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"There's an art to it"

Exploring Sami Health Culture and Empowering Communication through an E-health Application

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Abstract

Studies have shown that the Sami culture of communicating about health can often be indirect and reliant on implications and hints rather than clear unambiguous statements [1-3]. The style is described as "roundabout", circling around a topic before closing in on it.

Modern medicine typically values directness and unambiguousness in its mission of effective anamnesis and diagnosis. Due to these differing styles of communication, there can arise a clash of cultures in health care settings with Sami patients, where the patient may feel uncomfortable and suddenly confronted with personal questions.

The SAMINOR studies have shown a high prevalence of type 2 diabetes within the Sami community [4, 5]. Diabetes is a disease that requires daily awareness and permanent lifestyle changes in order to not cause severe complications such as heart disease, poorly healing wounds, worsening eyesight and sexual dysfunction [6]. Close cooperation and good communication with a primary care physician is important to achieve the best health outcomes.

This thesis aims to explore if a mobile application can be created to empower and encourage Sami diabetes patients to discuss their health concerns and treatment options confidently and openly with their primary care physician. To assess how such an app could be tailored to a Sami audience, a literature review was performed on the Sami culture of communication about health. Interviews with health care workers on the same topic were also conducted.

A mobile application was created which implements a novel chat-like functionality that users may employ to prepare for a routine visit with their doctor. The chat will ask the user questions that are likely to come up during the visit, offering the user a safe space to consider these questions in a non-stressful environment before the consultation. The questions are based the guidelines for yearly diabetes control sessions, created by the Norwegian Directorate of Health. The user may also track their blood glucose level and bodyweight using the app, and the registered data will influence the questions that appear in the chat. The application avoids confrontational language, offers explanations and supplementary information to questions, and starts the questioning with more general topics before asking

about sensitive issues. The northern Sami language was used for the applications user interface and contents.

The application was tested by Sami individuals with type 2 diabetes. The application was well received, and all test participants were of the opinion that the application would be a useful tool in preparing for a consultation with their doctor.

Foreword

Have you ever heard of the frequency illusion? It's the feeling that something you recently learned about suddenly seems to appear everywhere. Of course, it's not that the thing is actually appearing more frequently, but rather that you've gained an increased awareness of its existence, and now notice it when it does occur.

I got this very feeling while working on this thesis. When I first had a look at the literature, I did not have the sense that the traits of Sami communication about health were particularly pervasive in my own circle, despite my Sami heritage. As time went on, however, I started noticing these topics popping up in casual conversations: "The doctor gave me this medicine, though I'd rather avoid taking it if I can." "I suppose we all have our time." "I really should go see the doctor, but—"

Now I can't help but notice it.

Working on this thesis has been a challenging, but ultimately rewarding experience. I have received help and contributions from numerous people during my project, and I am deeply grateful for their time and efforts.

Thank you to my supervisors Gunnar Hartvigsen, Eirik Årsand and Tina Rishaug for helping me navigate through this project, and for all your advice and guidance.

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Karianne Aho

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1 Introduction

Several interviews with Sami patients and health care workers have shed light on the fact that Sami people have their own unique way of discussing topics related to health and illness [1-3]. This way of communicating is described as indirect or roundabout, spending time talking around a topic before circling to the core of the issue. Confrontational language and direct questioning are seen as inappropriate in this context, and one should rather choose one's words with more care, finding a more "suitable" manner of talking.

This way of communicating can clash with the modern standards of medicine, which typically values directness and unambiguousness for efficient anamnesis and diagnosis. Needless to say, this difference in culture can lead to misunderstandings and challenges in healthcare settings with Sami patients, making the patients feel uncomfortable or unsafe.

Research conducted on the Sami population in Norway, as part of the SAMINOR studies [4, 5], has shown a high prevalence of type 2 diabetes within this community. Type 2 diabetes causes the body to not produce enough insulin or makes the produced insulin work less effectively that what is normal [6]. This further causes the person's blood to contain more glucose than is healthy, which can lead to complications in the long run [6]. The complications are connected to blood vessels being damaged by the excessive glucose, and may include conditions such as heart disease, poor wound healing, worsening of eyesight, and sexual dysfunction [6].

Type 2 diabetes requires daily awareness and management, and permanent lifestyle alterations. Good communication and cooperation with healthcare providers is an important factor for a patient's daily and long-term diabetes management. As open communication may be more difficult for patients with a Sami background, empowering and encouraging these patients to discuss their health concerns and treatment options confidently and openly with their health care provider would improve communication and cooperation, which would be beneficial in improving their overall health outcomes.

1.1 Research question

This thesis aims to explore how a bespoke mobile application for Sami diabetes patients can improve communication and collaboration between Sami people with type 2 diabetes and healthcare providers, ultimately leading to better diabetes management. The research problem is the following:

> "How can a mobile application be created to empower Sami people with type 2 diabetes to communicate with more confidence and openness with their primary care physician?"

To guide research into what cultural factors may introduce friction to communication, and how those factors could be considered during application development, a second research question is defined as:

> "What cultural factors could introduce challenges to the interaction between a Sami patient and their health care provider?"

1.2 Methods

An application intended for Sami user should inherently reflect Sami culture and values. To lay the groundwork of understanding of the Sami culture of communicating about health and illness, first a literature review was conducted to explore what research has been done on the topic in the past. Next, healthcare professionals with experience in working with Sami patients were interviewed to gain their insight and perspective on how Sami patients tend to communicate their health concerns. Online availability of high-quality information about diabetes in Sami languages was examined, along with other mobile applications intended for people with diabetes.

The application was implemented using the Android framework, and the project was organized using a waterfall approach. Testing of the application was performed by Sami individuals with type 2 diabetes. The participants had the application installed on their phone and were asked to use and examine it for some time before answering a survey online.

1.3 Major findings

The results of the literature review and interviews reflect what was alleged in the start of this introduction, namely that Sami people have a health culture that values indirectness and non-confrontation over clear, unambiguous communication. Sami patients will be reluctant to speak up about pain or other issues, or ask questions during consultations. Many feel uncomfortable in the rushed setting of an office consultation and feel that the restricted time significantly reduces the value they receive from the visit. Sami patients may to a higher extent feel that they lack the power to improve their health, and tend to be more skeptical of the value of treatments and medicine. Online availability of high-quality information about diabetes in Sami was also investigated, and was found lacking.

Based on what was found, an application for Sami people with type 2 diabetes was designed. The application takes Sami culture into consideration and provides a platform for patients to manage and learn about their condition and prepare for a routine visit with their doctor. The goal is that by preparing for their consultation, the patient will feel empowered to discuss their diabetes management and treatment with more confidence and openness, leading them to gain more value from their appointments and encourage a stronger collaboration between the patient and health care provider.

The main features of the application include functionalities to record and keep track of relevant health metrics, these being blood glucose level and bodyweight. The application also includes general information about diabetes in the Northern Sami language, which is otherwise not easily available.

The paramount feature of the application is its novel chat-like functionality, where users may prepare themselves for an upcoming visit with their physician. The chat mimics a typical control session that a person with diabetes will attend at least once yearly and is based on the guidelines by the Norwegian Directorate of Health. The user will be asked questions that their physician might ask them during the consultation, and so the user may take what time they need to consider the questions in the comfort of their own home. Registered health data from the blood glucose and bodyweight trackers also influence what questions the user will receive.

Questions may come with explanations of their context within diabetes treatment, so the user understands what the purpose of the question is, or with example answers or further questions to consider, encouraging the user to thoughtfully assess their health, habits, and experiences.

As such, when the patient arrives at the doctor's office, they will be prepared to answer questions, they will understand the purpose of the questions that are asked and may have prepared topics and questions that they would like to discuss with their doctor. The typical order of the questions from the official guidelines are altered to better reflect Sami communication culture, with more general questions appearing first, and more delicate questions appearing towards the end.

Testing showed that the participants were generally happy with the application. The participants gave the application scores in the mid-to-high range for how well it worked, ease of use, and understandability. All participants answered "yes" to the question of whether the app would be useful to them for preparing for a doctor's appointment

1.4 Strengths and limitations

A significant amount of literature already exists on the communication style of Sami patients, as will be seen in the results of the literature review. Although the existing literature comments on the challenges Sami patients can face in healthcare settings, the papers generally do not suggest any remedy for the situation beyond increased awareness by healthcare workers. The strength of this thesis lies not only in the contribution of a literature review on the topic of Sami health communication, and the new research it brings to the field in the form of interviews with health professionals. The thesis further designs and implements a mobile application meant to aid Sami patients in healthcare settings. Developing a practical tool to empower Sami people with type 2 diabetes to engage with confidence poses a new approach to addressing communication barriers, beyond simply raising awareness.

As we'll later learn from the literature review and interviews, Sami people tend to be more private about their health, and more reluctant to share health information with others. Due to this, recruiting people for health-related projects poses a challenge. I was unable to recruit as many participants for testing the application as I had liked. Though contact was established initially with six people who were willing to participate, one of them did not own the required hardware to run the application, and another ceased contact before receiving the application for testing. Four participants therefore completed testing of the application, which I recognize is a rather small amount. Ideally. I would have liked to recruit a greater amount, and from a more diverse background diabetes-wise, as all the participants have had the diagnosis for over

10 years. Examining how the application would be received by those that had been more recently diagnosed with diabetes, and therefore were less experienced managing their condition would have been very valuable, but this was unfortunately not achieved during the project, partially due to restricted resources and time.

