

SUPPORTING PATIENTS WITH DIABETES’ DISEASE MANAGEMENT THROUGH IMROVED PRESENTATIONS OF TEST RESULTS

A QUALITATIVE STUDY

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MASTER’ S THESIS

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Abstract:

E-health services are considered an important resource to increase the involvement and empowerment of patients in the Danish healthcare sector. All adult citizens have access to their own health data but most of it is presented in the same way as it is to healthcare professionals which can be difficult to make sense of for the patients.

This study addresses this problem through an investigation of the experiences of patients with diabetes in relation to accessing and interpreting lab results. The aim is to present design concepts based on the patient's experiences, that can inform the future design of the presentation of lab results.

The empirical material is collected through 7 semi-structured qualitative interviews with patients with diabetes at a smaller Danish Regional Hospital. The interviews included a sketching exercise that contributes to the understanding of the participant's needs. Through a phenomenological hermeneutic approach, six themes are generated that are interpreted in the perspective of the READHY model.

The study shows a need for more customisable presentations of lab results that can support the patient's individual needs. The participants all request easier identification of specific results through visual cues and simplified language. The study and the existing literature find that patients experience negative emotions in relation the checking test results. Better tools for confident interpretation might reduce this.

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1. Introduction

Denmark is described as one of the leading countries in The European Union and the OECD countries when it comes to public digitalisation (Danmarks Statistik, 2023). In the Danish government's latest digitalization strategy, digital solutions are considered an important tool to meet the expected challenge of labor shortage within the healthcare sector (Regeringen, 2023). Digital tools are expected to help increase effectiveness in the workflows of healthcare providers and help to create more flexible options and improved possibilities for patients and citizens to access and gain an overview of their own treatment and healthcare plans (Regeringen, 2023).

In 2022 the Danish Association of Doctors initiated "the Prioritization Council of the Healthcare Sector" whose 20 members among others represent patient associations, healthcare personnel, the Danish Ethical Board, and public municipalities and regions (*Sundhedssektorens prioriteringsråd.* 2024). The council has been established to contribute to the public debate and bring forth recommendations on how politicians from both government and municipalities prioritize the resources of the healthcare sector. In their latest report, consisting of 20 recommendations, they recommend better use of technologies, more treatment outside the hospitals, and more active involvement of patients and citizens in their treatment (Sundhedssektorens Prioriteringsråd, 2024). The aim is to create flexibility and treatment adjusted to the individual patient's needs as well as a better use of healthcare personnel resources to ensure help to those who need it most (Sundhedssektorens Prioriteringsråd, 2024).

1.1 Patient involvement

The benefits of involving patients in their treatment include better adherence to health recommendations, more trust between patients and healthcare personnel, and less risk of death due to a major event such as acute myocardial infarction (Coulter, 2012). These benefits have been increasingly recognised in the Danish healthcare sector for years with the establishment of the Knowledge Centre for User Involvement in Healthcare in 2011 and the first Danish professorship in patient involvement in 2012 (Pedersen et al., 2015).

The focus on engaging patients in their treatment is also reflected in the Danish Law on Healthcare's chapter 5 "Patient Involvement in Decision-making". Here it is stated that patients have the right to be informed about their health condition and treatment options, including the risk of complications and side effects. It also states that the information must be provided on an ongoing basis and give an understandable presentation of the disease, the examination, and the intended treatment. The information must be given in a considerate manner and adapted to the recipient's individual prerequisites regarding age, maturity, experience, etc. (Indenrigs- og Sundhedsministeriet, 2023). Access to your health data is thus considered a basic right and prerequisite for patient involvement as it provides patients with the same information as healthcare professionals.

The patient portal Sundhed.dk is the digital solution to provide patients access to their health data in Denmark. The portal has existed since 2003 and according to Sundhed.dk in 2023, 96% of Danish citizens knew about the portal (Sundhed.dk, 2023a). In 2004 the portal launched the function that allowed Danish citizens to see their lab results, but until 2015 this access was however deliberately delayed ensuring that healthcare professionals could see the answer before the patients (*Sundhed.dk.* 2015). The delay was removed because of an increasing demand for faster access to health data from the citizens and Danish Regions which lines up with the increased awareness of the benefits of patients being actively involved in their treatment.

The fast access to health data includes both notes and test results from past tests and treatments as well as access to new test results. Especially during the Covid-19 pandemic, this was valued and in the period March 2020 to March 2021 the number of visits to Sundhed.dk, and the associated app MinSundhed, increased by 379%, establishing the portal and app as a part of the most critically important national infrastructure (Sundhed.dk, 2023b).

To most citizens, the result of a Covid-19 test was easy to interpret and as a recent test was often a requirement to participate in activities, school or work outside your home, the direct access to your results as soon as they were available, was essential. The increased activity suggests that the pandemic motivated many citizens not familiar with the patient portal or app to learn how to use it, and in 2022 an analysis of the Danish citizens' internet usage showed that 66% of the citizens between the ages of 16 and 74 years have used the internet to see health data on themselves or family members (Tassy & Tömfelt, 2023) (s. 32). This shows an increase from 2016 when this was only the case for 18% of citizens the age 15 or above (Tassy, 2016).

1.2 The future diabetes clinic

In an effort to spend the resources of the healthcare system on the patients who need it the most the Danish Region of Middle Jutland has started the initiative "The Future Diabetes Clinic of Region Middle Jutland". One of the main targets of this effort is to set people with diabetes free and be there for them with the right services when they need them and, in this way, also secure a more sustainable use of healthcare resources, to help those who need it most (Region Midtjylland & Steno Diabetes Center Aarhus, 2022). One of the initiatives in this study is to combine the yearly consultation with one of the screenings for accompanying diseases patients with diabetes are offered. By doing this, the aim is to have fewer consultations for each patient, making the amount of time between consultations in the hospital longer (Region Midtjylland & Steno Diabetes Center Aarhus, 2022).

In this extended period between hospital consultations, the optimal use of resources for the healthcare system is to empower the patients to manage their disease on their own. Besides daily measurements of blood glucose and awareness of symptoms, one of the ways to monitor the progress of diabetes is to analyze blood samples in the laboratory. The tests are often taken days before a scheduled appointment to ensure that the result is ready in time and allow the patient to schedule it as it fits in their daily lives. Besides being visible to the healthcare personnel, the patients also have access to the results online. This access will, in line with the implementation of other new technologies, affect the involved users and entail unforeseen consequences that can be both positive and negative (Lassen & Thygesen, 2023). While the possibility of patients seeing their test results independently of a consultation with a healthcare practitioner offers flexibility and access to their health data, it can also put citizens in other, less desirable positions.

1.3 The irony of information

In 2022 Jønsson et al investigated what happens when different citizens look at their test results through sundhed.dk. This investigation resulted in a discussion of what they call "The Irony of Information" where the wish to provide transparency and thereby patient involvement can cause insecurity and harm to some patients because patients do not always have the necessary prerequisites to understand and interpret the results (Jønsson et al., 2022). The layout and language of lab results are often directed toward healthcare personnel who have training in combining test results with other patient information and interpreting whether a seemingly abnormal result is normal in this particular context. The patients however can perceive them as definitive truths and harmless abnormal results can be a catalyst for anxiety as well as extra consultations initiated by anxious patients (Jønsson et al., 2022).

1.4 E-health literacy

Digital technologies such as online platforms where patients can access their health data are often referred to as e-health. The challenges related to finding, understanding, using, and assessing information and services regarding your health are often connected to socio-economical factors and labeled 'Health literacy' (Norgaard et al., 2015). The combination of the two created the concept of 'e-health literacy', which describes the field where digital technologies become the mediator of health information, requiring both literacy and capabilities regarding the use of digital technologies (Norgaard et al., 2015).

These capabilities are important to make online test results an empowering experience for the patients and not a source of insecurity and extra work for their healthcare providers.

While access to lab results can lead to anxiety for some citizens, the study by Jønsson et al. suggests that citizens with chronic disease might have a different perception and approach to the test results due to their experience as patients, equipping them with strategies to cope with the results (Jønsson et al., 2022).

Around 1 million Danish citizens have at least one chronic disease, with diabetes being the second most occurring chronic disease (Kleist, 2023). There are 360.000 citizens diagnosed with diabetes, and the expectation is that by the year 2030, the number will be 467.000 citizens or 7,7 % of all Danes (Carstensen et al., 2020). To "set them free" and ensure sufficient resources for the patients who need it most, as described by the Future Diabetes Clinic, the ability to interpret and act on lab test results can be a part of the solution. However, international studies find that patient portals were generally not presenting test results in a way that was meaningful to patients and that there was a need for additional strategies to help patients interpret their test results (Giardina et al., 2017), and a systematic review from 2019 points out that though some patients find patient portals easy to use, and make them feel empowered and more engaged in their care, some patients find the portals difficult to use due to a complex interface (Dendere et al., 2019).

1.5 Rapid literature review

To assess the existing knowledge related to this field, I conducted a rapid review following a systematic approach but performed within an abbreviated timeframe compared to a full systematic review (Sutton et al., 2022). This approach is appropriate for this study as the purpose is to produce evidence of the existing literature on the field in a time-efficient manner allowing me to prioritise my resources for the study appropriately.

The review was performed using one database which was Scopus. The database was chosen because it is the largest database containing abstracts and citations of peer-reviewed literature. Though the subject for this study is closely related to healthcare, it includes aspects that can be approached through several disciplines, why a database not focused on a specific discipline is appropriate.

The search was performed with the criteria that the date of publication should be between 2004 and 2024 as it was in 2004 that Danish patients were given access to test results at Sundhed.dk for the first time (Sundhed.dk, 2023a) and the language should be English.

Studies were excluded if they focused on the HCP perspective, if studies collecting empirical material did not present the participants of the study, or if the study investigated use of EHR or health-related webpages in general.

1.5.1 Presentation of included studies

The following will summarize the included articles. The full review including search strings and flow chart of the search process is available in Appendix 1.

Systematic scoping review (1 article):

One of the included studies is a scoping review performed in 2023 reviewing both patient and professionals' perspectives on patient access to various types of test results (lab results, radiology results, DXA scans, etc.) via patient portals (Petrovskaya et al., 2023a). This provides a helpful overview of the literature but is not possible to categorize with other studies.

The remaining articles can be divided into three general themes:

Studies investigating and highlighting aspects of health literacy and inequity in health, studies investigating consumers' general understanding of lab results, and studies focusing on evaluating UX/design aspects. The categories are tightly connected and many articles in the two first categories also provide recommendations for design changes to make portals more user-friendly.

Health literacy and inequity in health (3 articles):

This category contains one article based on a study performed in the Netherlands (Tossaint-Schoenmakers et al., 2021), one American-based review (Lazaro, 2023), and one internet-based survey performed in the USA (Zikmund-Fisher et al., 2014). They all point to factors such as age, chronic disease, numeracy, literacy, and health literacy as influential to consumers' ability to understand and apply test results. Platforms must be adapted to take different groups into account to not increase inequity in health.

General (mis)understanding of test results (8 articles)

This category contains 8 articles aiming to investigate the challenges and needs of consumers when looking at their test results. Three articles are based on studies performed through interviews and questionnaires with Canadian citizens (Monkman, Helen et al., 2023) (Monkman, H. et al., 2022) (Joseph et al., 2022), one is Canadian and interviewing 21patients from one specific clinic (Robinson et al., 2019), one is a Dutch study using the e-health impact questionnaire to evaluate a patient portal (Talboom-Kamp et al., 2020), and three are American analyzing respectively questions from a social Q&A site, and using mixed methods (questionnaire and interviews) to assess the challenges and information needs of patients (Zhang et al., 2019a) (Zhang et al., 2020), (Giardina et al., 2017).

The articles display that people generally appreciate the possibility of seeing their test results online but experience a variety of challenges in understanding and using the test results. There is a gap between what is presented and what is needed from the people looking at the test results including the need for additional information, highlighting of abnormal results, and guidance on what to do next. As a result, they are only slightly helping people using their test results to manage their health. Some of the articles also suggest changes in design to support usability, connecting this category closely to the next.

UX/design focus (6 articles)

In this category, there are 6 articles. Three of them are based on interviews with Canadian citizens (Monkman, Helen et al., 2024) (Joseph et al., 2024) (Monkman, Helen et al., 2022). One is based on 8 user evaluations of a patient portal prototype performed by American citizens (Zhang et al., 2021), one is based on questionnaires answered by Israelian citizens (Bar-Lev & Beimel, 2020), and one is using eye-tracking methods to investigate how interface design affects patients search behavior and risk interpretation (Fraccaro et al., 2018). The articles all point to a need for greater attention regarding the interface design of patient portals as the design of the interfaces affects people's abilities to interpret their results and misinterpretation leads to both too much and too little contact with healthcare personnel.

Of special interest in relation to this study is Fraccaro et al. which is the only included study investigating how persons with a specific diagnosis use and understand test results from patient portals. The patients in this study have all undergone a kidney transplant and are hence patients with chronic disease that demands continuous treatment and tests to follow the development of their disease (Elung-Jensen, 2022). The patients are shown different presentations of test results and asked to interpret the severity of the results and what action to take. Besides this, their eye movements are tracked, and their interpretation of the results is compared with a professional's interpretation to evaluate their accuracy. The participating population and study design with different presentations of test results have some similarities with this study, making its results a valuable supplement to the findings of this study. The study concludes that patients underestimated the need for action despite interface design with visual cues, and that the patients who were most consistent in correct assessment showed a higher visual search efficiency and better strategy for coping with information overload (Fraccaro et al., 2018).

1.5.1 Review Summary

The result of this review suggests a growing attention to how providing access to test results is not necessarily the same as providing information. Different factors affect people's ability to use the test results actively and can lead to too much or too little action from the patients. The review also suggests that a very limited number of studies specifically investigating the needs and challenges of patients with chronic diseases concerning laboratory test results.

1.6 Delimitation

The Clinic for Diabetes, Bone- and Hormone Diseases at Silkeborg Regional Hospital is one of the collaborative partners in The Future Diabetes Clinic. According to the local study- and development nurse the clinic has around 800 patients. In an effort to increase the patients' knowledge and awareness of their disease, the clinic encourages the patients to look at their medical records including their test results. This study aims to investigate how patients with diabetes experience checking their laboratory results through Sundhed.dk. The Clinic for Diabetes, Bone- and Hormone Diseases a Silkeborg Regional Hospital treats adult patients with type 1 diabetes and adults with type 2 diabetes that are too complicated to be treated by their general practitioner. The study is thus limited to this group of patients.

2. Problem statement

The introduction and literature review demonstrate an increasing interest and expectation of patients to be active in the management of their health. While decisions made on a political and organizational level suggest that patients use access to their health data to become more independent and empowered in relation to their treatment, the literature suggests that this is not accomplished by simply providing the same access to data as healthcare professionals. This leads to the following problem statement:

How can the presentation of online lab results be improved to support the patient with diabetes' understanding and ability to manage their disease?

3. Method

This study is based on my collaboration with the University Research Clinic for Innovative Patient Pathways, Silkeborg Regional Hospital, and The Clinic for Diabetes, Bone- and Hormone Diseases at Silkeborg Regional Hospital.

In this section, the study's methodological approach will be described. The empirical material consists of interviews with 7 patients with diabetes and is combined with personal notes made after each interview. The transcripts and notes are available in Appendix 2 where the participants are named by their initials. They will be referenced by initials in the text.

3.1 Hermeneutic phenomenological approach

The study has a hermeneutical phenomenological approach as the purpose is to uncover and understand phenomena related to the participant's life with diabetes and interpret these in the context of e-health literacy, specifically their usage of lab results via Sundhed.dk or the app MinSundhed.

3.1.1 Phenomenology

The phenomenological method was initially established by the philosopher Husserl around the year 1900. Central to this approach is the ambition to investigate phenomena as they appear without the ideas, stereotypes, and impressions that we all carry and assign to them (Tanggard, 2018). The phenomenology has since Husserl undergone further development through the work of Heidegger, Sartre, and Merleau-Ponty to also include the human lifeworld, the body, and human actions (Tanggard, 2018).

A central concept in phenomenology is *lifeworld* which is the concrete reality that can be experienced by humans and that we in daily life are comfortable with when making decisions, acting, and communicating. Our lifeworld is a prerequisite for other experiences, and based on this we can distance ourselves from the preconceptions, stereotypes, and cultural norms that affect our understanding of the world (Tanggard, 2018).

Phenomenology has been utilized within qualitative research, where the aim is to describe and understand how the world is experienced by the actors. This is done on the assumption that reality is what humans experience it to be and that our only opportunity to understand the world and the meaningful phenomena is to include the observed object or actor (Tanggard, 2018).