A possibility for this project would be attempting to include automatic readings from Continuous Glucose Monitors (CGMs) into the application. A CGM is a device consisting of a sensor worn on the skin, that gives the user blood glucose readings on a regular basis throughout the day. Readings are typically done every few minutes and can be displayed on its own receiver or on a smartphone. There are several different CGM systems and models available on the market. A CGM is an alternative to traditional fingerstick testing where a person draws a small amount of blood from their fingertip and transfers it to a blood meter for measuring. For patients with type 2 diabetes that do not use insulin, frequent measurements of blood glucose are typically not necessary, and as such CGMs are not as frequently utilized among this group as among people with type 1 diabetes [7]. In this project, due to the application being directed towards people with type 2 diabetes and CGMs not being utilized to a great extent within this group, implementing this functionality was not prioritized.

1.5 Structure

Chapter 1 serves as the introduction, summarizing some of the background, methods, and major findings of the thesis. The thesis' strengths and weaknesses are also discussed.

Chapter 2 presents relevant background information about diabetes and the Sami people.

Chapter 3 presents the theoretical framework for the project. First, current standards of diabetes treatment as determined by the Norwegian Directorate of Health are presented. Second, two widely used development strategies for software design are compared. Finally, the chapter discusses topics that relate to behavior theory, and how people process information and experiences.

Chapter 4 presents the methods that were used to research Sami culture of health communication and availability of diabetes information in Sami. Methods that were used for development and implementation of the application are also presented, along with a look into related work.

Chapter 5 presents the results of the research that was done according to the methods described in chapter 4.

Chapter 6 presents the requirements of the application and discusses some of the alternatives that were considered.

Chapter 7 presents the design of the application and explains what functionalities have been implemented.

Chapter 8 describes how user testing was performed.

Chapter 9 presents the results of user testing.

Chapter 10 discusses project management and how the application was shaped by the preliminary research. The results of user testing are discussed, and the number of potential users for the application are estimated. Points for potential future improvements are listed. In addition, experiences from the author attending the 2024 ATTD conference are discussed.

Chapter 11 concludes the thesis by examining the project against the main research question.

2 Background

This chapter will present some background information about diabetes and its prevalence among the Sami people.

2.1 Diabetes

Diabetes is one of the most common diseases in Norway, with about 270 000 people having the diagnosis, around 5% of the population [6]. Of these, about 23 000 have type 1 diabetes, leaving 247 000 with diabetes type 2 [6]. Type 2 diabetes is as such far more common than type 1 in the population, accounting for 90% of cases [6]. In addition, it is estimated that about 60 000 people are living with undiagnosed diabetes [6]. The disease contributes significantly to the burden of disease in Norway, and globally [6]. The prevalence of diabetes globally has been estimated to be 451 million for the adult population, expected to increase to 693 million by 2045 [8]. Of these, almost half are believed to be undiagnosed [8].

The risk of diabetes in an individual is somewhat influenced by genetics, though genetics alone will rarely cause the disease to develop, with some rare exceptions [6].

Diabetes will cause an individual's blood glucose level to be too high [6]. This is due to the lack of, or poor impact of, insulin [6]. High blood glucose levels can over time damage blood vessels and nerves, leading to complications [9]. Complications include heart- and kidney disease, neuropathy, damage to the eyes and teeth, sexual dysfunction, and joint pain [9].

2.1.1 Type 1 Diabetes

Type 1 diabetes is the most common form of diabetes in children and youth, and about 400 people under the age of 18 develop type 1 diabetes in Norway every year [6]. However, type 1 diabetes can emerge at any age, also in adulthood [6]. At this time, there are no known ways to prevent the disease from developing, and it will often develop with no forewarning [6, 10].

Type 1 diabetes is a form of autoimmune illness [10]. The body's own immune defense attacks and destroys the cells in the pancreas that produce insulin, leading the body to stop producing, or greatly reduces the production of, insulin [10]. Individuals with type 1 diabetes need to supply the body with insulin at regular intervals for the rest of their lives using

injections [10]. Blood glucose levels must be measured and insulin levels adjusted depending on food intake, especially carbohydrates, and physical activity [10].

2.1.2 Type 2 Diabetes

In individuals with type 2 diabetes, their body is unable to produce enough insulin and/or the insulin is not as effective as usual [11]. This leads to glucose in the blood after a meal not being sufficiently absorbed by the cells in the body [11]. Type 2 diabetes is correlated with lifestyle [6]. A healthy lifestyle with sufficient physical activity and a healthy diet lowers the risk of developing the disease, while obesity, physical inactivity, an unhealthy diet, and smoking are factors that will increase the risk [6]. The symptoms of type 2 diabetes can in large extent be reduced by increased physical activity and body fat reduction [6]. Adopting good habits will reduce the risk of further health problems and reduce the need for medication [11]. Significant lifestyle changes can lead to remission, where normal levels of blood glucose are maintained [11].

Among adults, type 2 diabetes is more common than type 1 [6]. The prevalence increases with age, with over 10 percent of Norwegians over the age of 80 having the disease [6]. The number of people with type 2 diabetes is increasing in the Norwegian population [6]. Typically, between 14 000 and 18 000 people are diagnosed each year in Norway, equivalent to about 40 people a day [6].

2.2 The Sami

2.2.1 The Sami people

The Sami are an indigenous people, who traditionally have lived in the area known as Sápmi, spanning land areas across Norway, Finland, Sweden, and Russia [12]. Traditional Sami ways of living included reindeer husbandry, hunting, fishing, gathering and handicrafts [12]. Sami today live lives as diverse as any modern population, though their traditional heritage is still valued, practiced, and preserved [12]. Reindeer husbandry is still practiced by some, with approximately 2500 Sami owning reindeer [13].

No official registry of individuals with Sami heritage exists, so exact population numbers are not known [13]. Estimates range from 50 000 to 80 000 across all of Sápmi, Norway having the highest amount [13].

There are several Sami languages, though they are not spoken by all Sami [13]. The most spoken Sami language is Northern Sami, which is spoken by approximately 25 000 people [13].

The Sami have historically suffered through assimilation politics, undertaken by the Norwegian government [13]. Colonization of Sami areas has been around since the Middle Ages, but the years 1840-1945 are officially seen as the main period of organized, deliberate oppression by the government [13]. During these years, there was a mission to suppress Sami language and culture, assimilating the Sami into the Norwegian majority population [13]. This led to a loss of Sami language and identity, as well as historical collective trauma in the Sami population [13].

Organized assimilation politics by the government were abolished in the 1960's, and the Sami have experienced a cultural revitalization since the 1970's [13]. Still, many Sami report experiencing discrimination and prejudice even today [13].

2.2.2 Prevalence of diabetes within the Sami population

SAMINOR is a large population-based study on health and living conditions in regions with Sami and Norwegian populations [14]. It acts as one of the most important sources of information regarding health in the Sami population [14]. There have been two large studies conducted: SAMINOR 1 from the year 2003 to 2004, and SAMINOR 2 from 2012 to 2014 [14]. Mapping the prevalence of diabetes has been a part of these studies, gathering information through both questionnaires and blood sample analysis. The studies show high rates of diabetes within the population of the studied areas, but not much difference in the incidence rates in Sami compared to non-Sami participants.

In the SAMINOR 1 study, information on diabetes was gathered from 24 municipalities from individuals in the age range 36-79 years, totaling 15 208 men and women [4]. Information about the type of diabetes in participants, type 1 or type 2, was not gathered [4]. Table 1 shows the prevalence of diabetes as found by the SAMINOR 1 study [4].

Table 1: Prevalence of diabetes as found by the SAMINOR 1 study.

	Sami		Non-Sami	
	Men	Women	Men	Women
Diabetes (%)	5.4	4.3	4.5	4.4
Pre-diabetes (%)	3.3	2.6	3.3	2.2

The study found no significant difference in the incidence rate of diabetes in Sami compared to non-Sami participants in the scope of the total geographical area studied [4]. Differences were found in some geographical regions [4]. In the southernmost region, a higher prevalence of diabetes was found among Sami participants compared to non-Sami, while the opposite was found for Sami in inner Finnmark [4].

SAMINOR 2 gathered information from 10 municipalities from participants in the age range 40-79 years, totaling 5878 men and women [5]. Table 2 shows the prevalence of diabetes as found by the study. SAMINOR 2 found that Sami participants had slightly higher rates of diabetes type 2 and pre-diabetes than non-Sami participants [5]. In both populations, the rates of the disease were incredibly high, with over 40% of participants having either diabetes or pre-diabetes [5].

Table 2: Prevalence of diabetes as found by the SAMINOR 2 study.

	Sami		Non-Sami	
	Men	Women	Men	Women
Diabetes (%)	10.8	8.6	9.5	7.0
Pre-diabetes (%)	37.9	36.4	31.4	33.5

The study found that BMIs and waist-to-height-ratios (WHtR) were higher in the Sami population, making them more predisposed to develop diabetes [5]. Factors that contribute to

this difference are that Sami participants were on average about 5 cm shorter than non-Sami participants, and that Sami participants reported lower levels of physical activity [5].

Comparing the results of SAMINOR 1 and SAMINOR 2, we can see what seems like a staggering increase in both diabetes and especially pre-diabetes. Much of the difference is probably explained by the different ways in which the two studies measured the incidence of diabetes. SAMINOR 1 used self-reported diabetes and non-fasting plasma glucose as the metric [4]. The study explains that this is not a reliable metric and can usually only detect diabetes that is poorly controlled. SAMINOR 2 used self-reporting along with glycated haemoglobin (HbA1c) as the metric [5].

A third study looked at the developments between the SAMINOR 1 and SAMINOR 2 studies [15]. The study compared the cumulative incidence of diabetes, meaning new cases that have developed in the time between the two studies, among Sami and non-Sami [15]. 3303 participants were followed from SAMINOR 1 to SAMINOR 2, a time span of 8 years. No significant difference was found in the cumulative incidence of diabetes between Sami and non-Sami participants [15].

3 Theoretical framework

This chapter will present the theoretical framework for the project. First, current standards of diabetes treatment as determined by the Norwegian Directorate of Health are presented. These guidelines will in later chapters be adapted and play an important part in the application that is developed. Second, two widely used development strategies for software design are compared. Finally, some topics that relate to behavior theory, how people learn and change, are discussed.

3.1 Current standards of care for diabetes

The Norwegian Directorate of Health publishes the official guidelines [7] for diagnosing and treating patients with diabetes. What follows is a brief summary on how patients will be diagnosed with diabetes, and how diabetes follow-up commonly takes place. All the information originates from the official guidelines.

3.1.1 Diagnosis

A doctor will diagnose a patient with diabetes based on measurements of blood glucose levels [7]. Assessments on whether to run blood glucose tests for diabetes will depend on several factors, including the patients age, occurrence of diabetes in near family, body composition, and ethnic background among others [7].

The guidelines suggest that people with elevated risk of diabetes are offered lifestyle interventions and should have their HbA1c levels examined yearly at their general practitioner [7].

When diabetes is diagnosed, the doctor should clarify the type of diabetes, along with possible comorbidities, organ damage, and risk of cardiovascular disease [7]. The patient's psychosocial situation should also be investigated [7]. The doctor and patient should together set up a plan and goals for treatment [7]. Using a structured electronic form for diabetes (NOKLUS) is recommended [7].

The patient should receive a course on diabetes management [7]. For people with type 2 diabetes, the course will focus heavily on lifestyle changes such as diet, exercise, and ceasing

to smoke, though they might also learn about blood glucose measurements and relevant medication, depending on their situation [7]. The guidelines state the importance of building a good relationship with the patient, and that the patient and doctor should create realistic goals and plans together [7].

3.1.2 Follow-up

The guidelines state that patients with type 1 diabetes should be followed up by specialized healthcare services ("Diabetes teams") [7]. Follow-up should be adjusted to each patient's needs but should at least include one yearly control session at the general practitioner's office or with specialized healthcare services, based on the patient's situation and disease management [7]. One consultation between yearly controls is also suggested if the illness is well regulated, with some patients needing more frequent visits [7]. Children should receive care and follow-up at childrens' units [7].

The guidelines recommend a yearly control session that charts the patient's health extensively [7]. Some important points of examination and consideration [7] lists are:

- Symptoms of:
    - Macrovascular complications
    - Microvascular complications
    - Erectile dysfunction
    - Cognitive dysfunction
- Risk of complications:
    - Smoking habits
    - Weight (BMI and waist circumference)
    - Blood pressure / hypertension
    - S-lipids
    - S-creatinine and eGFR
    - Metabolism
    - Albuminuria
- Risk of psychological problems, including eating disorders:
    - Some questions have been suggested for this purpose in the guidelines, see further below

- Feet:
    - Inspection
    - Examine pulse
    - Examine sensitivity
    - Examine shoes
    - Consider pressure relieving shoes for patients experiencing neuropathy
- Eyes:
    - Ask patient about regular retinal examinations
- Age:
    - A patient's age should be considered
- If the patient uses insulin:
    - Examine injection site

The guidelines suggest some questions relating to the patient's mood and feelings about their diagnosis, and how the patient feels they are managing their illness [7]. The suggested questions are:

- How have you been doing since last time?
- How do you feel about having diabetes?
    - Many factors play into the patient's disease management. Mental health, social support, physical health, diet, stress, activity, and sleep among other factors all play a part. It's important to talk about diabetes as a sickness which causes insulin deficiency. The conversation should never be accusatory, judgmental, or demanding, but rather nondramatic and oriented towards the current reality.
- Asking about the patient's happiness and worries, what they manage well and what they find difficult:
    - What is going well for you?
        - Finding some aspect that the patient has managed successfully will increase the patient's motivation and confidence in their own ability.
    - When do you feel good?

- This is an open question which lets the patient speak about their daily life. Figuring out where the patient is successful can help them build upon that. How can they increase the amount of time they feel good?
    o Is there anything worrying you?
        - Building on what the patient is managing well will decrease their emotional stress, benefiting their diabetes management.
    o How do you think this affects your need for insulin?
        - Time should be spent to listen and explain the connection between emotional reactions and blood glucose.
- What do you think about the goals of treatment? What goals do you think is hardest to reach, and is there anything I can do to make it easier for you?
        - The patient and doctor should work together to define goals and find solutions.
- Is there anything else I can help you with today?

The guidelines again note the importance of creating a trusting relationship with their patient [7]. Identifying and understanding the barriers the patient is experiencing is crucial [7]. Barriers might include other priorities, not finding the goals of treatment meaningful, lack of faith in their own abilities, or lack of social support [7].

3.2 Development strategies

To organize a software development project, it's helpful to choose a development strategy suitable for the task. This chapter will discuss at two of the most common development strategies: waterfall and Agile. Although they both were created with the goal of having developed a successful product in the end, the strategies and timelines they employ are quite different, leading to the two approaches having different strengths and weaknesses.

3.2.1 The waterfall approach

The traditional waterfall approach is a linear methodology for development [16]. The project is divided into smaller chunks called phases, each with its own list of task that must be completed before moving on to the next phase [16]. Much like a waterfall will only move in one direction, development will always move forward through the phases, never going back

to a previous phase or iterating through phases [16]. A typical list of waterfall phases for software development may include gathering information, defining requirements, design, implementation, testing and deployment. Figure 1 illustrates a project flow through these phases.
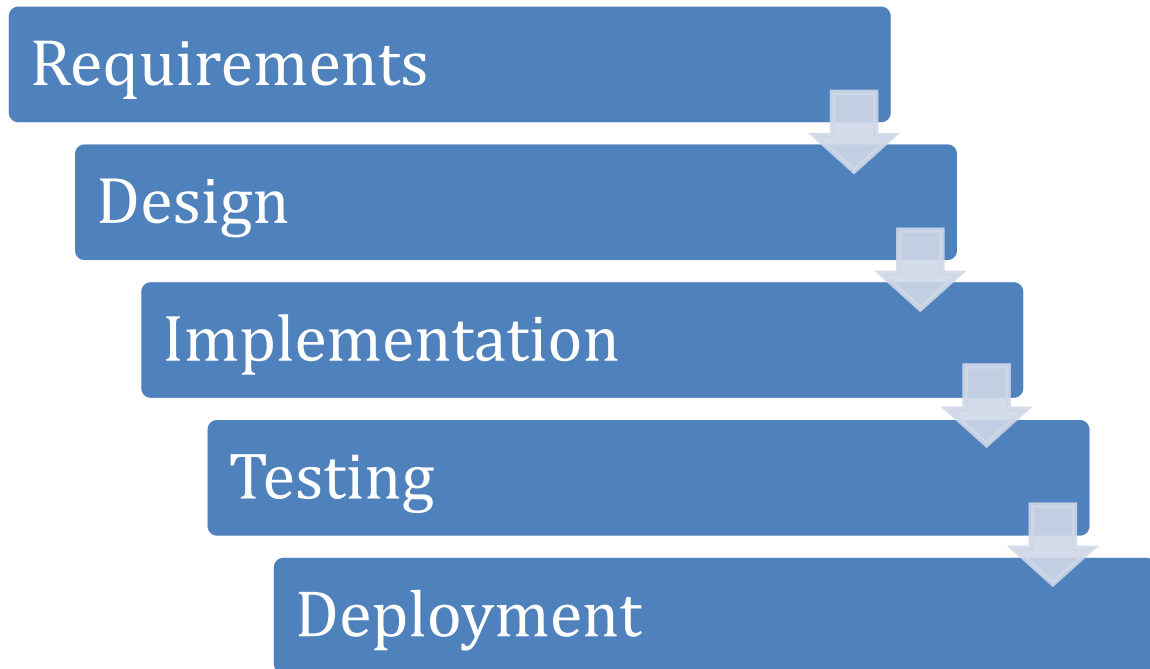
Figure 1: Example of a waterfall process for software development. The project will flow unidirectionally through the phases from beginning to end.