To apply the ideas of phenomenology in qualitative research the approach described by Giorgi is useful. The aim is to open the mind of the researcher in a manner that allows the phenomena to appear as clearly as possible without being affected by the researcher's preconceptions (Tanggard, 2018). The methods require the researcher to first acquire a description of a phenomenon as it is experienced by a person. Before analyzing this, the researcher must enter a state of openness to the material and step away from existing preconceptions of the phenomenon. The next step is reading the material - first in its entirety and afterwards slower to establish units of meaning that are in themselves small entireties. These units are then transformed into new categories and/or concepts that can express the subject the researcher seeks to shed light on. These concepts or categories are the foundation of a general structure to be formulated to express the phenomenon experienced by the person. The aim is to find the general in the concrete (Tanggard, 2018).

In relation to this study, exploring the phenomena in the lifeworld of the patients with diabetes is central to understand how receiving test results through sundhed.dk or the app minSundhed is experienced by the users. To describe these, one must aim to put away all preconceptions and restrain from applying standardized categories and explanations to the experienced phenomenon (Tanggard, 2018).

The work of Merleau-Ponty and Heidegger moves the phenomenology into the hermeneutic as Merleau-Ponty argues that interpretation of the basic factors that shape our experience such as history and the human body is necessary to understand the human condition.

3.1.2 Hermeneutics

The emphasis on interpretation can be found in both phenomenology and hermeneutics, but where the focus of phenomenology is on how phenomena present themselves and are subjectively experienced by individuals, hermeneutics is primarily interested in interpreting situated creations of meaning (Kristiansen, 2018).

The field of interest in hermeneutics is humans within a specific timely, societal, and spatial context whose experiences of the world are shaped by this context. Central to the hermeneutic ontology is the recognition of the inherent presence of preconceptions within all humans, which serve as the foundation for our understanding and subsequent actions. Applying hermeneutics as a method entails unique principles and procedures to facilitate the interpretation of phenomena (Kristiansen, 2018).

Hans Georg Gadamer stands as a seminal figure in modern hermeneutics, advocating the approach that knowledge cannot be entirely disentangled from prevailing values and interests due to the inherent influence of societal norms and values. This is because the scientists who seek to obtain knowledge on a subject are both scientists and participants within the existing society and thereby, they will necessarily bring with them a predisposed understanding of the phenomena they are studying (Kristiansen, 2018).

The acknowledgment and examination of one's preconceptions is an important part of hermeneutic analysis. This analytical approach can be explained through the hermeneutic circle, wherein individual elements and aspects are meticulously described before being comprehended within the bigger picture (Kristiansen, 2018).

In the context of this study, the coding of interviews aims to disentangle statements and actions from the situational context they appear in and form a new meaning in the context of the existing society, the healthcare system, and professional traditions. This understanding is continuously related back to the original units which ensures a dialectic relationship with the bigger entirety of the study. This methodology is continued in the interpretation of the themes through the dimensions of e-health literacy as described by Kayser et al. (Kayser et al., 2019).

3.2 Positioning

As stated in the section above, every person experiences their surroundings and relations in the context of their inherent preconceptions. Anthropologists use themselves as instruments to experience the inside of the world they investigate bringing their own social identity and experience into the field they investigate. Professional experiences grounded by theoretical traditions as well as personal experiences with social situations influence and shape these preconceptions (Overgaard Mogensen & Dalsgård, 2018).

Being an outsider and completely unknowing of the field you investigate can be an advantage because your perspective is not affected by implicit social norms and unspoken rules or assumptions related to other's actions or opinions. This can make it easier for the researcher to spot, question, and bring forth these unspoken cultural and social norms that the participants do not think about articulating because it is so embedded in their perception of their lifeworld.

With professional experience as a nurse, my preconceptions as a healthcare professional are an important consideration when investigating a field in relation to healthcare. In this case, I paid particular attention to my interaction with and perception of the patients in the interview situations. This situation has some resemblance to meeting a patient for the first time in an outpatient clinic which I have done many times in my previous job. A strategy to avoid drawing unconscious conclusions is reflecting on the situation with another participant (Overgaard Mogensen & Dalsgård, 2018). As I did the interviews alone this was not an option and acknowledging that I during the interviews tended to be focused on asking the right questions and less on controlling my preconceptions, I wrote down my immediate perceptions of the patient in an unfiltered manner after the interview. The details can ensure transparency with the researcher's interpretation of the participants' statements and provide a more "thick description" thereby enhancing the validity (Overgaard Mogensen & Dalsgård, 2018). Trying to understand the lifeworld of a patient with diabetes looking at test results I was however still an outsider with no experience of this. Besides this, I had never worked in a unit specialised with diabetes which I told all participants before the interview in an endeavour to avoid them withholding details about their life with diabetes because they expected me to know.

3.3 Access to the field

To investigate the experiences of patients looking at their lab results and gain background knowledge in the context of the healthcare system, required access to both patients and healthcare providers. Access to the field and people of interest of the study is often established through a positive relationship with a gatekeeper. This person can function as a link between the researcher and the field and facilitate contact and information in an otherwise closed environment (Rytter & Olwig, 2018).

This section will describe the negotiation of access to the field and recruitment of participants for interviews.

3.3.1 Finding gatekeepers

To establish access to recruit patients with chronic diseases, I contacted the secretary at the Unit of Quality, Innovation, and Research at the Regional Hospital in Silkeborg. I was immediately directed to the research managers to whom I sent a preliminary synopsis. They suggested my focus to be on outpatients with diabetes and/or hormonal disease and by the first meeting with the study nurse from the clinic and the nurse from the research unit, we agreed on focusing on the patients with diabetes. In the clinic at the Regional Hospital in Silkeborg, they have about 800 patients and an intention of educating the patients so they “achieve the best regulation and wellbeing possible in relation to their diabetes” as described in the clinic’s internal instructions for consultation (Dyreborg, 2022).

The study nurse from the clinic and the nurse from the research unit agreed on behalf of the clinic to help me recruit patients for interviews with the study nurse as my gatekeeper. She forwarded written material that allowed the nurses to quickly understand the purpose of the study and my request for them to help me (Appendix 3). This material was also meant as a support for them to explain the study to the patients who were there for consultation and ask their permission to provide me with their names and contact information.

Thus, my previous employment as a nurse turned out to be a big advantage concerning the negotiation of access and gaining background knowledge on the treatment of diabetes patients. As I had never worked in a unit specializing in diabetes my professional knowledge of the disease and treatment was sparse. It was however unproblematic for me to communicate and make positive relationships with the clinical nurses who showed and explained to me about the standards regarding treatment and consultations and the research nurses who functioned as gatekeepers and with whom I reflected on my immediate perceptions as I conducted my interviews.

3.3.2 Visiting the clinic

I visited the clinic where I briefly presented the study to the six nurses and provided them with the poster they had also received through their e-mail. I had the opportunity to spend some time with one of the nurses in the clinic where she explained what the clinic offered and recommended the patients regarding equipment, education, consultations, etc. I also had the opportunity to observe two consultations with two older, experienced patients. The visit provided me with important knowledge regarding the specific context the patients are a part of and allowed me to meet and talk to the nurses whose help I needed to recruit patients for interviews.

The nurse told me about individual targets for glycemic regulation. She explained to me, that for all patients, individualized treatment goals are created and that they depend on factors such as age, comorbidities, history with hypoglycemia, personal resources, and needs, etc. The target can be reassessed in case of changes in the patient's condition such as pregnancy or the development of new comorbidities. The treatment goals concern glucose levels, blood pressure, cholesterol, and BMI and vary from glycaemic control without major fluctuations to avoiding daily symptoms.

We talked about the different blood tests as it seemed at the consultations that the primary focus in the conversation regarding blood work was glucose levels and cholesterol levels which made up less than half of the lab results. She explained that they often focused on these tests because they are closely connected to the patient’s lifestyle choices and that some blood tests were controlled to ensure the validity of others (for instance can abnormal hemoglobin cause an unreliable result of hba1c (glycaemic regulation)). The importance of different blood tests was also depending on the patient’s comorbidities because different diseases and treatments affect each other and the target for glycaemic regulation.

3.3.3 Recruiting participants

I brought with me written material for recruiting patients that was put in every consultation room. A revised version for patients was put in the waiting room where patients were encouraged to either send an e-mail or ask the nurse to add their information to the list in the consultation (Appendix 3).

This process of recruitment where thus influenced by whether the nurse or doctor asked their patients if they wanted to participate. The nurses told me that they assessed whether the patient would be able to participate based on different parameters. Reasons for not asking the patients to participate included severe physical or psychological disabilities, lacking language skills, or that the nurses simply forgot to ask. No participants were recruited by the doctors though they were informed about the study. The reason for this was not actively evaluated, but one of the nurses mentioned that they were more likely to forget as their programs were a combination of patients from different specialties and not just diabetes.

During the period of recruitment, I regularly visited the clinic to check if there were patients added to the lists, but also because the nurses expressed that my appearance in the clinic reminded them to ask for participants for my study. Three days a week I had an office in the nearby research unit and the nurses could call me if they had a patient who wished to participate immediately after the consultation. One participant was recruited in this way.

The interviews were conducted as the patients were recruited by the nurses. 14 patients signed up for interviews and were contacted by the author by e-mail, a phone call, a text message (SMS), or both. Four patients changed their mind because they could not find time to participate within the time limit of the study, two did not respond to several phone calls and texts and one was excluded as she was a trained physiotherapist with professional expertise in diabetes.

3.4 Data collection

The method for collecting empirical material for this study was a combination of visits to the Clinic for Diabetes and Hormonal Diseases at the Regional Hospital in Silkeborg and interviews with patients treated in this clinic. This section describes the collection of data as well as arguments for the chosen methods.

The empirical material used in the analysis is collected through qualitative semi-structured interviews with seven patients. Three participants were female, four were male. Two participants were in the age group 30-40 years, two were in the age group 40-60 years and three were in the age group 70-80 years. Four participants had type 2 diabetes and three had type 1 diabetes. Additional information about the participants' educational level, years with diabetes, and comorbidities are available in Appendix 4.

The interviews were held at the Clinic for Diabetes and Hormonal Diseases and the Unit of Quality, Innovation, and Research, both at the Regional Hospital in Silkeborg. The visits to the clinic took place in February and March 2024 and the interviews with patients were held in the period between the 5th of March and 20th of March 2024.

The number of interviews for a study will always be determined by several factors regarding both scientific and practical concerns. A scientific concern can be the aim of conducting enough interviews to reach a sense of saturation where new interviews are not bringing forth any new insights to the interviews already completed. This is to be balanced with practical concerns regarding the time and resources available to conduct interviews and a thorough analysis of the collected data (Brinkmann & Tanggaard, 2010). These concerns were also a determining factor in this study as well as the possibility to recruit relevant participants.

3.5 The informal interview

The purpose of the visits to the clinic was primarily to qualify my understanding of the problem described in the problem analysis and to create an interview guide with questions relevant to patients from this exact clinic.

Throughout my visits and presence in both the clinic and the research unit, I took the opportunity to observe and listen to the internal conversations of the healthcare personnel. I performed small informal interviews with the nurses and research personnel inspired by *"The Friendly Conversation"* by Spradley who describes the friendly conversation as casual, following certain cultural rules and containing different elements. (Spradley, 1979b). Some of the elements that were used in this case were *asking questions*, *lack of explicit purpose*, *expressing interest*, *taking turns*, *pausing* and *leave talking* (Spradley, 1979b). These elements were used in the conversation with the nurses and the research personnel to establish a casual relationship and basis for friendly and informal conversations. The informal interview allows the informant to navigate the conversation in a direction that is natural or important for them instead of being led by the ethnographer (Spradley, 1979b). Informal conversations or interviews could provide insight into facts and more general reflections or ideas that could prove valuable to the study.

The informal conversation was also used to establish rapport with the patients before starting the semi-structured interviews. This is described by Spradley as establishing a basic sense of trust between the informant and ethnographer to allow the information to flow freely from the informant to the interviewer (Spradley, 1979a). These interpersonal interactions are by Brinkmann and Tanggaard described as being structured by the conversation as a social practice and they are essential to the knowledge that can be achieved through the interview (Brinkmann & Tanggaard, 2010).

There was a small walk from the waiting area to the office used for interviews and for the first interviews, I used this time for casual small talk. This was effective in some cases, while the walking in other cases made the participants too strained to be able to speak.

3.6 Semi-structured interviews

The qualitative interview is a method that can be used in almost any phase of a study whether you need to evaluate a product or, as in this case, you are exploring the needs and goals of users with whom you are not familiar (Lazar et al., 2017). It is an attempt to uncover the experience of a certain phenomenon from the perspective of another person.

When conducting a semi-structured interview, the interviewer is leading the conversation with a specific agenda in mind, often guided by prepared questions in an interview guide (Brinkmann & Tanggaard, 2010). A strength of the semi-structured interview is that the format allows the interviewer to deviate from the interview guide to explore the topic in a broader and deeper sense as comments or statements made by the interviewee can lead to questions and insights that the interviewer did not think of beforehand (Lazar et al., 2017). It can however also be a bigger challenge to the interviewer because it demands ongoing reflections on when to deviate from the guide to follow a lead and when to move the interview along (Lazar et al., 2017).

To generate a more visual understanding of the needs and wishes of the participants in this study, the interview included a practical exercise in the form of a sketching exercise. Sketching is a method that can be to produce low-fi prototypes for conceptual- and/or concrete design (Sharp et al., 2019). This prototype can be used to explore and evaluate ideas and can function as a communication device and clarification of vague descriptions (Sharp et al., 2019). The disadvantages of low-fi prototypes include the limited possibility to interact with the prototype, limited resemblance of the real product, and poor detail specification which was however not relevant to this study. The drawn format of a low-fi prototype has the advantage of being simple, cheap, and quick to produce which is appropriate for the use in this study (Sharp et al., 2019). In relation to this study, a challenge is that many people find the activity difficult as they feel inhibited by the quality of what they draw. It was however estimated that the benefits of the sketching exercise exceeded the disadvantages. The interview format chosen for this study was hence a qualitative semi-structured interview including a sketching exercise.

3.6.1 Interview Questions

The interview questions used through the interview were inspired by several sources including the information achieved during my visit to the clinic, findings from other studies, and Tanggaard and Brinkmann's chapter on how to use the interviews as a method for research (Brinkmann & Tanggaard, 2010).

Types of questions

Brinkmann and Tanggaard describe different types of interview questions such as introductive questions, follow-up questions, specific questions, structural questions, interpreting questions, and direct questions (Brinkmann & Tanggaard, 2010). The introductive questions aim to make the interviewee talk about something they know and often relate to concrete episodes. As my interview also aimed to understand the needs and goals of the interviewees, these question types were combined with high-level questions regarding existing and/or desired functionalities as these questions can help to understand the needs and challenges of this specific context (Lazar et al., 2017). These questions are characterized by being non-specific and not aiming for detailed responses, though it turned out detailed answers were easier for some interviewees than answering more broadly and abstractly.

Depending on the participant's reaction to the questions I adjusted my style from being active and aggressive, challenging the interviewees to elaborate and argue for their answers to being empathetic, asking supporting questions, and expressing my understanding of why the questions could be difficult to answer. Adjustments in style allow the interviewer to take into consideration the unique situation and relation to the interviewee which is essential to what knowledge is procured through the interview (Brinkmann & Tanggaard, 2010).

3.6.2 The interview guide

The interview guide functioned as a loose structure for the interview and supported me in getting back on track when the interviewee went in a direction not relevant to the study. I split the guide into three cells: Theme, question, and notes. The note column was used during the interview to note important observations or answers I wanted to return to. The interview guide is available in Appendix 5.

Adjusting the interview guide

The first interview conducted was planned a few days ahead of the rest to ensure time to adjust the interview guide if necessary. The patient in this interview responded with exhaustive answers to all questions and was, after a few seconds of hesitation, enthusiastic while drawing and explaining his sketch of how he imagined an improved presentation of his lab results. Hence, only slight adjustments were made before continuing the line of interviews.

After a few more interviews it became evident that the talkative first patient was to be considered an outlier as it in some cases proved difficult to keep them talking or encourage them to make a sketch.

Some also seemed embarrassed and tried to avoid answering clearly to questions regarding their understanding of the specific test results. Hence, I adjusted the interview guide by inserting a broader introductive question at the very beginning of the interview and paid more attention to explaining the purpose of the interview, stressing that this was not to be interpreted as a test of their abilities to interpret test results, but a conversation leading to a better understanding of the user perspective.

3.6.3 The interview

The participants were offered coffee or water and assigned a place across the table from the interviewer. A consent form was placed with their seat, and a bend-over laptop was placed at the side of the table showing the first page of the presentation used during the interview (Appendix 7). Placing the laptop like this hid the keyboard and made the laptop appear like an oversized tablet, aiming to create some resemblance with the units the participants were assumed to primarily use while maintaining a bigger screen size. This allowed for both interviewer and participant to see the screen easily and use zoom and swipe functions through the touch screen.