An advantage of the waterfall style of development is that it allows for the whole project to be laid out in full from the start [16]. This makes it suitable for projects with a strict deadline, as a full schedule can be created in the beginning, and time and resources can be divided and allocated appropriately between the different phases. On the other hand, this level of planning may be difficult for some projects, especially for projects where there are many unknowns. Even still, another advantage of the process is that requirements are resolved early on in the project, which makes further planning more straightforward and accurate. The more complete understanding of the requirements is also likely to lead to more efficient programming, as the entire architecture of the project can be taken into account from the start, reducing the likelihood of later additions leading to technical conflict.

The strict unidirectional flow of the waterfall method can be difficult to strictly adhere to in cases of delay. Waiting for a phase to be fully completed before moving on can be wasteful in

terms of time if a delay is caused by an outside factor that cannot be expedited. In such cases it might be necessary to prematurely move on the next phase, regardless of the former not being strictly complete.

3.2.2 Agile methodologies

Agile methodologies are the primary alternative to waterfall, primarily meant for teams of people [16]. As opposed to the waterfall approach's strict unidirectional flow, Agile is based on iterations with shorter time periods [16]. One single iteration is called a sprint, and will include sorting out requirements, designing, implementing, testing and deploying, all in a limited time span [16]. The sprint will conclude in a deliverable product, and another sprint will begin, adding on to the product [16]. Figure 2 illustrates how a project will flow through the phases iteratively. The methodology emphasizes close cooperation and communication with the customer of the product, who will actively review and evaluate the result of each sprint [16].
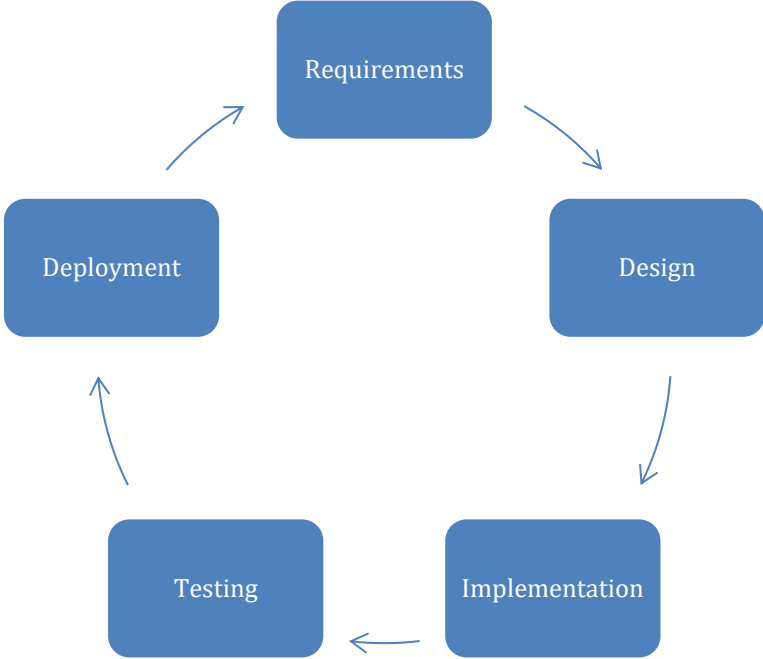
Figure 2: Iterations of development with an Agile approach.

The advantages of this methodology are that it quickly produces a product ready for testing by the customer, which can lead to a more successful and suitable product as customer input is

received on a regular basis. It also allows for more flexibility and changing requirements throughout the project.

The close collaboration can also offer challenges in that it relies on effective communication between customer and developers. Poor communication can lead to ambiguous requirements, resulting in a suboptimal product. The tight schedule of the sprints can also lead to a lower quality product if the scope of the sprint is set too large, leading to rushed development. Not having a full picture of the architecture of the product might also lead to technical conflicts when new functionality is added, leading to less efficient development and time being lost resolving these conflicts.

3.3 Behavior theory

What factors influence an individual's beliefs and behaviors? This chapter will explore how we will interpret new information based on our existing beliefs, how our experiences can shape our future decision-making and how we are shaped by our social influences.

3.3.1 Cognitive psychology

Cognitive psychology explores how people process information and make decisions [17]. When we receive new information, it may conflict with our previous knowledge, experiences, or beliefs. This conflict is called cognitive dissonance [17]. Holding two conflicting ideas at once is inconsistent so new information needs to be either accepted, rejected, or interpreted selectively to fit with current beliefs [17].

Learning is motivated by cognitive dissonance, by trying to accommodate new information [17]. To change someone's behavior, new information must be presented as notable and engaging, so as to create cognitive dissonance [17]. Effectively delivered information can increase knowledge and change attitudes and behaviors [17].

People process information and make decisions based on attitudes, which are beliefs and feelings about objects, people or actions [17]. A person with the attitude "There is little I can do to affect my own health" will not be motivated to take action to manage their health, while

the attitude "I have the power to affect my own health" will increase the likelihood of steps being taken to improve health. Some attitudes are more easily changed than others [17].

Attitudes will also influence the value that is placed on outcomes, and thereby influence decision-making [17]. Placing a high value on one's health will motivate healthy action, while conversely, values being inconsistent with health will not motivate behavior change toward health [17].

3.3.2 Reinforcement theory

Reinforcement is the idea that previous consequences of actions will impact our decision-making in the future [17]. When we encounter a situation or event, this is called a stimulus [17]. The stimulus triggers a response [17]. The response leads to a consequence [17]. From this consequence we learn how to respond in the future to similar stimuluses [17]. Responses that lead to a positive consequence tend to repeat, and so that response is reinforced [17]. Negative consequences tend to discourage reoccurrence [17]. Below follow two example situations to illustrate this mechanism.

Example situation 1: A patient has a health problem and goes to meet with their doctor. He feels anxious and ill-prepared for the consultation, as he has been avoiding seeking health care for a while. During the consultation, the doctor confronts him with questions he was not prepared to receive and does not understand the purpose of. He finds it difficult and uncomfortable answering the questions. He feels judged and unengaged. After the consultation, the negative experience leads to further healthcare avoidance.

Example situation 2: A patient has a health problem and goes to meet with their doctor. He feels a bit nervous for the consultation, as he tends to avoid seeking health care, but he has prepared for the appointment. During the consultation, the doctor confronts him with questions. He was prepared to receive them and understands the purpose of them. Though feeling a bit uncomfortable about some of them, he answers the questions and gets a good dialogue going with the doctor. After the consultation, the positive experience left him feeling empowered, and less wary of seeking health care in the future.

Table 3 summarizes the stimulus, response, and consequence of the two situations. We can see that both situations have the same stimulus, but different responses and consequences. While both patients do seek healthcare, their responses differ emotionally.

Table 3: Stimulus, response and consequence in two example situations.

	Stimulus	Response	Consequence
Situation 1	Health problem prompts seeking health care	Feeling anxious and ill-prepared, avoiding engagement	Negative consequence, avoidant behavior is reinforced
Situation 2	Health problem prompts seeking health care	Preparedness and willingness to engage	Positive consequence, seeking healthcare is reinforced

In situation 1 the patient feels anxious, ill-prepared and avoids engagement. Consequently, the patient has a negative experience during the consultation. This causes the patient's avoidant behavior to be reinforced, as it means avoiding the negative feelings and experiences that come with seeking healthcare.

In situation 2 the patient has a positive experience during the consultation due to their preparedness and willingness to engage. This reinforces the behavior, making the action of seeking healthcare more likely to repeat.

3.3.3 Sociology

We often share beliefs with those around us. Some of it is due to us seeking to be around like-minded people, while some of it us conforming to social norms and influences [17]. Sociology seeks to understand the behaviors of an individual by the context of the groups the individual belongs to such as social class, gender, political party, profession, and ethnicity [17]. Some of these groups we choose to enter, while other group memberships happen to us. Each group affiliation shapes us in different ways, our values and our behaviors [17].

All these group influences form a complex web of culture that is part of our identity, and that influence how we interpret new information and experiences [17]. Often we think of our behavior as universal, but culture influences us in ways that we are not even aware of [18]. As Edward T. Hall puts it in his book "The Silent Language": "Culture hides much more than it reveals, and strangely enough what it hides, it hides most effectively from its own participants" [18 p. 53]. The book concerns itself with the many cultural factors that are not immediately visible to an outsider, indeed "the silent language".