Introduction

The interview began with a short introduction of the purpose of the interview, the participant signed the consent form and was informed that the interview would be recorded and that they would be anonymous in the report. Introductive questions regarding age, educational level, number of years with diabetes, how often they view their lab results, etc were asked at the beginning of the interview. These questions were easy for the interviewee to answer without much reflection. This short introduction allowed me to assess their level of comfort in the situation and adjust my interview style, language, and level of explanation to my questions. Most patients were also asked to describe their everyday lives with a special focus on actions or precautionary measures related to their diabetes. These introductive, easy questions are also useful for building trust and preparing the interviewee for harder questions (Lazar et al., 2017).

The participants were then shown a display from Sundhed.dk displaying the first page you reach upon login. Following this, the interviewer navigated through the screenshots from sundhed.dk using the menus as one would on the real webpage, which was two clicks. When arriving at the example of lab results from a patient with diabetes (Appendix 7), they were asked open questions that aimed to invite the patient to talk about their experience with interpreting test results. This was combined with follow-up questions that could be both specific and interpretive to ensure the correct understanding of their comments on the tabular test results. The questions chosen depended on how elaborate they were in their description of the tabular view of the test results they were shown.

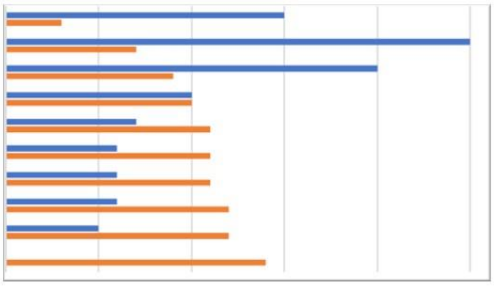
Sketching

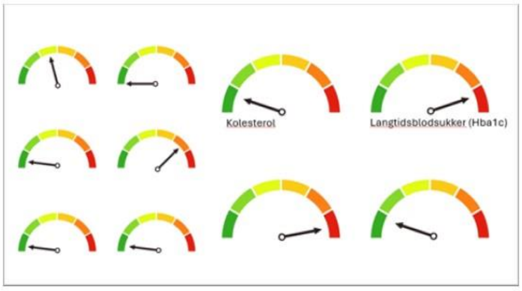
After the first part of the interview with introductive questions, and a conversation regarding the participant's experience with the existing solution, they were equipped with paper, crayons, and markers in different colors and asked to sketch how test results could be presented if not tabular as the example. If they had no idea how to draw anything they were reminded of the things they mentioned earlier in the interview and/or suggested to think about how graphs or other visuals could display the results. If they still did not have any idea how to start, they were shown the constructed examples (Appendix 7) one by one and encouraged to sketch with these in mind, and asked questions about what they liked and did not like in the different examples.

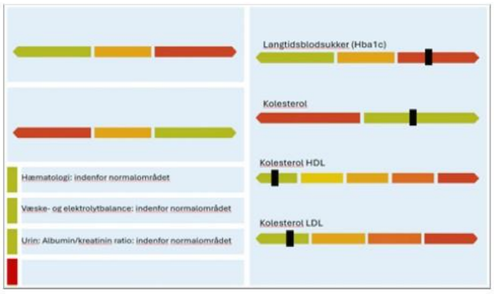
After making their drawings they were asked questions regarding their motivation for looking at test results and the context they look at it.

Examples

All patients except for one were also shown four different visualizations of how the test results could be displayed and asked questions regarding what they liked or disliked. This functioned well to discover the participants' immediate reactions to the level of detail, amount of information, and usage of colors they preferred.







The participants were encouraged to consider if the examples inspired them to add new elements or other adjustments to their drawings. They were also asked if they wanted to add anything else to the interview.

After the interview

After finishing each interview, I made a note of my observations and how I generally experienced the interview. These notes were not conducted in a specific or systematic manner but were made to help me remember the situations and the observations I made that would not be obvious through the transcripts when analyzing the interviews later.

3.7 Processing collected data

The recorded interviews were transcribed continuously and coded when all interviews were transcribed. This section presents how the interviews were transcribed and how data was coded.

3.7.1 Transcription

The interview was performed in Danish since this is the native language of participants and therefore transcribed in Danish. The interviews were transcribed to allow a systematic and thorough coding process and to use particularly meaningful citations in the analysis. These citations are translated to English in the analysis which encounters a risk of losing nuances in the translation as some words cannot be translated precisely. The translation has been performed with this awareness and is also translated back to identify issues that can make the meaning unclear (Brinkmann & Tanggaard, 2010). The citations can be found in original form in the transcription material Appendix 2.

The interviews are performed orally which requires certain editorial choices when transcribed to be meaningful in writing. A conversation contains many small acts that are natural and meaningful in the context but confuse the point when written. This can be incomplete sentences, pauses for thoughts, onomatopoeia, interjections, and encouraging words or sounds made while another person is talking. In this case, a part of the conversation also refers to physical objects such as the computer screen with test results and the sketches made by the participants that are not easy to follow when reading the transcript alone. The transcription is therefore performed following a method inspired by (Brinkmann & Tanggaard, 2010). After listening to the first interviews, I made some criteria to make the spoken language more understandable and readable:

- Abstain from interjections as "aah", "umm" and "mhm" “yes” or “okay” from the interviewer in cases where this is only functioning as encouragement for the participant to continue.
- Comments from the writer will be written in "()" to elaborate the understanding of the spoken word/words.
- There will be used improved language when transcribing to make the citations more understandable and readable.

The method is chosen to make the spoken language as clear as possible and the citations both readable and true to their original.

The transcription was divided into three phases:

1. The recorded interview was transcribed using the website goodtape.io. This is a service provided by the Danish news media Zetland and uses AI technology to make transcriptions. The page describes their handling of the uploaded material as fully GDPR-compliant (Goodtape, 2024) and assessed appropriate for this purpose by the author.
2. The interview was listened to by the author while reading the transcribed text. Corrections were made and comments regarding actions or other notes made by the author during the interview.
3. The interview was listened to while reading the transcript to ensure a correct transcription and that all notes made during the interview were added.

4. Analysis

When doing qualitative analysis of empirical material such as field notes or interviews, a deductive or inductive approach can be used, depending on the purpose of the study. For this study, an inductive approach for the coding of the material is chosen. In opposition to the deductive approach where the themes for coding are decided beforehand, the inductive approach can be described as an attempt to be as open as possible to identify themes that originated from the empirical material (Overgaard Mogensen & Bundgaard, 2018).

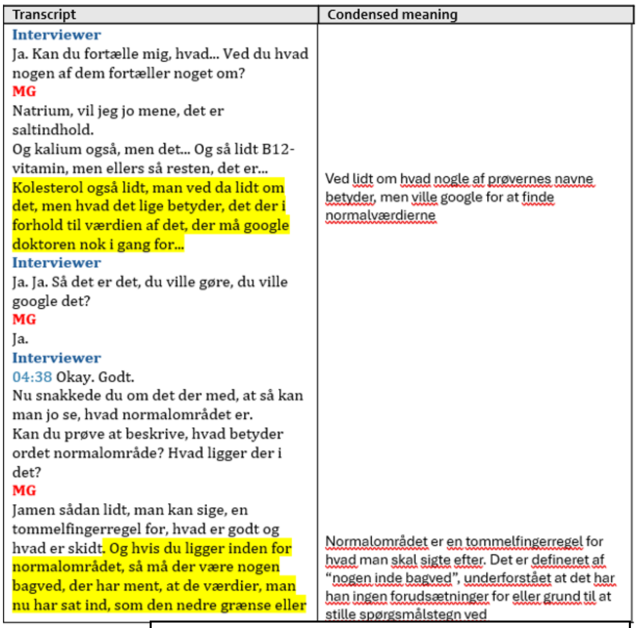
As previously stated, the coding of interview data aim to disentangle statements and actions from the situational context they appear in to form new meaning. This approach is central to follow the hermeneutic phenomenological tradition that emphasizes descriptions and interpretation of meaningful content (Brinkmann & Tanggaard, 2010).

This section will describe how the empirical material collected through interviews with patients is coded inductively resulting in six themes.

4.1 Condensing meaning

After finishing the transcripts of the interviews, I put them into tables to start the analysis by transforming the transcriptions into condensed units of meaning.

The first part of my process was to fill in the entire interview transcript in the column to the left. Then I read the interviews through one by one, condensing parts of the conversation into shorter descriptions of meaning. This allows me to get an overview of the content of my interviews and the condensed text will be helpful when coding as some points from the interviewees are made through a longer conversation and can be difficult to encapsulate in the coding process. Besides this, I marked citations that were descriptive of a certain point and were expected to be useful for analysis later in the process. The condensed sentences were written in the next column. Table 1 shows a small example of the process, while tables are available in full length in Appendix 2.



Transcript	Condensed meaning
Interviewer Ja. Kan du fortælle mig, hvad... Ved du hvad nogen af dem fortæller noget om? **MG** Natrium, vil jeg jo mene, det er saltindhold. Og kalium også, men det... Og så lidt B12-vitamin, men ellers så resten, det er... Kolesterol også lidt, man ved da lidt om det, men hvad det lige betyder, det der i forhold til værdien af det, der må google doktoren nok i gang for...	Ved lidt om hvad nogle af prøvernes navne betyder, men ville google for at finde normalværdierne
Interviewer Ja. Ja. Så det er det, du ville gøre, du ville google det? **MG** Ja. **Interviewer** 04:38 Okay. Godt. Nu snakkede du om det der med, at så kan man jo se, hvad normalområdet er. Kan du prøve at beskrive, hvad betyder ordet normalområde? Hvad ligger der i det? **MG** Jamen sådan lidt, man kan sige, en tommelfingerregel for, hvad er godt og hvad er skidt. Og hvis du ligger inden for normalområdet, så må der være nogen bagved, der har ment, at de værdier, man nu har sat ind, som den nedre grænse eller	Normalområdet er en tommelfingerregel for hvad man skal sigte efter. Det er defineret af "nogen inde bagved", underforstået at det har han ingen forudsætninger for eller grund til at stille spørgsmålstegn ved

Table 1. Condensing meaning

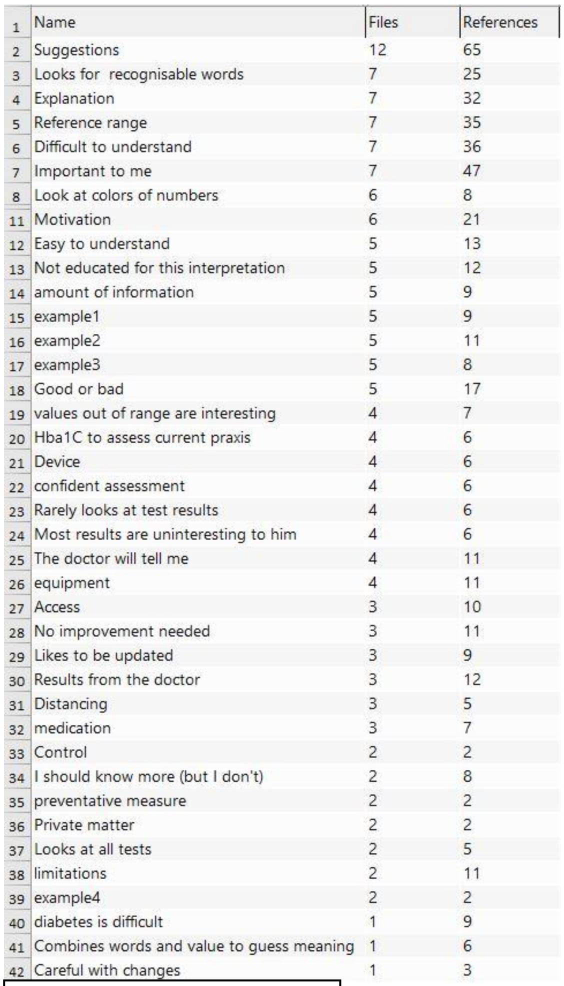
4.2 Coding

The next step was to code the transcript into codes collecting and describing the units of meaning reflected as direct quotations from the transcript as well as the formulated condensed meanings of units. In the example provided by Brinkmann & Tanggaard, the analysis and interpretation are noted in the column next to the condensed meaning while reflecting on the entire material and more explicit theoretical references (Brinkmann & Tanggaard, 2010). In this study, I chose to use NVivo software for this part. The software supported me in keeping track of a relatively large amount of data and allowed me to look at the data from different angles through queries, visualizations, and other functions that will be described as they are used during the coding process.

The transcripts were uploaded separately and their sketches and basic parameters I asked the participants for were connected to their cases. These parameters were: Age, sex, education length, type of diabetes, number of years with diabetes, comorbidities, frequency of test, and device for looking at test results.

Each table with transcript and condensed text was imported to NVivo and I reviewed each interview coding meaningful statements and condensed text inductively. When coding condensed text formulated by the author it was marked with (KHS) at the end of the sentence to ensure clarity that this represents a point of view from the participant, but it is not his or her exact words. This was chosen in cases where the citation in itself was unclear, or the meaning was created through a sequence of questions and answers. Because I went through the entire material to make the condensed units of meaning I had an idea of what categories and themes were represented in more than just one interview. The coding at this point helped me to a systematic approach to find out what themes were most prominent.

After coding all the transcripts, I had 41 different codes. The lists of codes at this point are displayed in Tables 2 and 3 respectively sorted by number of references and by number of files (interviews) they appeared in.



1	Name	Files	References
2	Suggestions	12	65
3	Looks for recognisable words	7	25
4	Explanation	7	32
5	Reference range	7	35
6	Difficult to understand	7	36
7	Important to me	7	47
8	Look at colors of numbers	6	8
11	Motivation	6	21
12	Easy to understand	5	13
13	Not educated for this interpretation	5	12
14	amount of information	5	9
15	example1	5	9
16	example2	5	11
17	example3	5	8
18	Good or bad	5	17
19	values out of range are interesting	4	7
20	Hba1C to assess current praxis	4	6
21	Device	4	6
22	confident assessment	4	6
23	Rarely looks at test results	4	6
24	Most results are uninteresting to him	4	6
25	The doctor will tell me	4	11
26	equipment	4	11
27	Access	3	10
28	No improvement needed	3	11
29	Likes to be updated	3	9
30	Results from the doctor	3	12
31	Distancing	3	5
32	medication	3	7
33	Control	2	2
34	I should know more (but I don't)	2	8
35	preventative measure	2	2
36	Private matter	2	2
37	Looks at all tests	2	5
38	limitations	2	11
39	example4	2	2
40	diabetes is difficult	1	9
41	Combines words and value to guess meaning	1	6
42	Careful with changes	1	3

Table 2. Codes sorted by files

1	Name	Files	References
2	Suggestions	12	65
3	Important to me	7	47
4	Difficult to understand	7	36
5	Reference range	7	35
6	Explanation	7	32
7	Looks for recognisable words	7	25
8	Motivation	6	21
9	Good or bad	5	17
10	Easy to understand	5	13
11	Results from the doctor	3	12
12	Not educated for this interpretation	5	12
13	No improvement needed	3	11
14	The doctor will tell me	4	11
15	example2	5	11
16	equipment	4	11
17	limitations	2	11
18	Access	3	10
19	Likes to be updated	3	9
20	amount of information	5	9
21	example1	5	9
22	diabetes is difficult	1	9
23	Look at colors of numbers	6	8
26	I should know more (but I don't)	2	8
27	example3	5	8
28	values out of range are interesting	4	7
29	medication	3	7
30	Hba1C to assess current praxis	4	6
31	Device	4	6
32	confident assessment	4	6
33	Rarely looks at test results	4	6
34	Most results are uninteresting to him	4	6
35	Combines words and value to guess meaning	1	6
36	Distancing	3	5
37	Looks at all tests	2	5
38	Careful with changes	1	3
39	Control	2	2
40	preventative measure	2	2
41	Private matter	2	2
42	example4	2	2

Table 3. Codes sorted by references

4.3 From codes to themes

The following section will describe the process of organizing the 41 codes into 6 themes.

Reviewing the content of the codes it became clear that some of them were closely connected and could be grouped into fewer codes with broader, but still covering titles. The process can be split into two steps where I first grouped the smaller codes into bigger ones. The process is described in section 4.3.1 and visualized in Table 4.

The second step included reviewing the codes paying more attention to creating themes and titles that described the content and that related to the question asked in the problem statement. This is described in section 4.3.2 and visualized in tables 5 and 6.

4.3.1 First step

The small code *careful with changes* was merged with *suggestions* as the content implicitly was a suggestion.

The code *Important* was merged with *amount of information* and *most results are uninteresting* as they all related to what the participants felt were important for them to look at. This can be expressed by saying "This is important" or by telling about what is not important.

Strategies were a fitting title for the codes *looks for recognisable words, look at colours of numbers, looks at all tests,* and *combines words and values to guess meaning*. These statements refer to what the participants look for to find meaning when they look at the results.

Feeling sufficiently equipped was a new code consisting of codes that all refer to statements that point to participants who feel they can interpret their test results and use them for different aspects of managing their disease. The new code was created by merging *easy to understand, confident assessment, Hba1C to assess current praxis, no improvement needed, likes to be updated, private matter,* and *preventative measure*.