One can think of culture as an iceberg where some parts are visible at the surface, such as clothes, foods, music, and arts, but there is a vastly larger part that is below the surface, needing a deep dive to understand [18]. This deeper culture includes beliefs and notions about values, manners, body language, gender roles, roles of children and elders, understanding of self, and so on. Figure 3 illustrates this cultural iceberg.
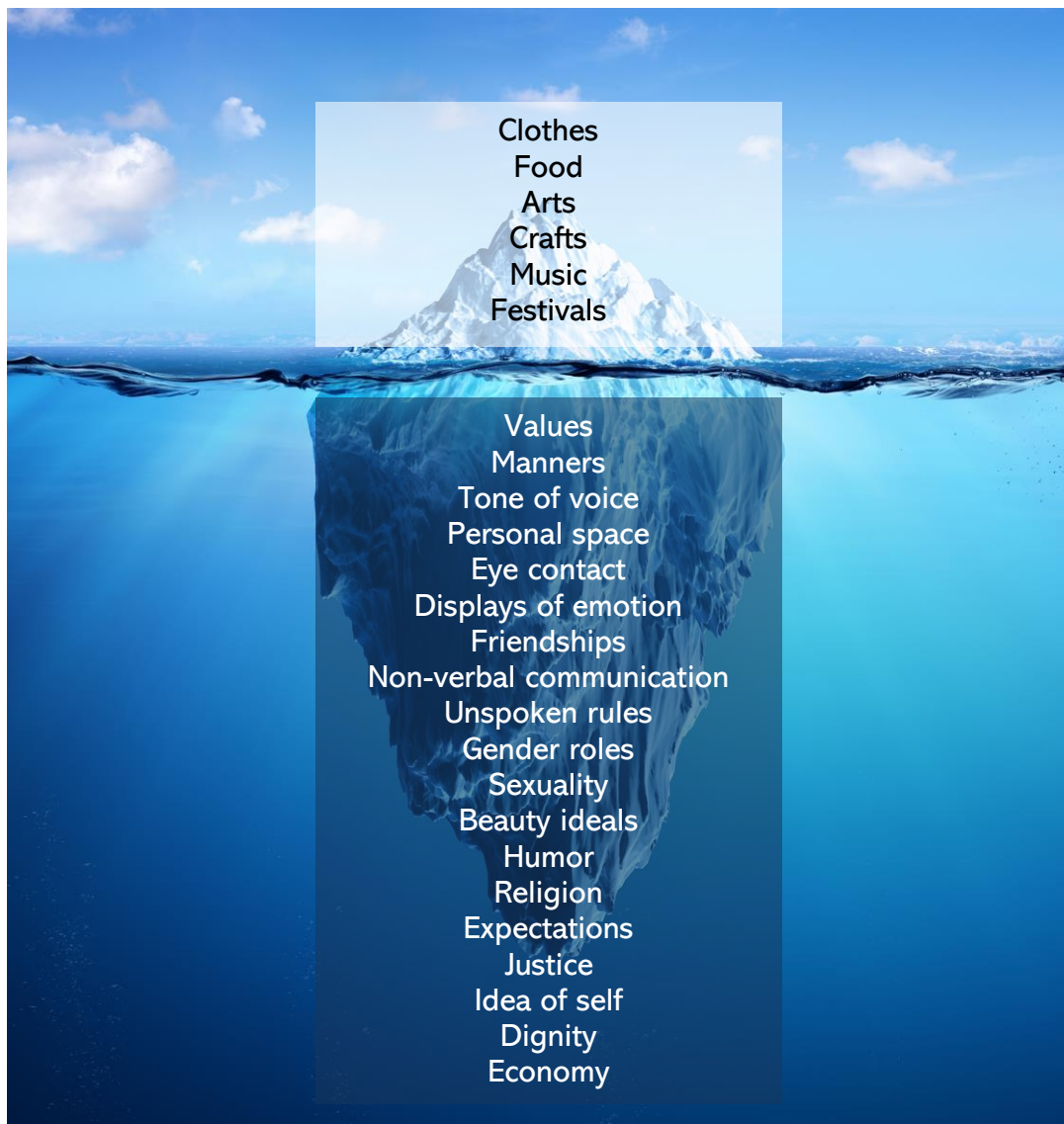
Figure 3: Cultural iceberg. Figure by: Karianne Aho

There are ways in which we communicate aside from language. The cultural context also provides nuance and meaning, and we can never assume that the receiver of our message has interpreted it exactly the way we intended [18]. "When someone says 'yes' it often doesn't mean yes at all, and when people smile it doesn't always mean that they are pleased," as Hall puts it [18 p. 59].

Different cultures have different ways of using language to convey meaning, which also predisposes us to think in different ways [19]. A primary way cultures will differ in communication style is whether low-context or high-context communication is more preferred [19]. In low-context communication, most of the meaning is found directly and explicitly in

the words that are spoken [19]. In a high-context communication style less of the meaning is contained in the words spoken, and the listener is expected to read into contextual clues and non-verbal communication to understand the full meaning of what is being said [19]. Cultures also differ in preferred quantity of words [19]. While some cultures will value elaborate, expressive language, others will think simple, understated utterances are more sincere and will prefer silence to small talk [19].

It can be difficult for two people of different social backgrounds to understand each other and communicate effectively. This can pose a major challenge in a health care setting where patient and health professional need to communicate effectively in order to achieve the best health outcomes. Healthcare workers need to understand the cultural backgrounds of the patients they are caring for in order to create a trusting and respectful relationship, leading to shared decision-making and better tailored treatment plans. Healthcare professionals that have knowledge on health disparities between groups can also advocate to reduce these disparities by way of suitable interventions.

4   Methods

The following chapter presents what methods were used in researching the need for, and potential requirements of, an application intended for Sami diabetes patients. Methods for project management and application implementation are also presented.

4.1   Literature review

A literature review was conducted on Sami culture and communication about health and illness. The review was conducted following the PRISMA framework. The reason for the review was to provide context for the thesis, as well as seeking out information that could improve the design of the application, to create a better and more relevant final product.

The question the literature review attempt to address is:

> "What cultural factors could introduce challenges to the interaction between a Sami patient and their health care provider?"

4.1.1   Search queries and databases

Based on the topic of study, the search terms shown in Table 4 were selected, categorized into three topics, and translated into Norwegian. Truncation (*) was used to include all grammatical variants of a word.

Table 4: Search terms for literature review on Sami culture of communication about health.

	Sami	Communication	Health
English	Sami* Saami* Sapmi	Communicat* Language Cultur* Consult*	Health* Illness* Sick* Doctor*
Norwegian	Same* Sami* Sapmi	Kommuni* Språk* Kultur* Konsult*	Helse* Syk* Lege*

It was found that the search terms "sami/saami/sapmi" constricted the results significantly, so it was decided to cast a wide net with the remaining two categories of search terms in order to make sure that no relevant results were missed. Similar searches were attempted in Northern Sami, but no results were found.

Searches were performed in the following four databases:

- Web of Science (English search in topic, title, abstract, keyword plus and web of science categories)
- Medline (English search in title, abstract, keywords and subject headings)
- Embase (English search in title, abstract, keywords and subject headings)
- Open Polar (English and Norwegian search in title and subject)

Searches in Medline and Embase were conducted simultaneously using the library search tool Ovid.

4.1.2 Processing the results

The following inclusion and exclusion criteria were used during screening:

- The study should be based on primary sources
- The previously defined question need not be the main focus of the study. The study may be included even if only parts of it are relevant.
- Discussions of both physical and mental health may be included.

The results were processed exclusively by this thesis' author. Duplicate studies were removed manually.

Below follows the PRISMA diagram of the result processing (Figure 4).

Identification of studies via databases and registers

Identification

Records identified from*:
Web of Science (n = 159)
Medline and Embase (n = 285)
Open Polar (n = 156)
n = 600

Records removed *before screening*:
Duplicate records removed (n = 301)

Screening

Records screened (n = 299)

Records excluded** (n = 255)

Reports sought for retrieval (n = 44)

Reports not retrieved (n = 0)

Reports assessed for eligibility (n = 44)

Reports excluded:
Out of scope (n = 38)
Secondary literature (n = 5)
Abstract (n = 1)

Included

Studies included in review (n = 9)
Reports of included studies (n = 9)

Identification of studies via other methods

Records identified from:
Organisations (n = 1)

Reports sought for retrieval (n = 1)

Reports not retrieved (n = 0)

Reports assessed for eligibility (n = 1)

Reports excluded:
n = 0

Figure 4: PRISMA diagram detailing the processing of search results for the literature review of Sami health communication.

4.2 Interviews with health care providers

Interviews were conducted with health care providers that have experience working with patients of Sami background. The interviewees were asked about their experience with caring for Sami patients, and if they had perceived any difference in communicating with Sami patients as opposed to non-Sami patients.

4.2.1 Assessment

The data protection officer (DPO) of UiT was contacted by email. In the email, the DPO was briefed about the project, the nature of the interview, and an interview guide was attached. The email further requested the DPO's guidance on proceeding with the interviews. The DPO advised that the project needed to be submitted to Sikt to be assessed. Sikt is an administrative body under the Ministry of Education and Research, and provides such services to the university.

The application to Sikt required the attachment of a consent form. Sikt also provides the outline for such a consent form in Norwegian. Based on this outline, a consent form was made in Norwegian for the purpose of the interview. As the plan was to include Sami speaking interviewees, a similar outline in northern Sami was searched for in Sikt's websites. When no such outline could be found, Sikt was asked through email whether such an outline existed. Sikt's response stated that they had no such outline. This led the author to translate the Norwegian request form into northern Sami herself, with the aid of an individual with higher education in the Northern Sami language. Both versions of the consent form were attached to the application before it was submitted to Sikt, whereupon it was approved. Northern Sami and Norwegian consent forms can be found in appendices A and B. The Northern Sami and Norwegian interview guides are found in appendices C and D.

4.2.2 Interview process

Participants were recruited by contacting them by email, through Facebook, or by phone. In many cases participants were asked if they could provide information about others that would be interested in participating. The interviews were conducted during December of 2023 and January of 2024. Those interviewed had a variety of experience within healthcare, in fields

such as primary care, nursing and emergency medical services. Interviews lasted anywhere from 20 minutes to about 2 hours.

As described in the consent form to the participants, the audio of the interviews was recorded on dictaphones. The audio was moved to lockable USB memory sticks shortly after the interviews, and then deleted from the dictaphones. The audio was transcribed on an off-line computer before being deleted. The participants were deidentified in the transcriptions, and in the final report.

4.3 Examining online access to high-quality diabetes information in Sami

The main resources for high-quality and up-to-date information about diabetes for a Norwegian person would be from the following organizations:

- Helsenorge
- Norsk Helseinformatikk (NHI)
- Norwegian Institute of Public Health (NIPH)
- The Norwegian Directorate of Health
- Norwegian Diabetes Association

To investigate the access a Sami person would have to information about diabetes in a Sami language, the official websites of these organizations were investigated. In addition, a Google search using the keywords "diabetes" and "sámegillii" (translation: "in Sami") was performed. The investigation was performed November 12, 2023.

4.4 Related work

In 2020, the Norwegian Diabetes Association published an article with recommendations for mobile application for people with diabetes [20]. This list includes applications to help with areas such as exercise, diet, and sleep. Many of the applications on the list are not created for people with diabetes specifically but are intended for anyone interested in keeping a healthy lifestyle. To study what applications may be in common use today in Norway for diabetes management, the applications targeted especially toward people with diabetes were examined.

Each application's Google Play sites were explored, along with the applications' websites where available. Free applications were downloaded onto an Android phone and explored.

4.5 Development strategy

As this is an individual project with a strict deadline, the waterfall approach seemed most suitable, and was therefore chosen to be used as the development strategy. The strategy allows for long term planning of an entire project, to ensure that the project will be completed with all necessary requirements by the deadline. Also, close collaboration with users in the target group throughout the entire project was not realistic, making an Agile approach not suitable.

An estimated time schedule was created at the start of the project, and was adjusted throughout the project as work progressed, delays occurred, or new ideas were explored. A Gantt diagram implemented in Microsoft Excel was used for this purpose.

4.6 Implementation

The application was implemented for the Android operating system using the official Android IDE, Android Studio. Java was used as the programming language. Git and GitHub were used for version control. An external library, GraphView [21], was used to implement the graphs for blood glucose and bodyweight tracking. The chat UI was based on [22], with some adaptations.

The application is built using the standard MVC architecture for Android applications. This architecture divides the internal logic of the application into three parts: Model, View, and Controller. The model is the representations of information, structured as objects and classes. The controller accesses and manages the model, the data, and sends it to the view, which is the visual presentation to the user.

4.6.1 Model

All information is stored on the phone's internal memory. Data is saved on a local database using the Android Room library. The Room library provides structured data storage in tables, and an abstraction layer over SQLite to access and manage the data. Object classes, or

"entities" are created to represent data, and are translated into Room tables for storage. Each instance of an entity is stored as a row in its respective table.

4.6.2 View

The navigation through the application is implemented using the Android Navigation component. Android Navigation provides tools to implement smooth navigation, app bars and other components. A single activity architecture is used, with several fragments for the different interfaces shown to the user.

4.6.3 Controller

The controller is what ties the model and view together. It is implemented according to the appropriate controller architecture for Room databases, using DAOs (Data Access Objects), observers and LiveData. DAOs translate database queries in SQLite into Java methods that can be called to interact with the database. Data that is returned from the Room database is returned as LiveData, which, as its name suggests, updates live when changes to the database occur. The application must implement observers that notice changes in the LiveData and update the view appropriately when this happens.

5 Theoretical results

This chapter presents the results of the investigations that were described in the previous chapter.

5.1 Literature review

The goal of the literature review was to find if there are, or to what extent there are, cultural factors among Sami that would shape the way they would speak to their physician during a consultation. As the results from the queries were examined, there appeared some reoccurring themes regarding Sami health culture:

- The use of traditional medicine/healing as a supplement to traditional medicine
- Avoiding seeking help from conventional health care if possible
- Distrust of conventional medicine and health care workers
- A somewhat different understanding of health, and to what extent health can be affected
- A different norm of communicating about health, characterized by non-direct and ambiguous communication, and even reluctance to speak about the topic at all

While it would be interesting to dive deeper into all of these characteristics, the review will focus mostly on the last point; the way that Sami patients will often prefer to speak indirectly and in a roundabout way about their health issues, rather than in clear unambiguous statements. It is worth noting that the mentioned characteristics of Sami health culture do not have strict boundaries. The norms are the cause and effect of each other, and so other themes may make appearances throughout the literature review.

5.1.1 Sami norms of communicating about health

Table 5 summarizes the key findings of the literature review.

Table 5: Key findings of literature review on Sami culture of health communication.

Authors; Title	Topic	Method	Key findings
NOU 1995:6; "Plan for helse- og sosialtjenester til den samiske befolkning i Norge" [23]	How to bring equal health and social services to the Sami	Large scale investigation by the social- and health department	• Indirect communication • Direct questioning may be seen as offensive • Circular way of approaching topics
Hedlund & Moe; "'De forstår ikke hva som er viktig for oss': Helsetjenester og sørsamer" [1]	Map the challenges to providing health care to South-Sami patients	Qualitative interviews of health care workers in South Sami municipalities and South Sami informants	• "The ideal patient" • May neglect to voice dissatisfaction • Will wait to seek help until the problem is severe
Dagsvold; "'In gille huma'. De tause rommene i samtalen: samiske fortellinger om kreft" [24]	How is the disease cancer talked about, or not talked about, in Sami society	Interviews with four Sami women	• Indirect approach • Some sickness-related words may be perceived as unpleasant or scary
Bongo; "Samer snakker ikke om helse og sykdom" [2]	Sami cultural view and communication around health and illness	Interviews with 21 Sami informants	• Indirect language and hints • Using humor • Speaking through third parties • Silence and body language • Confrontational language seen as inappropriate
Mehus et al.; "Important factors when communicating with Sami patients about	Sami communication about health when meeting	Interviews with 11 Sami informants	• Trust must be built before open communication may take place

health, illness and care issues" [3]	with health care workers		• Sami patients must be given enough time • Some topics are more difficult to speak openly about
Ness & Munkejord; "'All I expect is that they accept that I am a Sami', an analysis of experiences of healthcare encounters and expectations for future care services among older South Sami in Norway" [25]	Healthcare experiences of older south Sami	Interviews with 12 older South Sami	• Sami patients must be given sufficient time
Engnes et al.; "Sámi and Norwegian nurses' perspectives on nursing care of Sámi patients: a focus group study on culturally safe nursing" [26]	Nurses' perspectives of taking care of Sami patients	Focus group conversations with 26 Sami and non-Sami nurses	• Non-confrontational style of communicating
Dagsvold et al.; "What can we talk about, in which language, in what way and with whom? Sami patients' experiences of language choice and cultural norms in mental health treatment" [27]	The significance of Sami language and cultural norms when communicating about mental health issues	Interviews with four Sami patients receiving mental health treatment	• Indirect way of communicating • Use of hints and body language • Sami patients are able to adapt when needed
Dagsvold et al.; "Clinicians' assumptions about Sami culture and experience providing mental health services to Indigenous patients in Norway" [28]	Clinicians' assumptions and experiences in providing mental health services to Sami patients	Interviews of 20 clinicians, Sami and non-Sami	• Indirect and slow communication style • Use of body language, metaphors, and silence • Sami patients are able to adapt when needed

From the results, the picture that is painted is of a particular way of communicating that is indirect, in many ways non-verbal. Information is communicated through hints and implications instead of explicit, direct statements or confrontation. Body language and silence are used to convey meaning, and one would talk around a topic for some time before eventually circling to the core of the issue.

An investigation was done by the social- and health department in 1995 [23], aiming to bring equal health and social services to the Sami as for the Norwegian population. In this investigation, challenges in communicating with Sami are described. The Sami communication style is described as being indirect in its narrative, using implications instead of unambiguous, clear statements [23]. This could take the shape of significant information first is suggestively mentioned, so it apparently seems contextually meaningless [23]. The subject may later reappear, vaguely worded, or mentioned in passing [23]. A therapist should be aware of this and know that a direct and interrogative approach in gathering information will not serve much purpose and may be perceived as offensive by the patient [23]. It's pointed out that the Sami way of approaching a problem is to go in a circular way around it, getting to the core in the end [23].

A follow-up project sought to map the challenges to providing health care to South-Sami patients [1]. Interviewed health care workers describe Sami patients as "the ideal patient", non-demanding, easily satisfied, and trusting of the information given [1]. There are different ways of interpreting this non-demanding attitude. One way is that Sami patients indeed are happy with the care they receive, another is that Sami patient neglect to voice dissatisfaction or make demands when needed. The paper points out another trend that may suggest the second interpretation: Sami patients will wait to seek help until the problem is acute and severe [1].