The codes *good or bad, medication,* and *control* were put together with *motivation*

Distancing included *not educated for* this, *rarely looks at test results*, *the doctor will tell me, results from the doctor, I should know more (but I don't), limitations, diabetes is difficult*. These codes all related to statements where participants explained a reason for something being out of their control or not to be expected for them to be responsible for.

Equipment holds all statements within *device and access* as they all refer to technical issues and aspects.

Reference range and *difficult to understand* were not changed as the content did not appear to be closely connected to other codes.

To ensure my possibility to trace back the changes I made while coding and for practical reasons I kept the statements within the original codes, as subcodes under the code title.

The list of codes was now reduced from 41 to 11.

Code titles after coding interviews (41)	**Code titles after 1. step (11)**
Suggestions ~~Careful with changes~~	Suggestions
Explanation	Explanation
~~Reference range~~	Reference range
Difficult to understand	Difficult to understand
Important ~~amount of information~~ ~~Most results are uninteresting to him~~	Important
Strategies ~~Looks at colours of numbers~~ ~~looks at all test results~~ ~~combines words and values to guess meaning~~	Strategies
Motivation ~~Good or bad~~ ~~Medication~~ ~~Control~~	Motivation
~~Easy to understand~~ ~~confident assessment~~ ~~Hba1C to assess current praxis~~ ~~No improvement needed~~ ~~preventative measure~~ ~~Likes to be updated~~ ~~Private matter~~	Feeling sufficiently equipped
Examples comments	Example comments
Equipment ~~Device~~ ~~Access~~	Equipment
Distancing ~~Not educated for this interpretation~~ ~~Results from the doctor~~ ~~Rarely looks at test results~~ ~~The doctor will tell me~~ ~~I should know more (but I don't)~~ ~~diabetes is difficult~~ ~~limitations~~	Distancing

Table 4.

4.3.2 Second step

The code *suggestions* were not describing anything in itself and I decided to look at it from a different angle to see if this could help me create new codes that were more describing and connected to my problem statement. I started making a code with the working title “facilitators” to group all statements from the existing codes referring to things the participants found to function well or wished for. This logically meant that most of the content in *suggestions* was transferred to here, almost eliminating that code. However, the new code also contained statements from other codes. An example of this is statements from the code *motivation* where I initially coded statements regarding "is it good or bad" that can be considered a motivation. These statements can also be understood in the context that some participants just want to know if their numbers are indicating that they are doing okay or not.

"I need to know: Am I within the limits or not?" (PO p. 16)

This work led me deeper into the material and as I also reviewed my notes from the interview, I thought about how most of the informants seemed a bit reluctant to share their experience with me. I came across the quote

"Yes, that's actually what controls how I manage my diabetes" (EN p. 10)

Combining this quote with readings of sources unrelated to this study regarding the design of smart home technologies not supporting *"the mess of everyday life"* (Strengers, 2014), made me realise that the confrontation with the test results could also be a reminder of them (not) doing well in managing their disease and adjusting their lives sufficiently to take responsibility for their health. The numbers do not consider the mess of everyday life, yet they represent an unquestionable judgement on their efforts to manage their disease. This might explain the reluctant attitude from the participants as a feeling of guilt or embarrassment that they were only to a limited degree able to interpret their results. This was an important aspect of the meeting with test results.

To continue my work with adjusting the codes I used the "coding stripes" function to find statements that were coded into more than one code. An example of this can be found in Appendix 8. This showed me that the code *explanations* and what was left of the code *suggestions* contained statements that were also coded into other codes that better represented the most important findings from the interviews. The code *suggestions* and *explanations* were therefore deleted.

The code *example comments* were reviewed in the same way. The statements here were the participants' comments on the examples of how test results could be visualised that I showed them during the interview. The code did not describe anything independently, and reviewing the statements using the coding stripes, almost all statements were represented in other codes.

The code *motivation* contained the subcodes medication, control and good or bad. Reviewing them showed that they were more relevant if distributed with *medication* and *control* as subfolders with *not just test results* and *good or bad* became subfolders at *helps understanding results*. The code *motivation* was thereby eliminated.

The subcode *limitations* contained statements primarily regarding economical or technical limitations the participants knew or assumed were responsible for not providing the optimal functionality for them. The subcode was renamed *barriers out of my control* and the code *access* was moved to here.

The code *difficult to understand* contained statements regarding what the participants expressed difficulties understanding or finding and was not changed further.

The subcode *device* was deleted as it only contained statements regarding what device they used, which is registered in the cases.

The code *Amount of information* was renamed to *too much information* and moved to *difficult to understand*. The statements within *important* were almost all represented elsewhere, which was confirmed by the coding stripes showing coding density. The code was initially created because I saw that most participants pointed to 2-3 results they looked at and then ignored the rest. However, this is reflected in the codes *too much information, strategies* and *helps understanding results. Important* was hence deleted.

After this, five of the original codes were deleted and two new ones were created, resulting in 8 codes as presented in the table below.

Code titles after 2. step (11)	**Code titles after 3. step (8)**
Difficult to understand	Difficult to understand
Equipment	Equipment
Strategies	Strategies
Distancing	Distancing
Feeling sufficiently equipped	Feeling sufficiently equipped to understand
Reference range	Helps understanding results
~~Explanation~~	Not just test results
~~Important~~	Reference range
~~Example comments~~	
~~Motivation~~	
~~Suggestions~~	

Table 5

At this point, I attended a meeting with MedCom, a joint public organisation, funded and owned by the state, regions and municipalities. MedCom developed the standards supporting the exchange of data between labs and the presentation of results to the citizens at sundhed.dk. The meeting was set up to discuss recent research in the area which provided me with the opportunity to gain knowledge of their perspective and present my findings.

Presenting and describing my 8 codes made it clear to me that some were too interconnected to stand alone and had to be combined to avoid repetition. During this process, I thus reduced the number of codes further.

The code *reference range* was merged with the code *strategies* as the participants' reflections on the reference range were a part of their strategies to make sense of the test results. The code *Feeling sufficiently equipped to understand* turned out to make more sense if the content were used in relation to the codes *when it is difficult to understand, strategies and helps understanding test results* as the statements often referred to issues that to some participants were difficult and simple to others.

Code titles after 3. step (8)	**Code titles after 4. step (6)**
Difficult to understand	When it is difficult to understand
Equipment	Equipment
Strategies	Strategies
Distancing	Distancing
~~Feeling sufficiently equipped to understand~~	Not just test results
~~Reference range~~	Helps understanding results
Helps understanding results	
Not just test results	

Table 6.

This leaves codes that constitute the themes synthesised from the empirical material collected through the six interviews. The themes are:

- **When it is difficult to understand**
- **Helps understanding test results**
- **Strategies**
- **Not just test results**
- **Distancing**
- **Equipment**

4.4 Themes

In the following section, the themes will be presented.

4.4.1 When it is difficult to understand

Considering the known challenges described in the study's introduction and problem analysis the fact that the laboratory test results were difficult to understand is not surprising. The difficulties are however not universal for all portals or citizens. This theme contains some of the well-known issues but also issues tightly connected to the diabetes test results.

(Too) much technical information

The standard set of test results for the patients contains rows with 19 different tests spread on 5 different headlines and 3 columns (Appendix 7).

Some participants find the amount of information to be overwhelming making it difficult to figure out what tests are important to them. One participant expressed it this way:

> *"I think perhaps that for those who work in the [healthcare] system and know all the terms and what they mean, it's not a problem. But for the*

> *common man who plays music and sings and goes to work and has all sorts of things on their mind (...), it's a lot."*
>
> *(OM p. 9.)*

The interviews show that the amount of information combined with technical language that makes it difficult for several participants to distinguish test results from each other leads to frustration and resignation. When asked if they could explain some of the test results, one participant defensively shrugged his shoulders and told me that he had not looked that much at it while another participant described her difficulties in finding the most important results this way:

> "*Because it says all sorts of erm... All sorts of different haemoglo... I mean, the blood test (…) So there are different types of glucose, or whatever the hell it's called.”*
>
> *(AH p. 9)*

This patient knows that glucose levels are important to her, but the word “glucose” is a part of three different test names. She does not see other intuitive clues that can help her and gives up on interpreting the results on her own.

Another participant also describes difficulties understanding many of the test results, but seems to have a clear expectation of being presented with more information than he has any use making him less frustrated:

> "*Well, there are, of course, some details here that I have no idea what are. Sodium and creatinine and potassium etc. I don't know why they measure it, I've never heard anything about it. So there's more information than I can use for anything (…) I guess it's something that the doctors or nurses look at. But it's not something that matters to me”.* *(PO p. 5)*

This participant has many years of experience with type 1 diabetes and explained that his treatment has been severely improved over the last years in comparison to earlier. A similar statement was made by another participant with type 1 diabetes who started the interview expressing how much the treatment and possibilities to keep track of the numbers have improved since she was a child. In her opinion, she did not have any difficulties interpreting her results and could not see any point in making a sketch during the interview as the existing presentation worked fine for her. A third participant who also found the existing presentation sufficient was a parent of a teenager with autism and type 1 diabetes. Even if they did not understand all the results, they approached the interpretation with more confidence than the participants with type 2 diabetes. This can for some of the participants might be relate to them having more experience and education related to their disease or that they are typically more closely monitored as patients are often quite young when diagnosed, and they are at greater risk of acute severe distress than patients with type 2 diabetes (Almdal, 2024) (Almdal, 2023).

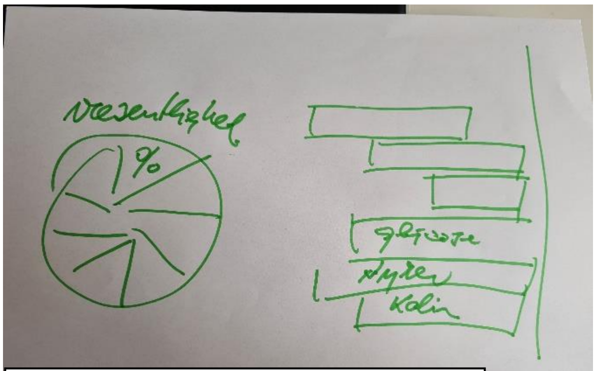
4.4.2 Helps understand test results

This theme is defined by statements regarding aspects that the participants have indicated would be helpful to them in their attempt to understand and use their test results regarding diabetes. Besides the various statements, the sketches made during the interviews are also a part of this theme as they make up a visual display of the participants’ thoughts and ideas of what the perfect visualisation of test results is to them.

More emphasis on specific test results

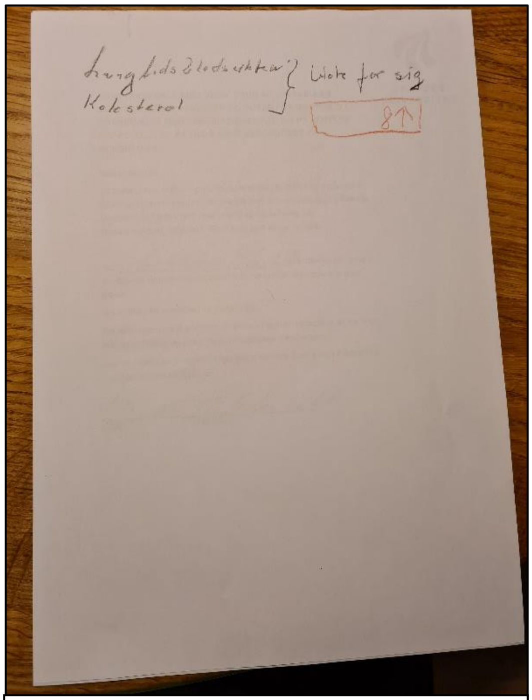
The sketches along with the conversations with participants show a wish to be presented of either exclusively 2-3 results or to have the most relevant results displayed with more emphasis, making it easier to filter away the less important results. One participant expressed this about the sketch on the right:

> *"It should pop up and make me say 'Hey, Madsen! How does what's important to you look? Your kidneys, your potassium, your sugar?' and it could also be other things that are important".* *(OM p. 12)*

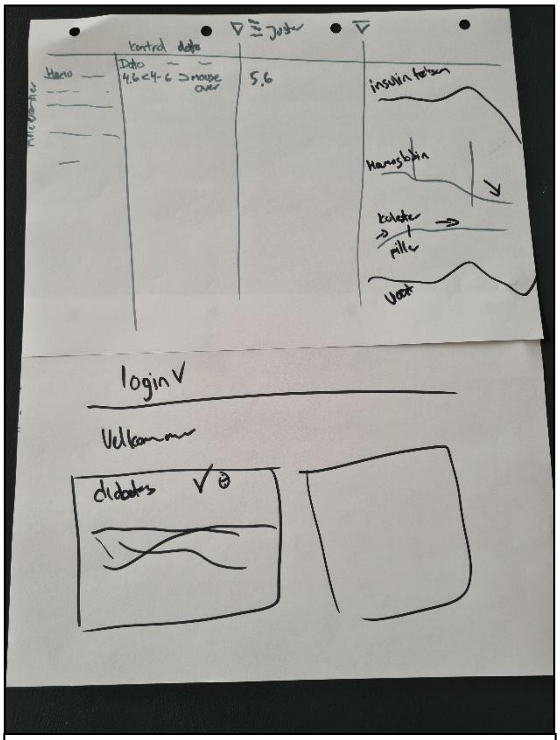


Sketch 1

During the interviews it became clear that glucose is a result all participants wished to be presented with along with an explanation of what the result means to them. All patients stated that the test result for long-term blood sugar (HbA1c) was one of the results they looked for, and most of them also mentioned it about their sketch as a result they wanted to be able to easily identify. Another value that was mentioned by several participants that they wished to be emphasised was cholesterol. Two participants explicitly noted it on their sketches while others mentioned it in the interviews as a value, they wanted to be able to find.



Sketch 2. This participant stated that the optimal presentation to him was to highlight cholesterol and long term blood sugar.



Sketch 3. Cholesterol and other results should be displayed in relation to each other along with information on changes in treatment. Test results should be grouped so they are easy to connect to a contact with the hospital.

Hence, there is a wish to make the most relevant results stand out more clearly instead of having to search through, in this case, 19 different test results, to find the two or three results that are relevant to them.

Language

Several participants mentioned that the language used in the presentations made it difficult for them to be certain of what result they were looking at. One participant said:

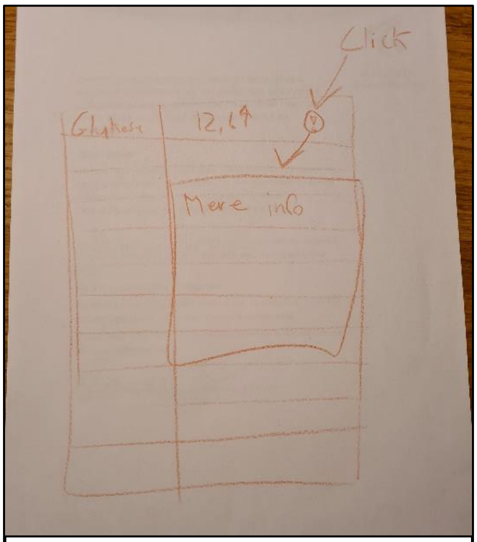
> *"Well, for me to know anything specific, it should say kidney count, liver count, and blood sugar count. Not all that stuff."* *(AH p. 25)*

This opinion was shared among all participants with type 2 diabetes in opposition to the three participants with type 1 diabetes who seem to have accepted that this is the terminology used in this context. However, the interviews show that none of them consistently use the acquired terminology but prefer the Danish versions of the test names when speaking. As stated earlier, the test Hb1ac is a test the participants all agree is important to them and several of them therefore looked for the word "glucose". In the presented test results three different glucose counts (long-term, estimated mean, and current) are included which made it difficult for some of the participants to distinguish them and connect them with the associated value. Besides this, most patients knew that they were to look for a test named something with haemoglobin, however, two different tests contained this word. One of the participants expressed her confusion by saying:

> *"…and up there is also some haemoglobin, and there are a few different abbreviations, well, I don't know what they are. "* *(AH p. 31)*

Another participant seemed to be well informed about the names and meaning of the tests most important to him, but he interchangeably used the words hba1c, long-term blood sugar and haemoglobin when talking about hbA1c which is also reflected on his sketch (sketch 3):

> *"I know it's the haemoglobin that is at the centre of it all (…) because it's the same term that's used. So because they kind of call it the same thing all the way through in consultations and [glucose]testing and in here, it works fine".* *(PO p. 22)*



Sketch 4: It should be easier to access more information.

Customisable presentation

The tabular presentation of test results recurred in two of the sketches (above and to the left). Another participant also clearly expressed that she found the tabular presentation easy to use and was not able to imagine an alternative before she was presented with the four examples. While making sketch 4, the participant said that it is dangerous to change what people are already used to look at and to make the presentation too fancy. He states that

> *"It's okay that it's boring. And well, intuitive and functional".* *(MG p. 15)*

The sketch here also displays a continued use of arrows to signal an elevated value and a wish to access explanations or further information about the tests through the page with test results for example with a mouse over function. During the interviews, most participants recognised arrows as a sign of elevated or decreased levels, but one interpreted the arrow pointing up as a symbol of the result being elevated compared to the last test which is not correct.

Some participants, including the ones who found the tabular presentation manageable, expressed that the possibility of customising the presentation to fit your individual needs would be good. One participant said that if he could choose between different templates, it would be quicker and easier for him to interpret the results which would motivate him to look at his lab test results more often:

> *"Because I find that when information is relatively simple, you are more inclined to look it up."* (CS p. 22)

Simple and easy are not the same for everybody, but if the information is not presented in a way that makes sense to the individual, it is less likely that they look at it.

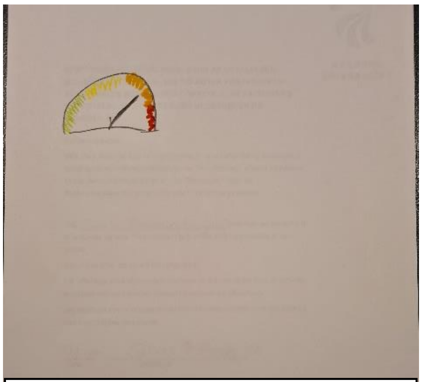
A participant, who has had difficulties stabilizing his weight after changing to pump and sensor, explains that the possibility of combining different parameters such as weight, changes in medication, and agreements made in consultations with test results would be an advantage to him:

> *"If you can see this and track these things then it will be easier to catch it earlier. Because you can see the trends."* (PO p. 22)

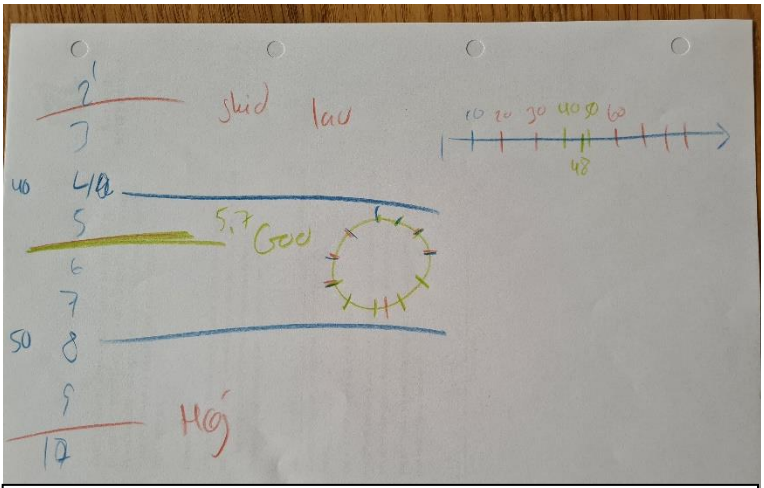
Visual cues

As well as arrows, one of the visual cues that were continued by the participants was the use of colours to signal "good" or "bad". Sketches 2, 5, and 6 all display a more distinct and emphasised use of colours than the one at sundhed.dk where only the number itself is marked with a colour. To some patients it was sufficient to know if the result was "good or bad" and some preferred the exact number.

The colours thus function in two different ways for the patients; To some, the colours are a way to see if you are within the normal range or not and to others they function as a way to quickly find the numbers and from there assess the results. The speedometer example that inspired sketch 6 was evaluated positively by several participants whereof one expressed that this is because the symbol is easy to understand for everyone with a driver's license and because even if there are several results on the same page they can be sorted with a glance at the position of the needles (CS p. 19). It seems that colours are of value to the patients but that they would like them to be even more emphasised.



Sketch 6. It was difficult to imagine alternative presentations but the speedometer from the example section of the interview could be an improvement.



Sketch 5. Colours should indicate if hbA1c or the present glucose levels are elevated.

4.4.3 Strategies

The visual cues as well as other aspects that the participants expressed to be helpful are related to the strategies they use to interpret their test results.

Words, colours and arrows

When asked what they looked for when initially looking at their results, most participants first mentioned that they looked for recognisable words and names of the test they believed to be the most important to assess, but that they also looked at the colours of the numbers and arrows. The colour helped them focus their attention on what they should look more closely at. Some patients were only interested in a few tests, ignoring the rest regardless of whether the numbers were red or black. One participant says*:*

> *"Well, I think it will really be limited to that. So the two things I've mentioned which is the long-term blood sugar and cholesterol levels"*
> (CS p. 8)

The strategy of trying to focus on a few tests they consider important and assess their current practice this way. One participant said that she was only interested in in what was out of range (SH p 7) pointing to a strategy where the eyes identify the colour and the number before the name of the test. To some participants this is sufficient, and they proceeded to investigate the meaning of the number, if necessary, but other participants describe that they look at each number regardless of colour and compare them to the reference range (MG p 3, EN p 3).

Reference range

The participants have different approaches to how to compare their results to the reference range that both depend on how they access their results (browser on computer, phone or through an app) and how they understand the reference range. One of the participants who like to look at all the results explains that:

> *"… what I do is, I look at them all because then I can see what's normal.*
> *(EN p. 2)*

This strategy makes sense because she appreciates seeing all the numbers and the presentation in the phone's browser supports it by allowing her to look at more test results and reference ranges at once while you must click on the individual tests to see the reference range if you are using or a computer browser or the app MinSundhed. Most of the participants relied on the colour and arrow to present the results as they did not remember the reference ranges for the different tests. Two participants with type one diabetes for many years were aware that the reference range for people with diabetes is slightly different than for others which they expressed to be a part of their assessment of their test results, yet they still describe that they are satisfied if their results are within the normal reference range. This indicates that colour-coding the results by the reference range defined by measurements from healthy people can be misleading to patients, even the ones with many years of experience with diabetes.

Consulting dr. Google

Most participants mentioned Google as a source of information, some of them with an ironical distance using names like dr. Google or Uncle Google to imply that they are aware of it not being a completely trustworthy source of information. One participant describes his strategy to understand his diagnostic tests like this:

> *"… and then it turned into a Google Doctor thing, because what does this [indicate] when it's too high? Because it doesn't explicitly say that this is what it is, then you're in the risk group for diabetes".* (MG p. 2)

Some also mentioned the risk of finding information that was misleading and inducing stress or anxiety:

> *"And I'm one of those people, I don't know if it's my generation, but I google. (..) And then, sometimes, horrible things show up. I mean, you either have cancer or, well... something completely…"* (SH p. 5)

Only one participant knew that an explanation from the patient handbook was accessible from the result page but described that it had not always been useful to her, so she used Google instead. Trying to find information online is a strategy six of the participants use and only two ask family members with knowledge of diabetes for advice.

4.4.4 Not just test results

This theme emerged because I observed many statements and changes in tension and mood during the interviews. Some of the patients said that their test results were a private matter that they only discussed with their nurse or doctor and felt the need to explain or excuse while they told me that their own test results were not always within the reference range:

> *"I mean, the blood sugar could be... Well, it could be better. I'm having a bit of trouble getting it all the way down there. Because I exercise a lot and go to the gym three times a week, I don't dare to run it too low".* *(EN p. 3)*

As diabetes is a disease where an important part of the treatment is maintaining a healthy lifestyle and control their glucose values before their meals, the participants all seem to be aware of their responsibility to take care of themselves and make healthy choices. The test results thus can become a confrontation with whether they succeeded in managing their disease and preventing further complications or not. As well as an important tool to assess how they manage their disease. One participant formulates it very clearly while sketching his suggestion to combine more parameters with the lab results:

> *"It's not just test results; it's how am I doing?"*
> (PO p. 13)

When asked how the participants would react to the presented results, the answers varied from paying attention to daily routines to statements like

> *"Get up and get moving and try not to lose to the couch"*
> (MG p. 9),

and participants who feel guilty for not checking their glucose levels as often as they believe they should:

> *"I mean, I should do it. And it's just sloppy that I'm not doing it. But it's just... It's sloppy."* (AH p. 20),

and

> *"If it hasn't dropped as much as I had hoped it is probably because I haven't been very good at checking."* (CS p. 5)

Feeling guilty and overwhelmed and abstaining from checking glucose levels are related to a reaction called diabetes distress which is found in approximately 25 percent of all patients with diabetes (Videncenter for diabetes, 2022). This condition is outside the scope of this study and will not be elaborated further, however, it is a parameter it is relevant to consider in relation to these findings. The reactions described in relation to the lab results can thus be considered a part of a bigger picture that generates negative emotions and reactions.

Other participants point to emotions as excitement and curiosity to see how it goes and satisfaction and happiness when the results are where they should be. One participant seemed so focused on her results being perfectly in order that I after the interview noted the following:

> *"As a nurse, I imagine she is the type of patient who looks at her numbers to figure out how she feels instead of feeling her body first."*
>
> *(Note from the interview with EN p. 14)*

If this is the case, it is tempting to conclude that the test results enable the continuation of an undesirable behaviour. However, taking into account that especially older persons with type 1 diabetes have lived many years by strict rules because treatment was more difficult, this might be a tool that can act as support and verify that they are doing okay.

4.4.5 Distancing

This theme is about how the difficulties interpreting and using the lab results can lead to patients distancing themselves from the test results. It is closely connected to previous themes that have displayed how test results are not always just numbers but can also be a verdict of your effort to manage your disease. Some patients experience this to be difficult, and spending time and energy to familiarise themselves with interpreting lab results can seem unrealistic.

Three participants point to the fact that they are not educated for this interpretation like the doctors and nurses are and hereby imply that they cannot be expected to understand this and take action accordingly.

> *"… it's not something you go around thinking about. Or at least I don't. Because well, you're not educated for that. We have others for that."*
>
> *(OM p. 4)*

This can be seen as a way to deal with a difficult situation by defining it as an aspect you can neither control nor take responsibility for hence protecting yourself from worrying or failing to do so. It also indicates a high level of trust in that the healthcare personnel follow them closely enough to help them if needed. Six of the participants stated that they trust and expect the healthcare personnel to tell them if there is something important for them to know. Only one mentions the test results as an opportunity to ensure that nothing is overseen and forgotten, however, this can be related to a recent transition from the paediatric department which monitors the patients more closely than in the clinics for adults. The participants generally seem satisfied with the treatment performed by the doctors and nurses at the clinic while other measures out of their control frustrate them and create barriers they do not know how to remove:

> *"I just think, you do it with your mobile phone, choose the background and everything else. So why not do that too? But then there's also the question of whether you [the Region] are willing to spend the money on it."*
> *(CS p 21)*

This participant talks about how a different presentation of the lab results would be an improvement for him and expresses his assumption that this is a need that will not be prioritised economically which prohibits him from actively using the results. Other participants also express how technical barriers they have no control over can be discouraging in their attempts to achieve an overview of their treatment and results. This will be further elaborated in the theme *equipment.*

Another way of creating a distance is found in this statement where a participant talks about his Hba1C level:

> *"Yes, she [the nurse] would like it a little lower, but it's pretty stable. But I think nurses are hard to please."* *(OM p. 8)*

In this statement, the participant distances himself from an unsatisfactory test result by making it the nurses' study instead of his own, an example of the duality where the participants are well aware of the complications they risk if not managing their disease but act like elevated numbers are not their problem or responsibility.

Besides being a field with many technical terms that can seem unfamiliar to the untrained eye, there is also a physical and timely distance between the blood samples taken at the lab and the numbers on the screen and a delay time related to test results that describe levels of for example glucose over a longer period. This distance can make the test results seem even more intangible compared to the results they get in their daily checks that are closely connected to your actions here and now.

4.4.6 Equipment

The utilisation of technical appliances to monitor and manage the disease is an integrated part of the participants' treatment. The participants' attitudes regarding their equipment are both positive and negative. A participant with type 1 diabetes describes his usage of a sensor or pump in this way:

> *"Well, I'm actually very blessed. I've got a sensor that talks to the pump, this Guardian 3.4 (...) so for the most part, it's pretty straightforward for me. I don't pay much attention to it anymore."*
> *(PO p. 1)*

Especially the participants who have had type 1 diabetes seem to experience their equipment a big relief, maybe because they have previously experienced severe limitations because of their disease and need to constantly be aware of their glucose levels. The data from the equipment regarding glucose levels is not only used by the participants in their daily lives but are available to the healthcare personnel making it an integrated part of the treatment and conversion during the consultation. One participant excitedly tells me about how she has now managed to also register her insulin pen within the app which she thinks is brilliant. The nurse has encouraged her to use the app for as much as possible as this provides the nurse with the opportunity to look at the same data as the patient.

Most patients with type 1 diabetes at this clinic are offered to use a sensor that continuously monitors their glucose levels and alarms them is they are too low or high. They can choose to read the results using the sensor or an app on their smartphone (LibreLink). The app allows a wireless connection to transfer data to the hospital (libreView) and allows to register insulin pens.

One participant reflected on the possibility of importing data from his senor and pump to Sundhed.dk to see correlations between this data, medicine and lab results revealing some prior frustrations with equipment not working properly:

> *"Well, it's interesting if it's about actually being able to do it where it works so you don't have to spend an hour trying to make the system work"* (PO p. 19)

He expands on this statement by explaining that his endeavors to make it work showed him that some of the trouble was because the software was only updated to Apple phones, not Android as he used. A similar challenge was experienced by another participant who explained why she hesitated to answer how she accessed the lab results:

> *"Right now I don't think I have the app, but sometimes I do. I have a bit of, what do you call it, [disc]space constraints on my phone. It's not brand new. So sometimes I delete the app. Right now, I don't have it." (SH p. 9)*

The participants with type 2 diabetes are not automatically offered a sensor but test their blood by disinfecting a skin area and using a lancet to extract a drop of blood to a strip that can be inserted into a meter. This procedure requires a bit more equipment and is by one participant referred to as *"the diabetes toolbox".* Her attitude towards it is not positive but it does not seem to be related to difficulties using the equipment or understanding the results:

> *"*[It contains] *that blood glucose meter. And then you need to bring those lancets. And you need to bring that test[strip]. And then you must bring some fast-working insulin with you. Yes, I think it's a lot that you must make sure you have on you all the time." (AH p. 2)*

This can be interpreted as an expression of practicality being an important issue to the participants and that using digital equipment to manage their disease is not unfamiliar to them but practical issues can be determining for their willingness and ability to use it.

4.5 Summary of the analysis

The empirical material consisting of transcripts of seven interviews with participants with diabetes and notes from the researcher were coded with an inductive approach. The coding followed a hermeneutic approach where the units of meaning were separated to find new patterns while continuously being reflected back to the context they originated from. The initial coding resulted in 41 codes that were further processed and grouped into larger codes. This process resulted in 6 themes describing the most significant findings of the interviews.

'When it is difficult to understand' describes how some participants feel overwhelmed by being presented with too much technical information, and how others approach the information with confidence regardless of their ability to understand all of it.

'Helps understand test results' contains the sketches made by the participants. It describes how there is agreement on Hba1c and cholesterol to be the most important test results though some participants look at all results. The essential results should be emphasised more than they are now and the presentation of results should be customisable. This would support the participants' individual preferences for the level of detail displayed. The language should be simplified, and the visual cues should be easier to see and interpret.

'Strategies' show that the participants look for recognisable words, colours and arrows to interpret their results. Most participants are satisfied if their results are within the defined reference range and use Google to search for additional information if they want to know more, though they are aware that the information can be misleading.

'Not just test results' shows a possible connection between access to test results and diabetes distress. The test results are an evaluation of the participants' ability to follow the recommendations regarding lifestyle and treatment and the test results can lead to both satisfaction and negative emotions.

'Distancing' shows how situations the participants experience to not influence are handled by distancing themselves from it, avoiding additional worries or risks of failure. This relates to difficulties in the interpretation of test results as well as technical barriers that could be removed but are not prioritized. The participants have great trust in their healthcare practitioners and most of them leave the responsibility of deciding how to respond to their lab results to them.

'Equipment' describes how technical equipment is not unfamiliar to the participants who have both positive and negative experiences with it. To type 1 diabetics the equipment is primarily a relief, to the extent that it is well functioning. The participants with type 2 diabetes are more focused on the (in)practicalities of bringing "the diabetes toolbox" with them everywhere. Practical issues can be determining for the patients' willingness and ability to use it.