In Inger Dagsvold's 2006 master's thesis "'In gille huma'. De tause rommene i samtalen: samiske fortellinger om kreft" [24], which translates to "'I won't bother speaking'. The quiet parts of a conversation: Sami stories of cancer", she conducts interviews with four Sami women about how cancer is talked about in Sami society. One of the women is herself a survivor of cancer [24]. A theme throughout the thesis is that Sami people in general have a harder time speaking about cancer or illness openly, and will choose an indirect approach when they do speak [24].

A topic of discussion within the thesis is the Sami word for cancer: "Borasdávda". The word is comprised of two parts: "boras", coming from the word "borrat", meaning "to eat", and "dávda" meaning "sickness". A sickness that eats you. The interviewed women differ in their opinion of the word [24]. Two of the women find the word suitable, as it is descriptive of the disease, but also think that the word is not very "nice" and might negatively affect those who suffer from it [24]. The other two women will not use the word, saying they don't like it, and that it is frightening, preferring in it stead a loan word from Norwegian; "kreafta" [24].

In her 2012 doctoral thesis "Samer snakker ikke om helse og sykdom" [2], meaning "Sami do not speak about health and illness," Berit Andersdatter Bongo interviewed 21 Sami persons on the topic of the Sami cultural view and communication around health and illness. All the participants of the study share the view that Sami people typically do not readily express themselves openly on the topic [2]. The Sami way of communicating about the topic of health and illness is using indirect language and hints [2]. Humor might often be used, as well as indirect communication through third parties [2].

Silence and body language are also used as ways of indirectly communicating [2]. One Sami health care worker's opinion is that a Sami patient expects that they as trained health care staff should have the knowledge, and that they should see and understand without the patient needing to describe their situation in detail [2]. A patient's feelings about their health care experience will also not be expressed directly to the workers involved, though they may hear about the patients' opinions, good or bad, from a passing third party at a later date [2].

Confrontational or direct language can be seen as inappropriate, or even judgmental by Sami [2]. Direct questions are rarely asked and may be seen as rude when the topic is another's body or health [2]. One participant says that here is a foundational morality in not being too direct, and that confrontation has no place in Sami interactions [2]. Another says that using too direct questions can bewilder Sami patients to the extent that they cannot give correct answers [2]. A Sami patient will not open up to a stranger during a first meeting. One must be careful, and not go at the issue directly [2]. The Sami patient will use few words, and one needs to ask many questions to eventually getting a hold of the real issue [2].

These norms of being indirect and non-confrontational stand in odds of the modern health care philosophy, where a patient should be empowered and involved in their own health journeys and treatment [2].

This indirect and roundabout language has the purpose of preventing conflict and hurt feelings, and "talking suitably" is as such seen as promoting health [2]. That is not to say that the problems are ignored. Those around the person are expected to notice that there is an issue, and quietly initiate helping measures [2].

Some participants expressed a distrust of the health care system and the people within it, saying that one should always consider carefully what one tells strangers, and use special caution in what one tells Norwegian health care workers [2].

A similar 2018 paper [3] interviewed 11 Sami people about this topic. Nearly all the participants emphasized the importance of not rushing when talking with Sami patients [3]. Sami patients will not readily open up to people they have just met, and trust needs to be built first by talking about broader topics [3]. One nurse describes how, even when the patient is in pain, they will not state this outright:

> My experience is that Sami do not complain. If they have a lot of pain, they tell you that they only have a little pain. I have to engage in everyday conversation and thereby get to the real problem, the pain. Then they might be honest and tell me how they really feel. [3, p. 293]

Sami patients will find it especially uncomfortable to answer questions around more embarrassing topics such as bowel movements and passing gas, another participant who has worked in health care states:

> I have worked in the gastrointestinal unit. In the Norwegian language, there are many fancy words to describe bowel movements, passing gas, etc. Perhaps this makes it easy to answer in Norwegian. But Sami patients find it uncomfortable when they are asked whether passing intestinal gas has been functioning normally, or whether he has had normal stool. These are private matters. A little time must be spent explaining why it is important to pay attention to these things before one poses direct questions about them. [3, p. 293]

In such cases it was described as important to approach the topic respectfully and carefully, taking one's time and not rush into direct questioning, as it will be seen as impolite or disrespectful [3]. One way to do this is to explain to the patient the need to share this information to ensure positive health outcomes. [3]

This notion of Sami patients needing time to express themselves fully is mirrored in a 2022 study of healthcare experiences of older south Sami [25]. One participant tells a story about having a very positive relationship with their Norwegian general practitioner:

> I can talk with him about everything, he has time to sit and listen to me. After I got my disease, he said I could just come to him and talk when I wanted. I do not think many GPs says that. (. . .) He gives me time when I need it. [25, p. 4]

Another participant expressed feeling deprioritized when consultations are rushed:

> I get the impression that physicians today are so busy, they want to conduct as many consultations as possible, and they don't even have time to look up from the computer. They hardly look up. Who wants to talk to a physician who doesn't have the time to listen? [25, p. 4]

While it would be ideal that practitioners could spent as much time as they would like on each and every patient, not just Sami, this approach does not fit in with the realities of the current Norwegian health care system. Doctors have only limited time with each patient and exceeding that time with one patient usually leads to other patients having to wait.

A 2021 study [26] asked 26 nurses, 13 of them Sami-speaking, about their perspectives on nursing care of Sami patients. The nurses described differences in Sami and Norwegian styles of communicating, describing the Sami way as "non-confrontational" [26]. One Sami nurse describes her experience:

> My experience with Sámi patients is not to behave in a too direct or confrontational way, not to ask too personal or too blunt questions. Sámi patients have a non-direct way of communicating, you have to be able to read between the lines. [26, p. 6]

The nurses noted similar experiences from elderly Norwegian patients, and pointed out that the most important thing was still to treat each patient as an individual [26].

While the papers discussed above have mostly been centered around physical health, it seems this unique style of communication is as prevalent in a mental health context. A 2015 paper [27] interviewed four Sami patients receiving mental health treatment in Norway. All the participants expressed that they had experienced difficulties in communicating with health services, attributing this to cultural differences [27]. The participants described a "Sami way

of talking" similar to what previous studies have found; less verbal and direct, use of hints and body language, and not complaining. One participant puts it:

> The Sami way to ask for help is by hinting... because you don't want to force your needs on anyone. The way to tell others you're having a hard time is very indirect, cautious, roundabout, maybe as a joke… [27, p. 6]

This style of communication was contrasted with the more straightforward or confrontational style of typical health providers. One participant describes not readily sharing struggles:

> And then there's the thing that we don't like to talk much about personal stuff. To keep things to yourself is typically Sami. I don't talk much, I've never been a person who said much, and when I need to react to something, I go off by myself. Because that's a typical Sami thing, you tend to spend a long time working through things, and you don't talk. [27, p. 6]

The paper further describes the patients deciding to change their ways in favor of getting the help they needed, and finding that opening up helped them receive better treatment [27].

A 2020 paper [28] interviewed 20 clinicians in the northern Sami area on their assumptions and experiences in providing mental health services to Sami patients. 11 of the clinicians self-identified as Sami [28]. The participants described an indirect and slow communication style common to the Sami, and the use of body language, metaphors and silence for communication [28]. They also described a culture of managing on one's own, avoiding seeking help and hiding one's problems [28].

Despite this, their descriptions of their clinical experience with Sami patients were more nuanced. They stated that Sami individuals did seek out treatment and did talk about their problems during therapy [28]. Some pointed out that Sami patients may be influenced by culture in their way of expressing themselves [28]. One clinician stated that Sami patients were as communicative as Norwegian patients, as once they had sought out treatment, they had acknowledged their need for help [28]. Sami patients were described as "adapting to the context" in that case [28].

These last two studies paint the picture that patients do have the ability to set aside their established cultural norms and to communicate with more openness in some contexts.

5.1.2 How could these results help shape the application?

Some of the major recurring themes that can help shape the design of the application are:

- Sami patients will want to talk about more general topics before getting to details.
- It can be advantageous to explain to the patient the reason why the requested information is relevant.
- Patients will find it more difficult to speak about topics that are seen as embarrassing or taboo.
- Sami patient will avoid voicing complaints.
- Sami patient heavily dislike feeling rushed when answering questions

From this, some design choices that could be made are:

- A patient would reflect on the general state of their health first, before going deeper into specifics.
- The patient should be offered an explanation of the relevancy of the topics raised, to provide context and reassurance.
- Topics that could be seen as more difficult to speak about should appear towards the end of the session.
- Patients should be encouraged to voice dissatisfaction to their physician, should they be unhappy with something.
- It should be made clear to the patient that they are in no rush and can take as long as they like to go through a session on the application.

5.2 Interviews with health care providers

The results that emerged from the interviews with health care providers mirrored what was found in the literature review, namely that Sami have an indirect manner of communicating. The communication style is described as moving around a topic before closing in it. Those interviewed also expressed that Sami tend to avoid or delay seeking healthcare if possible. Sami patients are also less likely to speak up about pain they are having, to ask questions, or disagree with their doctor. One potential factor explaining this may be a belief in fate taking its course.