5. Theory

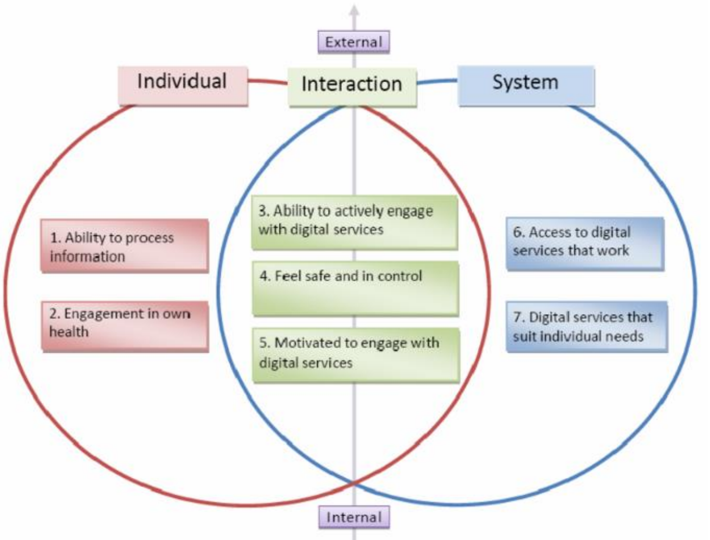
The development of well-functioning e-health services is a complex task, and presentations of lab results are no exception. The description of the six themes derived from this study's empirical material shows that several factors are implicated when patients look at the test results. Some of them are straightforward and tangible such as statements from the theme 'Equipment' that relates to challenges when technology does not work or are impractical to bring with you. Or from the theme 'Helps understand test results' where the ability to read unfamiliar words and relate them to their disease shows that literacy and knowledge of your disease is a factor. Others are more implicit and difficult to define such as the reflections on what people look for when trying to make sense of their test results described in the theme 'Strategies' or the emotions the confrontation with (un)satisfying results can produce or reinforce as described in the theme 'Not just test results'.

5.1 e-health literacy

The e-health literacy framework (eHLF) consists of seven domains constructed as a model that aims to identify the elements that are relevant for individuals using e-health technologies. (Norgaard et al., 2015) The framework refers to e-health services in general and is based on empirical data collected from both e-health professionals and patients with a chronic health condition. It can support the understanding of what capabilities affect how individuals or populations can use e-health technologies to promote and maintain their health (Norgaard et al., 2015). By including both known domains such as basic digital skills, health, and information as well as the elements related to the dynamics that occur when the individual meets the system, the framework can help bring forth an important understanding for developing and improving existing e-health services (Norgaard et al., 2015).

The seven domains are depicted in the model below, that also places them according to the context they exist in and depend on from the individual to the system on the horizontal axis and internalised and externalised aspects on the vertical axis (Norgaard et al., 2015).

The model and the domains have since they were first described in 2015 undergone further development and generated questionnaires and models to support the development of e-health services, including the e-health literacy questionnaire (eHLQ) (Kayser et al., 2018) and the Readiness and Enablement Index for Health Technology (READHY) instrument (Kayser et al., 2019). The eHLQ can be regarded as operationalisations of the framework and is designed to be used as a tool to understand and evaluate people's interaction with e-health services (Kayser et al., 2018).

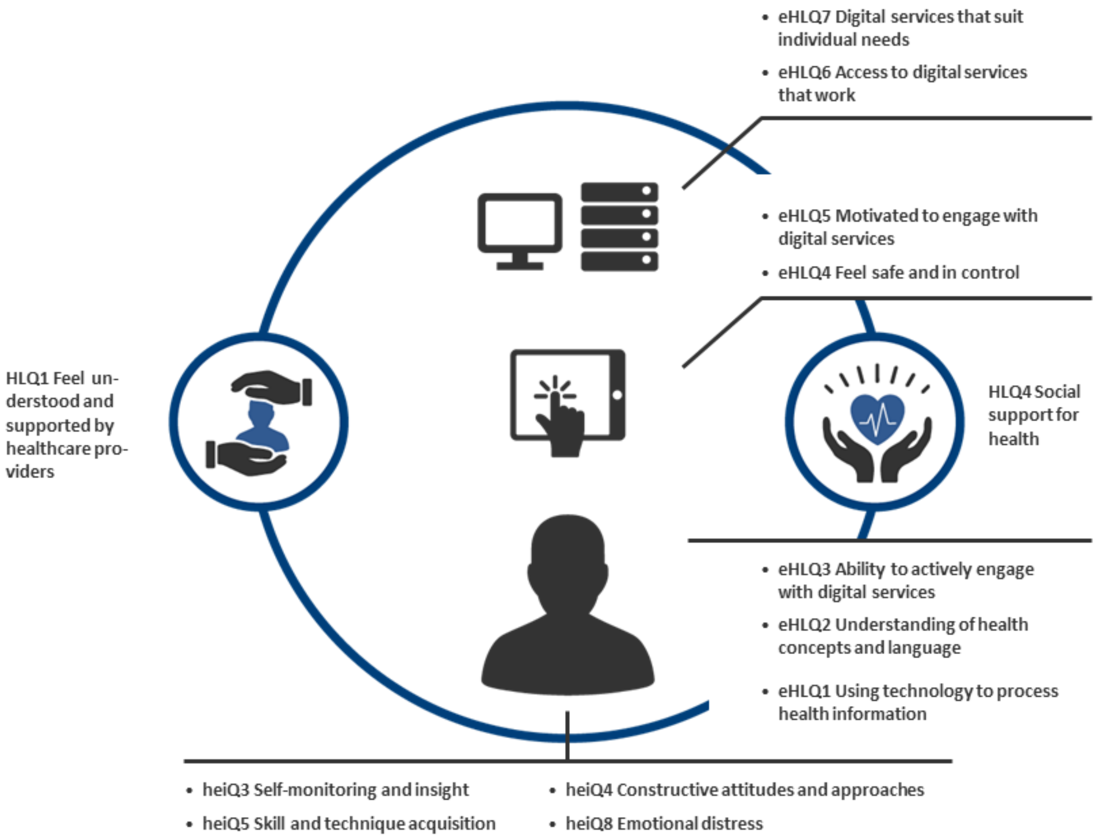


The e-health literacy framework
(Norgaard et al., 2015)

5.5.1 The READHY model

The READHY model combines the dimensions from the eHLQ with additional areas from other instruments to include aspects of social support and self-management and thereby create an instrument that can describe the level of readiness and degree of enablement (Kayser et al., 2019).

The READHY model consists of 13 dimensions depicted in the model below:
Feeling understood and supported by healthcare providers, Social support for health, Using technology to process health information, Understanding of health concepts and language, Ability to actively engage with digital services, Feel safe and in control, Motivated to engage with digital services, Access to digital services that work, Digital services that suit individual needs, Self-monitoring and insight, Constructive attitudes and approaches, Skills and Technique Acquisition, Emotional distress.



The READHY model, Kayser et al. 2019

6. Interpretation of themes

Interpreting the themes from the interviews from the perspective of this model can deepen the understanding of the patient groups' needs and abilities in relation to interpreting lab test results. This insight can support the study's aim to investigate how the presentation of lab results can be improved in relation to patients with diabetes.

In the following, the study's six themes will be connected to the dimensions of the READHY model. The analysis will entail 11 of the 13 dimensions as the two dimensions *Skill and technique acquisition* and *Feel safe and in control* are not relevant in relation to this study's empirical material.

6.1 Feel understood and supported by healthcare providers

This dimension entails that the patients experience to have a relationship with their healthcare providers and trust that they support them with advice and information to understand and make decisions regarding their health (Osborne et al., 2013).

The theme 'Distancing' shows that the participants trust and expect that the personnel will tell them if there is something important from their test results to know. Further, the transcript of the interviews shows that several participants mention their nurse or doctor by first name which implies that they experience having a relationship with this specific nurse/doctor, who knows them. One participant seems to be lower in this domain and more inclined to use test results as a possibility to ensure that nothing is forgotten by the healthcare providers. As the theme 'distancing' refers to participants distancing themselves from actively attempting to understand the lab tests, this suggests that the healthcare providers' relationship with the patient is a balancing act. Too much support entails the risk of discouraging the patients from engaging in understanding their test results because they do not feel it is their responsibility, but too little support is associated with poorer health literacy (Osborne et al., 2013).

6.2 Social support for health

This dimension regards whether the patients have a social network that supports them in relation to their disease (Osborne et al., 2013).

The dimension is reflected in two themes: 'Strategies' and 'Not just test results'. The theme 'not just test results' shows that some patients find their test results to be a private matter because the results implicitly can be perceived as an indicator of their ability to manage their disease, which includes making healthy lifestyle choices. These choices consist of being disciplined with routines such as exercising, being aware of nutrition and measuring blood glucose levels, and are of several participants described with terms negatively loaded with self-blame. The instinct to keep the results private can thus point to a lack of social networks that the participants consider close or trusted enough to share this kind of information. In 'Strategies' we see that patients are more likely to search for answers online than to discuss them with relatives. This can however also be a reflection of the fact that only two patients express to have relatives with personal or professional knowledge about diabetes and most of the remaining participants have confidence in their ability to find and filter the needed information online.

6.3 Emotional distress

This dimension concerns the overall negative effects of illness such as stress, anxiety, depression, anger, and a negative attitude to life (Osborne et al., 2007).

The negative emotions of this dimension are clearly reflected in the theme 'Strategies' and 'Not just test results' that suggest that test results can trigger and/or amplify both negative and positive emotions related to diabetes. The test results can be perceived as a sort of evaluation of their effort to manage their disease but because the participants primarily perceive the standardised reference range as the goal to strive for, the participants strive for unrealistic targets and have greater risk of experiencing emotional distress. The theme also suggests a connection between the negative emotions and the reaction 'Diabetes distress' that might also influence the participants' experiences with the test results.

6.4 Constructive attitudes and approaches

This dimension refers to the shift in how the impact of disease is perceived by the individual. High levels are associated with a determination to minimize the effects of the disease on their lives (Osborne et al., 2007).

First and foremost, this dimension can be seen in the empirical material through the fact that the participants have all actively engaged in looking at their test results and attempted to understand and interpret them to some extent. Besides this, the dimension is reflected in the theme 'Helps understand test results' where the participants are willing and able to reflect on, sketch, and explain what they believe would support them to better understand their test results. The theme also shows that some approach the test results by focusing on a few results they know are important in the management of their disease and the development of complications. This focus helps them avoid being overwhelmed by not understanding it all.

The theme 'strategies' also shows constructive approaches as this describes some of the endeavours the participants demonstrate to become an active part of the conversation when discussing the results with their healthcare practitioner. This includes taking an active stance concerning results outside the reference range, and the attempt to learn more about the results through online resources. Lastly, the theme 'Equipment' also shows a constructive attitude as the participants are positive in the experience that well-functioning equipment can be a relief. However, equipment that is considered impractical or not living up to its potential is on the other hand frustrating to the participants as they experience that their influence on this matter is limited, as described in the theme 'Distancing'.

6.5 Digital services that suit individual needs

The dimension regards services that are adjusted to the individual's needs and are characterised by being easily adaptable to the needs of the individual (Kayser et al., 2018). This dimension is highly dependent on the system and less on the individual as the technical solutions available are highly defining of the possibilities of use (Norgaard et al., 2015).

The themes 'Difficult to understand' and 'Helps understand test results' show that this is not the experience of the participants of this study. They suggest more focus on what is relevant to them, better possibilities to adjust the presentation to what is most relevant to them and a more straightforward language. Most of them feel challenged by the existing presentation that are designed in a way that provides a lot of information with few visual cues guiding them in what to look for. This might be logical to clinicians who are trained to process and interpret the many results, but it is challenging for the participants to engage with. The suggestion of creating a customisable page where patients can choose what results they want displayed together suggests that the existing solution is not fulfilling the needs of the individual patients.

6.6 Access to digital services that work

This dimension refers to the experience that technical equipment works as anticipated and that the individuals have unproblematic access to their data (Kayser et al., 2018). This is a factor largely dependent on the system and the technical services that the patients have access to (Norgaard et al., 2015).

The way to access the lab results is not necessarily determined by active choices regarding the existing options, but also by what is technically possible and practical in relation to easy login or available space for apps on the phone. The participants use respectively an app, a browser through a laptop and a browser through a smartphone. Their point of access is determining for the presentation they retrieve, and from the interviews performed in this study, it seems that the users most satisfied with the current presentation are the ones who use a browser through their phone, a point of access another participant described being problematic because of difficulties with loading the data. Given the inclusion criteria for this study, all participants have succeeded in accessing their test results at least once, and most of them have done it frequently which suggests that they have access and the service works. However, the challenges described are worth noticing as they may be a barrier to other patients. This is supported by the theme 'Equipment'. Here it is described how practical matters out of your control, such as the amount of equipment you must carry with you as well as software updates for apps only made for iOS making the Android version useless, can cause frustrations and less frequent use.

6.7 Motivated to engage with digital services

This dimension relates to the experience that the engagement in utilising digital services will be helpful for them in the management of their health (Kayser et al., 2018). The dimension is placed in the middle of the model above as it is dependent on the interaction between the system and the individual (Norgaard et al., 2015).

This dimension appears clearly in the theme 'Not just test results' where statements like *"It [lab test results] actually controls how I manage my diabetes" (EN p. 10)* describe how the motivation for looking at test results is the awareness that this is a way to assess if their efforts to manage their disease are working or not. The theme 'Helps understanding test results' shows that the motivation to determine if the results are good or bad is connected to their ability to interpret what that means to them and their situation. The theme 'distancing' shows how the participants rely on their healthcare professionals to interpret the results for them when they experience it to be unmanageable.

6.8 Ability to actively engage with digital services

This dimension refers to whether the individual feels comfortable when it comes to using digital services for handling information (Kayser et al., 2018). The dimension is placed in the middle of the eHLF model as it depends on the interaction between the system and the individual in the sense that it requires some technical skills from the individual but whether these skills can be used depends on the nature of the system (Norgaard et al., 2015).

The theme ‘Equipment’ shows that technical equipment is an integrated part of the management of diabetes and is generally perceived as a way to relieve them of some of the difficulties and impracticalities their disease entails. The participants all seem confident that they can learn how to use technologies if they need to, but frustrated when they experience problems, they have no influence on and therefore cannot solve on their own or get help to solve.

6.9 Using technology to process health information

The dimension refers to how technology is used to find, understand, decide, share, or organize health information and is derived from the construct that contains general literacy and numeracy, the ability to understand context-specific language, the ability to process information, and critical sense when assessing information (Kayser et al., 2018).

The themes ‘Distancing’, ‘Not just test results’, and ‘Strategies’ reveal that the participants use the possibility to find their test results and search for information to understand and assess how the results reflect their effort to act reasonably in relation to their disease. Most of the participants do however not use the technology related to their lab results actively to decide or organize health information. This is likely related to the challenges the participants describe in relation to understanding the context-specific language described as technical language in the theme ‘Difficult to understand’. All patients do however use daily measurements of glucose with sensors or “the diabetes toolbox” to make decisions about insulin injections and meals. The patients who have sensors also use that technology to share information with their healthcare providers as described in the theme ‘Equipment’.

6.10 Understanding of health concepts and language

This dimension is about whether users experience the available information regarding their health status and medical results as understandable, helpful, and promoting participation (Kayser et al., 2018).

This dimension is related to the themes ‘Helps understand test results’ and ‘Strategies’. Health concepts can in this context be seen as the connection between lab results and the treatment of diabetes. The understanding of health concepts is necessary to use lab results actively to self-management of current situation and to prevent future complications. In ‘Helps understand test results’ we see that most participants knew that tests regarding their glucose levels were especially important to monitor, but the language challenged their confidence in the interpretation as it caused uncertainty when test results were difficult to distinguish from each other. Several participants suggested that these results should be more clearly highlighted, moved to the top or presented in a separate box to make them easier to identify. The identification seemed easier for the participants who had adapted the terminology of the healthcare providers as this enabled them to recognise the words used in consultation as described in the theme ‘Strategies’.

6.11 Self-monitoring and insight

This dimension captures the ability to monitor the condition, physical and emotional responses leading to the insights that allows the individual to self-manage. This includes the individual’s acknowledgement of realistic limitations and confidence and ability to adhere to these as well as it relates to monitoring sub-clinical indicators of disease status. High levels are associated with persons who self-monitor, self-manage, set reasonable targets and have insight into living with a health problem (Osborne et al., 2007).

This dimension is highly relevant to this study as lab test results are a sub-clinical indicator of disease status that all participants monitor to some extent. It is an action the patients are encouraged to take to provide them insight and monitor their disease. As such, the dimension is not specifically connected to one or more of the themes.

In the case of this study, the themes described through the remaining dimensions are defining the participants' opportunities to obtain insight that can support them in monitoring and managing their disease.

However, lab test results are only one of the insights assisting the participants in managing their disease. Treating diabetes involves the patients setting individual and realistic goals for their treatment in cooperation with their healthcare providers. As mentioned in section 3.3.2, the goal varies from reducing symptoms in daily life to striving for glycemic control without major fluctuations. To reach this goal the patients must know how to monitor how their disease develops, but the themes derived from the empirical material suggest that only few patients know what goal to strive for when they look at their lab test results. This results in most of them assuming that they should aim for the defined reference range that represents the normal value for people without diabetes, a range that to most participants is not realistic.

6.12 Summary of Interpretation

The interpretation of the themes through 11 of the 13 dimensions of the READHY model shows that the participants feel supported and understood by their healthcare providers, though this support to some patients becomes an opportunity to distance themselves from engaging in their lab results.

Most feel that lab results are a private matter, and they prefer to search for information online, which suggests limited social support for health.

The participants showed a constructive attitude as they attempted to check their results and engage in efforts to suggest improvements. Using strategies such as focusing on specific results to avoid being overwhelmed and approach new equipment with the assumption that it will be functioning also shows constructive attitudes.

The themes display that the participants do not experience that lab results suit their individual needs and suggest more straightforward language, more focus on relevant tests and the opportunity to customise the presentation.

The participants have to a large extent access to services that work, however, what access they choose is defined by practical matters and might prove difficult to other patients. The participants are motivated to look at the results because it can help them manage their disease. Some lose motivation because of their difficulties in interpreting the results and leave it to their healthcare practitioners.

Digital services are highly integrated in the treatment of diabetes and the participants are confident that they can use or learn to use the services if adjusted. They use their equipment to process health information and online resources to find information, but context-specific language prevents some from using it to make decisions.

They generally struggle to connect the health concepts presented in the lab results to their treatment. The language especially lowers their confidence in identifying the most important results, except with the participants who have adapted to the professionals' language.

The lab results are a digital, sub-clinical indicator that, based on the themes, are challenging for the participants to use to monitor their health. They know what test to look for, but most of them strive for unrealistic targets which can induce or enhance emotional distress.

7. Discussion and perspectives of future work

The discussion of the findings will be focusing on the findings related to the following six dimensions:

Understanding of health concepts and language - Using technology to process health information - Digital services that suit individual needs - Constructive attitudes and approaches - Emotional distress - Feel understood and supported by healthcare providers

The remaining dimensions are not discussed due to two factors: 1. The time frame of the study does not allow an in-depth discussion of all aspects. 2. To avoid repetition. Some of the READHY model's 13 dimensions are very closely connected which can lead to overlap in some contexts (Kayser et al., 2019). Examples of this in relation to this study are the *ability to actively engage with digital services* and *Access to digital services that work* that are discussed through other dimensions such as *Using technology to process health information* and *Digital services that suit individual needs*.

7.1 Mind the gap

This study was designed to contribute to further the understanding of the patients with diabetes' experiences of checking their lab test results online by including their perspective. These findings can contribute to the improvement of the design of test results in a way that allows the patients to use them actively. This entailed asking them about their approach to the test results, what they looked for, why, and how they found it. In line with other studies, this shows a gap between the needs of the presented information and the actual needs of the participants that can inform future design of online lab results (Monkman, H. et al., 2022), (Zhang et al., 2019b). While this study was not an attempt to test the participants' ability to find and interpret the results, the answers showed that the participants found this challenging and coped with this in different ways that affected their ability to use the lab results actively. The interpretation of the empirical findings in this study through the READHY model allows a discussion of the dimensions most relevant to the participants in this study.

The challenge of finding the important information within all the presented information is one of the findings in this study. In this study, the understanding of health concepts and language are closely connected to the participants' experience of confidently using strategies to identify the test results they consider to be important. The sketches made by the participants show a wish for further emphasis on specific results that are important to this group of patients. This finding supports the recommendation by Fraccaro et al. to interface designers to further highlight the information most relevant to the patients to enhance their interpretation. Better interpretation can lead to an enhancement of their readiness and enablement to use health technologies (Kayser et al., 2019), in this case, lab test results.

The highlighting of results specifically important to the patient group is in line with the findings of Tossaint-Schoenmakers et al. They describe the need for enhanced highlighting of specific test results as a way to adjust the presentation to a certain group as their study argues that it is necessary to tailor patient portals to specific groups to enhance usability and self-efficacy. They encourage to further investigation into tailoring and integrating the use of portals for different groups (Tossaint-Schoenmakers et al., 2021). The findings of this study can thus supplement the findings of their questionnaire-based study by exploring the experiences of a specific group of patients with chronic disease through a qualitative approach.

One of the recommendations made by Tossaint-Schoenmakers et al. is to tailor the presentation of test results according to age groups as older persons scored lower on the usability of the tested portal (Tossaint-Schoenmakers et al., 2021). The need for special consideration for older persons is supported in a report by the Epinion for the Danish Organisation for Older People, who argues that older Danish people experience more challenges using digital services in contact with public institutions than others (Epinion, 2023). This is not found in this study as the themes reflect that the participants who find the portal easy are not all young and the participants who find the portal most difficult to use are not all older. The need for adjustment to age can however not be rejected based on this study due to the limited number of participants and the fact that all included patients had accessed their results before. However, a study of Danish patients with type 2 diabetes argues that sociodemographic characteristics including age cannot identify the most vulnerable groups when it comes to IT-supported treatment of diabetes (Thorsen et al., 2020).

7.2 Individual customisation

The need for tailoring the presentation of lab results for different groups can be accommodated by offering individual customisation of the presentation which could lead to the participants experiencing a higher level of the dimension Digital services that suit individual needs. While many participants had similar experiences with the test results, they also had different needs and suggestions for improvement. An example of this is when asked about the level of detail they wanted when viewing their results. Some participants simply wanted “good or bad” and others were very specific in their wish to see the exact number. Some participants suggested the possibility of choosing between different models for how their results were presented, which would allow the patients to see their results in different degrees of detail and support their individual abilities to use the technology to process information.

Prototypes offering a more graphical presentation with easy access to explanations of medical terms have positive responses from patients who especially like the possibility of having context-specific information based on demographics, medical context, and laboratory results (Zhang et al., 2021) . Studies show that patients have a more positive attitude towards graphic presentations than tabular/numeric formats, yet they still find it difficult to identify abnormal results and assess how to react, leading to concerns regarding patient safety (Monkman, Helen et al., 2022)(Bar-Lev & Beimel, 2020), (Fraccaro et al., 2018). Instead, the patients’ ability to target their search of test results to the most important ones by using effective strategies to cope with the information overload is key to correct risk interpretation (Fraccaro et al., 2018). In this study, one participant was particularly sceptical of fancy layouts and anticipated that he would use a tabular layout even though he had other options, on the assumption that a design that was “boring” would support his ability to get an overview as it would not distract his eyes when looking at it. As previously mentioned, the sketches made by the participants can be considered low-fi prototypes. Kanstrup uses the term design concepts to describe a similar research stage in her study that aims to understand and transcend digital diabetes practice (Kanstrup, 2014). The findings of this study can be considered as design concepts and can be a contribution to further development and testing of hi-fi prototypes or simulations.

The individual customisation could take inspiration from the project SAMBLIK-diabetes, a study between several collaborators in Danish healthcare to provide healthcare professionals with an easier overview of the patient’s medical history (Munksgaard & Klausen, 2023a). Especially one visualisation is very close to one of the sketches made by a participant in this study, showing correspondence with Hba1c, changes in medication and individual goals for treatment (Munksgaard & Klausen, 2023b). Even though the development of the solution targets the needs of the healthcare professionals it indicates a recognition of the need to combine different information in the same picture which is a recognition that can also benefit the patients.

7.3 Language

The use of words and phrases that are unfamiliar outside healthcare and difficult to read is known to be a barrier to patients with low literacy and numeracy (Zikmund-Fisher et al., 2014) (Lazaro, 2023). Though no participants in this study declared to have general reading difficulties, the technical language was a recurring issue to the participants indicating a low level of Understanding of health concepts and language.

Some participants suggested the use of Danish words that are commonly used to translate the results, for example, “long-term blood sugar” instead of “haemoglobin A1C(IFCC);Hb(B)”. This suggestion is not unfamiliar to MedCom who facilitates the communication of lab results through Sundhed.dk. As a participant in an informal meeting at MedCom and through personal communication with a representative at MedCom, I have become aware that this change entails considerable technical difficulties related to the internal coding of the tests with unique names. Another argument for the technical names is that they provide precision unlike slang like “Long-term blood sugar or blood percentage”. The project entails several stakeholders and while the final decision was to keep the names and work to provide better explanations it was not a unanimous decision. Considering the increasing focus on providing healthcare on the patients’ premises, this is an interesting choice. From 2013 and onwards several Danish hospitals have changed their names from Latin terms to Danish names that also explain what kind of diseases the ward or clinic treats (Jensen, 2015). This change is made with the arguments that it will provide the patients with an enhanced feeling of being safe and welcome as well as an effort to improve communication between healthcare personnel and patients (Jørgensen, 2022). Further investigations of the effect of this change could provide valuable insights into the considerations of the names of test results. From the perspective of this study, a suggestion could be to reverse the order of presentation; Instead of keeping the technical names and supplement with a Danish explanation, the tests could be presented with Danish names first and supplemented with the technical names.

7.4 Ways to obtain additional information

The participants in this study primarily used Google as their source of additional information, even though they were aware that this might show misleading or exaggerated consequences of their results. As this seems to be a very intuitive action for the participants it is relevant to provide easier access to high-quality tools for the interpretation and education of patients (Giardina et al., 2017). This can be provided by clearly highlighting medical terms with blue colour and line underneath making it easy to identify as a link you can click on (Zhang et al., 2021). This might be more intuitive than the book icon linking to the patient- or doctor handbook on Sundhed.dk. Only one participant knew it existed but rarely used it as she found the content difficult to understand. The deselection of the handbook provided in the portal is not unique to this study (Robinson et al., 2019) and further exploration of this could support the improvement of patient-oriented explanations of test results in general.

Fraccaro et al. also point to the importance of patient education which this study also slightly indicates as participants with many years of experience with type 1 seem to handle the information overload more confidently than the participants with type 2 diabetes who have fewer years of experience. As this seems to be based on the participants having heard the names of the test results during their consultations, more targeted education might be useful to empower less experienced patients to engage in understanding their lab test results. This should however be balanced and discussed carefully with healthcare personnel and patients to avoid creating a new information overload that makes the patients feel overwhelmed. These patients are already encouraged to engage in education about diet, exercise, medication, mental health etc. to manage their disease in their daily lives and prevent further complications (Holm Andersen et al., 2015). This study shows that the participants feel understood and supported by healthcare providers and the perspective of these should be investigated further. This could provide valuable insights to understand how this support affects the patients' motivation to participate actively.

7.5 Emotional and constructive reactions

The participants in this study generally have a constructive attitude and approach to technical equipment when they acknowledge that it can support them to manage their disease more effortlessly. While the constructive approach and the number of digital tools they use, might make this group of patients better equipped to implement other digital services in their daily lives, it is important to be aware that this might not be the case for all patients. During the recruitment of participants for this study, the nurses at the clinic reported a vast number of patients not eligible for this study as they had never attempted to access their test results. Further research on why they have not checked their lab test results could provide important perspectives in making the portal more accessible and usable to all.

A reason for not checking the results is found in the theme 'not just test results' that is closely connected to the dimension Emotional distress. Checking test results can both add to the reaction "diabetes distress" and to negative emotions of feeling unsuccessful in managing the disease, especially if the patient strives for a reference range that is unrealistic to reach when having diabetes. This might be the reason for the participants to consider their test results a private matter which they do not involve their social network in. Another perspective outside the scope of this study is that they do not want the "patient part" of their identity to dominate their social relationships.

A recent scoping review describes an overall tendency of patients feeling negative emotions when receiving abnormal results as well as when they are uncertain about how to interpret the results (Petrovskaya et al., 2023b). The theme 'Distancing' shows how some participants in this study avoid the emotional distress of not understanding all test results by accepting this fact and trust the healthcare personnel to inform them of important abnormalities. A benefit of this is the reduced risk of letting abnormal, but unimportant tests steer the conversations between the patient and healthcare personnel (Kristensen et al., 2022).

7.6 Method and limitations

The presentation of lab test results shown to the participants during the interviews was based on the presentation designed for the format of a computer screen. During the interviews, it turned out that only one of the participants sometimes accessed the results through a computer while all participants had experience with using their phone either through the app or a browser. This confused one participant who had difficulties answering the questions related to the presentation. It might have affected other the participants' ability to identify the test results and describe what they look for and how they do it as well. This group of patients monitor and note other information in their daily lives through apps on their phones and the future development of the presentations for app and phone browsers should take priority over the computer format.

The interviews are conducted in an office at the hospital with fictive test results. This was chosen based on practical and ethical considerations. From an anthropological perspective, the aim is to investigate the experiences of the participants in the most natural and realistic setting possible (Rytter & Olwig, 2018). Interviews conducted in the participants’ homes with their test results instead of the fictive ones could hence have provided a ‘thicker’ description of the participants’ experiences and life world. Using the participants’ test results and devices could provide a more realistic representation of their actions and abilities.

The study focuses on the participants' experience only and has limited information on the perspective of the healthcare personnel and the technical contributors to the solution. A further investigation of their perspectives could provide important insights related to the prioritization and counselling of patients regarding treatment, and technical possibilities and limitations in the involved systems.

The READHY instrument is originally developed as a questionnaire to index the Readiness and Enablement for Health Technology among individuals (Kayser et al., 2019). It is hence most obvious to use it as a tool to stratify groups (Thorsen et al., 2020), (Nielsen et al., 2021). In the context of this study, it provides the themes with the perspective of readiness in relation to the experience of using lab test results by the patients in this specific clinic. This might make the study a contribution especially valuable to smaller clinics comparable to the one in this Regional Hospital. Another approach could have been to code the interviews by applying some of the dimensions and thereby approach the coding deductively. The dimensions could also be used more systematically as inspiration for the interview, ensuring that all dimensions are addressed during the interview.

The participants are included by the criteria that they should have checked their test results at least once before. This entails the risk of only investigating the group of patients who are already motivated and able to use the solution to some extent. This excludes the perspective of more vulnerable groups.

The findings of this study can be considered design concepts that can form the basis of more concrete design solutions.

8. Conclusion

The study aims to answer the following problem statement:

How can the presentation of online lab results be improved to support the patient with diabetes' understanding and ability to manage their disease?

The qualitative interviews provided valuable information on the participants' experiences of checking their lab results. The sketching exercise was challenging to some participants but the task created a valuable base for the continuation of the conversation as well as a practical preservation of data. The fictive test results used in the interview were difficult to some participants to engage in and the use of their own data and device might have provided deeper insights from these participants.

Based on the analysis, interpretation and discussion it can be concluded that patients at the Clinic for Diabetes and Hormonal Diseases at Silkeborg Regional Hospital experience a variety of challenges in understanding and interpreting their lab results that are in line with other studies. This study's most significant findings are the general need for more individually adjusted, customizable lab results with simplified language, and clear visual aids to enhance comprehension. Especially important is to allow for an adjusted reference range for the patients as this would support their assessment of their status and might induce fewer negative emotions. Emotional distress is one of the dimensions from the READHY model that are affecting the participants negatively, though it cannot with certainty be related to lab results. However, a more accurate presentation of whether the patients are within their individual reference range might induce a feeling of success and encourage the patients to involve their social network.

Allowing the users to customize the presentation can support them in filtering away unnecessary information and be presented to the level of interpretation and details they need and want. The interviews show that the amount of information is overwhelming and that the participants use different strategies to manage this. These strategies can support the understanding of what is important and intuitive for this patient group. The sketches made by the participants show a need for further highlighting of results specifically important to this patient group to support them in identifying the results they need to manage their disease.

There seems to be a slight tendency to more confident interpretation by participants with type 1 diabetes suggesting that besides a more intuitive and individualised design, more education could support the interpretation of test results. One of the biggest challenges is to connect the language used in the lab results to the treatment of diabetes. A more straightforward language was a recurring suggestion in the interviews, but this improvement seems to be technically and politically difficult. The findings of this study suggest a continued discussion on whether precise descriptions of tests or patients' ability to understand them is most important.

While this patient group are confident in using technology in the treatment of their disease and generally perceives them as a relief, the access to digital services that work can still not be taken for granted and attention should also be paid to the patients not eligible for this study because they had never checked their results.

Future contributions to the field could be made by including perspective of more stakeholders. The findings of this study can contribute to further development of design through prototypes or simulations.

9. References

Almdal, T. (2023, Oct 30). *Type 2 diabetes.* Sundhed.dk. Retrieved May 14 2024, from https://www.sundhed.dk/borger/patienthaandbogen/hormoner-og-stofskifte/sygdomme/diabetes-type-2-hvad-er-det/type-2-diabetes/

Almdal, T. (2024, Apr 04). *Type 1 diabetes.* Sundhed.dk. Retrieved May 14 2024, from https://www.sundhed.dk/borger/patienthaandbogen/hormoner-og-stofskifte/sygdomme/diabetes-type-1-hvad-er-det/type-1-diabetes/

Bar-Lev, S., & Beimel, D. (2020). *Numbers, graphs and words – do we really understand the lab test results accessible via the patient portals?*. Springer Science and Business Media LLC. 10.1186/s13584-020-00415-z

Brinkmann, S. (.)., & Tanggaard, L. (.). (2010). Interviewet: Samtalen som forskningsmetode. In S. (.). Brinkmann, & L. (.). Tanggaard (Eds.), *Kvalitative metoder : en grundbog* (pp. 29-53). Hans Reitzel.

Carstensen, B., Rønn, P. F., & Jørgensen, M. E. (2020). Components of diabetes prevalence in Denmark 1996–2016 and future trends until 2030. *BMJ Open Diabetes Research & Care, 8*(1), e001064. 10.1136/bmjdrc-2019-001064

Coulter, A. (2012). Patient engagement-what works? *The Journal of Ambulatory Care Management, 35*(2), 80-89. 10.1097/JAC.0b013e318249e0fd

Danmarks Statistik. (2023, *Digitalisering.* dst.dk. Retrieved Feb. 10 2024, from https://www.dst.dk/da/Statistik/temaer/digitalisering

Dendere, R., Slade, C., Burton-Jones, A., Sullivan, C., Staib, A., & Janda, M. (2019). *Patient Portals Facilitating Engagement With Inpatient Electronic Medical Records: A Systematic Review*. JMIR Publications Inc. 10.2196/12779

Dyreborg, B. (2022). *Diabetes sygeplejersken og den ambulante patient*. Diagnostisk Center, Hospitalsenhed Midt, Region Midtjylland.

Elung-Jensen, T. (2022, Nov 17). *Nyretransplantation.* Sundhed.dk. Retrieved May 11 2024, from https://www.sundhed.dk/borger/patienthaandbogen/nyrer-og-urinveje/sygdomme/diverse/nyretransplantation/

Epinion. (2023). *Befolkningens oplevelser og udfordringer i et digitalt samfund med fokus på aeldre.* Epinion.

Fraccaro, P., Vigo, M., Balatsoukas, P., Van Der Veer, S. N., Hassan, L., Williams, R., Wood, G., Sinha, S., Buchan, I., & Peek, N. (2018). Presentation of laboratory test results in patient portals: Influence of interface design on risk interpretation and visual search behaviour. *BMC Medical Informatics and Decision Making, 18*(1), 11. 10.1186/s12911-018-0589-7

Giardina, T. D., Baldwin, J., Nystrom, D. T., Sittig, D. F., & Singh, H. (2017). *Patient perceptions of receiving test results via online portals: a mixed-methods study*. Oxford University Press (OUP). 10.1093/jamia/ocx140

Goodtape. (2024), *Goodtape.io.* Retrieved Mar 17 2024, from https://goodtape.io/security

Holm Andersen, B., Kolding Kristensen, J., & Friis Bak, J. (2015). *Forløbsprogram for type 2 diabetes 3. udgave Revideret maj 2015 Samarbejdsaftale under Sundhedsaftalen mellem Region Midtjylland og de 19 midtjyske kommuner*. Region Midtjylland.

Sundhedsloven, (2023). https://www.retsinformation.dk/eli/lta/2023/1011

Jensen, E. (2015, 03 sep,). *Danske navne på hospitalsafdelinger.* dr.dk. Retrieved May 29 2024, from https://www.dr.dk/ligetil/indland/flere-hospitals-afdelinger-skal-have-nye-navne

Jønsson, A.,Brandt Ryborg, Kristensen, B. M., & Brodersen, J. B. (2022). Informationens ironi: Patienters frie adgang til sundhedsdata. *Tidsskrift for Forskning i Sygdom Og Samfund, 19*(36), 39-57. 10.7146/tfss.v19i36.133049

Jørgensen, c. (2022, 28 jun,). *OUH dropper latinske navne.* tv2fyn.dk. Retrieved May 29 2024, from https://www.tv2fyn.dk/odense/mere-mundret-ouh-dropper-latinske-navne

Joseph, A. L., Monkman, H., MacDonald, L., & Kushniruk, A. W. (2022). *Contextualizing Online Laboratory (lab) Results and Mapping the Patient Journey*. IOS Press. 10.3233%2fSHTI220690

Joseph, A. L., Monkman, H., Macdonald, L., & Lai, C. (2024). *Interpreting Laboratory Results with Complementary Health Information: A Human Factors Perspective*10.3233/SHTI231127

Kanstrup, A. M. (2014). *Design Concepts for Digital Diabetes Practice: Design to Explore, Share, and Camouflage Chronic Illness*

Kayser, L., Karnoe, A., Furstrand, D., Batterham, R., Christensen, K. B., Elsworth, G., & Osborne, R. H. (2018). *A Multidimensional Tool Based on the eHealth Literacy Framework: Development and Initial Validity Testing of the eHealth Literacy Questionnaire (eHLQ)*. JMIR Publications Inc. 10.2196/jmir.8371

Kayser, L., Rossen, S., Karnoe, A., Elsworth, G., Vibe-Petersen, J., Christensen, J. F., Ried-Larsen, M., & Osborne, R. H. (2019). Development of the multidimensional Readiness and Enablement Index for health Technology (READHY) tool to measure individuals' health technology readiness: Initial testing in a cancer rehabilitation setting. *Journal of Medical Internet Research, 21*(2), e10377. 10.2196/10377

Kleist, B. H. (2023). *Kronisk sygdom i befolkningen.* ().KL. https://www.kl.dk/analyser/analyser/social-sundhed-og-aeldre/kronisk-sygdom-i-befolkningen

Kristensen, B. M., Brodersen, J., & Joensson, A. B. R. (2022). The Tyranny of Numbers: How e-Health Record Transparency Affects Patients' Health Perceptions and Conversations with Physicians. *Medicine Anthropology Theory, 9*(2), 1-25. 10.17157/mat.9.2.5529

Kristiansen, S. (2018). Fortolkning, forforståelse og den hermeneutiske cirkel. In M. Järvinen, & N. Mik-Meyer (Eds.), *Kvalitativ analyse : syv traditioner* (1st ed., pp. 153-172). Hans Reitzel.

Lassen, A. M., & Thygesen, H. (2023). Betydningen af velfærdsteknologi i den kommunale socialpsykiatriske praksis: Et analytisk perspektiv på de forskellige formål og nye roller velfærdsteknologien online bostøtte medfører medarbejdernes arbejdspraksis. *Tidsskrift for Velferdsforskning, 26*(2), 1-14. 10.18261/tfv.26.2.2

Lazar, J., Feng, J. H., & Hochheiser, H. (2017). Interviews and Focus Groups. (pp. 187-228). Elsevier Science & Technology. 10.1016/B978-0-12-805390-4.00008-X

Lazaro, G. (2023). When Positive is Negative: Health Literacy Barriers to Patient Access to Clinical Laboratory Test Results. *The Journal of Applied Laboratory Medicine, 8*(6), 1133-1147. 10.1093/jalm/jfad045

Monkman, H., Griffith, J., MacDonald, L., Joseph, A. L., & Lesselroth, B. (2022). Why Do People Use Online Lab Results and What Do They Look For: A Qualitative Study. Paper presented at the *, 294* 599-603. 10.3233/SHTI220539 https://www.scopus.com/inward/record.uri?eid=2-s2.0-85131107145&doi=10.3233%2fSHTI220539&partnerID=40&md5=088a6a820cad6af659e65505ecafbd9d

Monkman, H., Griffith, J., MacDonald, L., & Lesselroth, B. (2023). Consumers' Needs for Laboratory Results Portals: Questionnaire Study. *JMIR Human Factors, 10*, e42843. 10.2196/42843

Monkman, H., Macdonald, L., Joseph, A. L., & Lesselroth, B. J. (2024). Tabular, Annotated, Visual, or Trends + Contextual Information? Preferences for Online Laboratory Results Displays. Paper presented at the *MEDINFO 2023 — the Future is Accessible * 10.3233/SHTI231123

Monkman, H., MacDonald, L., Nøhr, C., Tanaka, J. W., & Lesselroth, B. J. (2022). *Hidden in Plain Sight: Overlooked Results and Other Errors in Evaluating Online Laboratory Results*. IOS Press. 10.3233%2fSHTI220203

Munksgaard, P. P., & Klausen, M. B. (2023a, *SAMBLIK.* www.samblik-diabetes.rm.dk. Retrieved May 29 2024, from www.samblik-diabetes.rm.dk

Munksgaard, P. P., & Klausen, M. B. (2023b, *SAMBLIK Hba1c og medicin viz.* www.samblik-diabetes.rm.dk. Retrieved May 29 2024, from https://www.stenoaarhus.dk/globalassets/generel-overflytning/steno-fagfolk---overflytning/z-old-blokke/4.-tvars/2.-tvarsektoriel-organisering-og-ledelse/samblik/screendumbs/billede-2.jpg

Nielsen, A. S., Appel, C. W., Larsen, B. F., Kayser, L., & Hanna, L. (2021). Patient perspectives on digital patient reported outcomes in routine care of inflammatory bowel disease. *Journal of Patient-Reported Outcomes, 5*(1), 92. 10.1186/s41687-021-00366-2

Norgaard, O., Furstrand, D., Klokker, L., Karnoe, A., Batterham, R., Kayser, L., & Osborne, R. H. (2015). The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems. *Knowledge Management & E-Learning, 7*(4), 522-540. 10.34105/j.kmel.2015.07.035

Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health, 13*(1), 658. 10.1186/1471-2458-13-658

Osborne, R. H., Elsworth, G. R., & Whitfield, K. (2007). The Health Education Impact Questionnaire (heiQ): An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient Education and Counseling, 66*(2), 192-201. 10.1016/j.pec.2006.12.002

Overgaard Mogensen, H., & Bundgaard, H. (2018). Analyse: Arbejdet med det etnografiske materiale. In H. Bundgaard, H. Overgaard Mogensen & C. Rubow (Eds.), *Antropologiske projekter : en grundbog* (1st ed., pp. 163-179). Samfundslitteratur.

Overgaard Mogensen, H., & Dalsgård, A. L. (2018). At være til stede: Deltagelse og observation. In H. Bundgaard, H. Overgaard Mogensen & C. Rubow (Eds.), *Antropologiske projekter : en grundbog* (1st ed., pp. 163-179). Samfundslitteratur.

Pedersen, L. H., Wandel, A., Freil, M., & Jönsson, A.,Brandt Ryborg. (2015). Involvement of patients has not been fully implemented in Danish health care. *Ugeskrift for Læger, 177*(18)

Petrovskaya, O., Karpman, A., Schilling, J., Singh, S., Wegren, L., Caine, V., Kusi-Appiah, E., & Geen, W. (2023a). Patient and Health Care Provider Perspectives on Patient Access to Test Results via Web Portals: Scoping Review. *Journal of Medical Internet Research, 25*(1), e43765. 10.2196/43765

Petrovskaya, O., Karpman, A., Schilling, J., Singh, S., Wegren, L., Caine, V., Kusi-Appiah, E., & Geen, W. (2023b). Patient and Health Care Provider Perspectives on Patient Access to Test Results via Web Portals: Scoping Review. *Journal of Medical Internet Research, 25*(1), e43765. 10.2196/43765

Regeringen. (2023). *Danmarks digitaliseringsstrategi*. Digitaliserings- og Ligestillingsministeriet.

Region Midtjylland, & Steno Diabetes Center Aarhus. (2022, *Fremtidens Diabetesklinik i Region Midtjylland.* rm.dk. Retrieved Apr 21 2024, from https://www.stenoaarhus.dk/om-os/samarbejde/fremtidens-diabetesklinik/

Robinson, S., Reed, M., Quevillon, T., & Hirvi, E. (2019). Patient perceptions and interactions with their web portal-based laboratory results. *BMJ Health & Care Informatics, 26*(1), 0. 10.1136/bmjhci-2019-000012

Rytter, M., & Olwig, K. F. (2018). At snakke om det: Måder at interviewe på. In H. Bundgaard, H. Overgaard Mogensen & C. Rubow (Eds.), *Antropologiske projekter : en grundbog* (1st ed., pp. 163-179). Samfundslitteratur.

Sharp, H., Preece, J., & Rogers, Y. (2019). Design, Prototyping, and Construction. In H. Sharp, J. Preece & Y. Rogers (Eds.), *Interaction design (5th. edition)* (pp. 421-466). John Wiley & Sons, Incorporated.

Spradley, J. P. (1979a). Asking descriptive questions. In J. P. Spradley (Ed.), *The ethnographic interview* (11th ed., pp. 44-53). Holt, Rinehart and Winston.

Spradley, J. P. (1979b). Interviewing an informant. In J. P. Spradley (Ed.), *The ethnographic interview* (11th ed., pp. 55-68). Holt, Rinehart and Winston.

Strengers, Y. (2014). Smart energy in everyday life: are you designing for resource man? *Interactions (New York, N.Y.), 21*(4), 24-31. 10.1145/2621931

Sundhed.dk. (2015, Sundhed.dk. Retrieved Feb. 13 2024, from https://www.sundhed.dk/borger/service/om-sundheddk/nyheder/hurtigere-adgang-til-data/

Sundhed.dk. (2023a, Dec). *Danskerne kan fejre 20 år med digitale sundhedsdata på sundhed.dk.* Sundhed.dk. Retrieved Feb. 10 2024, from https://www.sundhed.dk/borger/service/om-sundheddk/nyheder/ritzau/13763785/

Sundhed.dk. (2023b, *Historien om Sundhed.dk.* Sundhed.dk. Retrieved Feb. 27 2024, from https://www.sundhed.dk/borger/service/om-sundheddk/om-organisationen/hvem-er-sundheddk/historien-om-sundheddk/

Sundhedssektorens Prioriteringsråd. (2024). *SÅDAN AFLASTER VI SUNDHEDSVAESENET.* ().

Sundhedssektorens prioriteringsråd. (2024, laeger.dk. Retrieved Feb. 21 2024, from https://laeger.dk/foreninger/laegeforeningen/sundhedssektorens-prioriteringsraad

Sutton, A., Clowes, M., Martyn-St James, M., Booth, A., & James, M. M. (2022). Meeting the review family: an overview. *Systematic approaches to a successful literature review* (pp. 1-21). SAGE.

Talboom-Kamp, E., Tossaint-Schoenmakers, R., Goedhart, A., Versluis, A., & Kasteleyn, M. (2020). Patients' attitudes toward an online patient portal for communicating laboratory test results: Real-world study using the ehealth impact questionnaire. *JMIR Formative Research, 22*(3), e17060. 10.2196/17060

Tanggard, L. (2018). Fænomenologi som kvalitativ forskningsmetode. In M. Järvinen, & N. Mik-Meyer (Eds.), *Kvalitativ analyse : syv traditioner* (1st ed., pp. 81-102). Hans Reitzel.

Tassy, A. (2016). *It-anvendelse i befolkningen 2016.* Danmarks Statistik. www.dst.dk/Publ/ItBefolkning

Tassy, A., & Tömfelt, C. (2023). *It-anvendelse i befolkningen 2022.*Danmarks Statistik. www.dst.dk/Publ/ItBefolkning

Thorsen, I. K. æ, Rossen, S., Glümer, C., Midtgaard, J., Ried-Larsen, M., & Kayser, L. (2020). Health technology readiness profiles among danish individuals with type 2 diabetes: Cross-sectional study. *Journal of Medical Internet Research, 22*(9), e21195. 10.2196/21195

Tossaint-Schoenmakers, R., Kasteleyn, M., Goedhart, A., Versluis, A., & Talboom-Kamp, E. (2021). The Impact of Patient Characteristics on Their Attitudes Toward an Online Patient Portal for Communicating Laboratory Test Results: Real-World Study. *JMIR Formative Research, 5*(12), e25498. 10.2196/25498

Videncenter for diabetes. (2022, Feb 17). *Diabetes stress.* Videncenter for diabetes. Retrieved May 15 2024, from https://videncenterfordiabetes.dk/viden-om-diabetes/diabetes-og-psyken/diabetes-distress

Zhang, Z., Citardi, D., Xing, A., Luo, X., Lu, Y., & He, Z. (2020). Patient challenges and needs in comprehending laboratory test results: Mixed methods study. *Journal of Medical Internet Research, 22*(12), e18725. 10.2196/18725

Zhang, Z., Kmoth, L., Luo, X., & He, Z. (2021). User-centered system design for communicating clinical laboratory test results: Design and evaluation study. *JMIR Human Factors, 8*(4), e26017. 10.2196/26017

Zhang, Z., Lu, Y., Kou, Y., Wu, D. T. Y., Huh-Yoo, J., & He, Z. (2019a). Understanding patient information needs about their clinical laboratory results: A study of social Q&A site. *Studies in Health Technology and Informatics, 264*, 1403-1407. 10.3233/SHTI190458

Zhang, Z., Lu, Y., Kou, Y., Wu, D. T. Y., Huh-Yoo, J., & He, Z. (2019b). Understanding patient information needs about their clinical laboratory results: A study of social Q&A site. *Studies in Health Technology and Informatics, 264*, 1403-1407. 10.3233/SHTI190458

Zikmund-Fisher, B., Exe, N. L., & Witteman, H. O. (2014). Numeracy and literacy independently predict patients' ability to identify out-of-range test results. *Journal of Medical Internet Research, 16*(8), e187. 10.2196/jmir.3241