There were differing opinions on differences between younger and older patients. Some interviewees had noticed no difference, while others thought younger patients communicated a bit more openly.

Letting a patient speak their mother tongue was expressed to be a substantial benefit. A patient will feel safer and be able to communicate more effectively in their native language.

Particular difficulties for Sami diabetes patients that were mentioned were the lack of information about the disease in Sami, and lack of guidelines tailored to the Sami population. There was also a lack of focus on complications that may arise from diabetes. Some topics were thought to be more difficult for Sami patients to discuss. Issues concerning weight and intimate parts were brought up as examples.

Table 6 summarizes the key findings of the interviews.

Table 6: Key findings of interviews with health care providers.

Topic	Key findings
Communication style	- Will not emphasize or overstate symptoms - Reluctant to express pain - Will not speak openly at first - Roundabout manner of talking - Information is revealed bit-by-bit - Need time to open up - Younger patients might be more open
Avoidance and distrust of healthcare	- Will wait to seek help - Will have more severe symptoms due to healthcare avoidance - Distrust of conventional medicine
Belief in fate	- Believe their condition has been predetermined - Will not ask for symptoms to be relieved - Believe medication can only have limited effect - Low faith in their own power to affect their health
Language	- Patients can give more detailed and accurate information in their mother tongue - Process of anamneses and diagnosis is more efficient when the patient can speak their mother tongue - An interpreter should interpret culture as well as language - Important that patient receives information in their mother tongue - The patient feels safer when treated by a Sami speaker due to increased trust - Better communication also has physiological benefits
Diabetes	"Sohkárdávda" may seem stigmatizing - Lack of information in Sami - Need for specialized recommendations that consider Sami norms and culture - Not enough focus on complications that may arise
Taboo topics	- Weight and diet may be uncomfortable to talk about - Difficult to talk about sexual functions and complications - Sami language lacks neutral words for intimate body parts and processes

5.2.1 The Sami communication style

Participants for the interviews are differentiated by codenames P1-P6 in the following chapters.

The health care providers all expressed that Sami patients have a different openness and way of communicating about health than non-Sami patients. Sami patients generally are more reluctant to fully state their condition from the get-go, but will rather hold back and only reveal information bit by bit, as necessary.

> P4: There is a big difference. At least that is how I experience it. Maybe there isn't such a big difference between Sami patient's a north-Norwegian patients, they have a similar manner, though there still are differences. As a lot of literature probably suggests, Sami patients are not the sort to whine, so to speak. They do not emphasize how their symptoms are affecting them.

> P4: It seems to be a different manner... As I experience it, the Sami will not want to bother the doctor too much. Maybe that is why they do not speak as openly. That you will have to drag it out of them, know what to ask and understand their answers to get to the problem.

Just as what was found in the literature review, the Sami communication style was described as roundabout and indirect, circumnavigating the real issue before closing in on it. One healthcare worker described it as "building a path" of communication to the patient.

> P2: You have to chat with the patient in a roundabout manner, and ask with a sort of craftiness, 'How is your feeling here? Do you sense that?' (A patient might answer,) 'Yes, I feel something there. There is a little something there too.' In that manner you start approaching the real problem, they open up then. You create a path to the patient, and they open up and start to explain.

> P3: You kind of swerve. The way Sami communication often is, you're not too direct immediately. There's an art to it.

Another health care worker portrayed how, say, asking about the weather was an important first step in a consultation. This goes against what is typically taught in medical studies, that asking direct and unambiguous questions immediately is preferred, to make examinations the most efficient.

P3: There's this way of talking and being a bit clever about it. A Sami, I don't know if it's this inherent fear of health authorities, I don't know what it is, but you have to make them trust you. The first few minutes with a patient are very important. Especially as doctors, we are trained throughout our studies to ask direct questions, and to go straight to the point immediately. But in Sapmi, I think the first five minutes of a consultation, or if a patient comes to the emergency room and you are talking with them, it's more important to talk about things like, 'how was your journey [coming here]? Was the weather terrible?' Those are important questions because you start building a relation that way, and it builds the foundation of what they are going to tell me moving forward.

This style of communication will naturally clash with the current realities of health care consultations, where patients should preferably be in and out of the office as quickly as possible, as there are other patients waiting in line. One common complaint that was encountered by one health professional was that patients felt they didn't get enough time with their doctor.

P2: One thing I experience a lot, especially among older patients, when they meet a doctor. They feel that they are given so little time to speak with their doctor during their visit. That's a very common thing that I hear again and again when we speak to the patient. That the visits are so strange these days, they don't have time for anything, they didn't get to tell them even half of what they had to say. The time is so restricted. When a Sami patient has booked a visit with their physician, they often feel, from what I have heard, that these days the doctor has no time to chat, no time to listen to what they want to say.

5.2.2 Communicating pain

Many of the interviewees expressed the opinion that Sami patients can be quite reluctant in expressing pain. Many of the interviewees have even come to change their method of communicating in the exact same way; they will not ask a Sami patient if they are in pain, but rather if they are experiencing discomfort. Asking in that manner is seen as a more "suitable" way of talking.

P4: You have to pull it out of them, especially from older patients. You can't ask an older patient if they have any pain because they will say no. Because for there to be pain, there has to be a lot of pain, like their leg is broken. I noticed that when I started working here, I would try to ask the same as I would ask my Norwegian patients; 'do you have pain anywhere?' But that doesn't work. So, you have to ask 'do you sense that?' That's a different type of word. Or 'do you have any discomfort anywhere?' or 'do you feel something anywhere?' They you might catch onto something, and you can ask about it further. You might figure out that it is in fact quite painful, but they won't want to emphasize that.

P1: I think that the Sami maybe understate their symptoms, at least pain. I have almost entirely stopped asking 'are you having any pain?' I will ask, 'are you uncomfortable? Do you have any discomfort?' Then it's easier to say, 'yes I do, I have this discomfort in my chest,' or something.

P2: Yes, it's quite common this word 'discomfort.' You don't ask directly if it hurts but if there's discomfort. That's a typical word in Sami. You don't ask straight out 'do you have any pain?' Especially with older people, they might say 'yes, there's a discomfort there.' I might then ask, 'does it hurt?' 'Well, I feel it sometimes, yes sometimes there's a pain.' In that way I get closer to knowing they have pain, but I ask in a nicer way, or a more suitable way.

P2: I've seen that many times when a doctor questions a patient. I've talked with the patient in the ambulance or at their home when we pick them up. When the doctor asks in Norwegian, the patient says 'no, there isn't [any pain].' It's not the same communication at all. Many times, I've said 'but a while ago you said it was uncomfortable,' 'yes, I have this discomfort here.' So, in a way they haven't understood the question. But in Norwegian it's very straightforward, direct. It's not always suitable to talk to people that way. You have to talk a bit around it. And then they might admit that it hurts there sometimes. You have to move toward it in that way.

One doctor noted that this way of communicating also has some positives:

P4: [About the Sami way of communicating] I have to say that I like that, I'm used to working in that way, so I don't find that it's a problem. In my opinion it is a nice

manner that you shouldn't whine, so to speak, and you shouldn't be too demanding. I think that's good. There's a lesser risk of overmedicating with this manner.

Comparing Sami patients to non-Sami patients, it seems the occasional non-Sami patient will overstate their pain, but this phenomenon is rarely, if ever, seen in Sami patients.

> P3: It's certainly easier to get them (non-Sami patients) to admit that they're in pain and talk about their pain. But due to my Sami background, I often experience that even though I have a Sami patient they will admit to me if they're in pain. But I've also experienced that I've asked if they have any pain, they tell me no, but I can see on their body that it probably does hurt somewhat. And then you have to dig a bit further and question them. But what I experience, where I see a difference between Sami and non-Sami patients is that non-Sami will say they have more pain than they really do. I see that often. It's rare for a Sami patient to tell me they're in pain unless I ask, but non-Sami might say 'oh, they are in such pain,' even if you haven't asked them if they have any pain. So, I experience a difference there. But I think because I have the language and cultural knowledge that they are more honest with me when I ask if they're in pain, and also then they can explain it better. But they certainly don't exaggerate any pains.

> P1: We would use this scale from 0 to 10, 10 being the worst possible pain, and 0 being no pain. I tend to see here that, in comparison to (a hospital with a lower ratio of Sami patients) where I also have seen patients, there I often was told 10 and 9, even if it didn't seem that painful. Here, the patient can seem to be in intense pain, you can see that they're in pain, but they'll tell you it's not that painful. They may call it a 7 or an 8. If it's an 8 they are nearly about to die, right? But it's never 9 or 10.

Not knowing or understanding this tendency in Sami patients can in the worst case lead to examinations by doctors that are not thorough enough, leading to the patient not receiving the help that they need.

> P5: One patient that I know privately, I heard he had been here to emergency care. At once I thought that he must have been in real pain or been in a real emergency because this person wouldn't have come for nothing. The doctor that was here at the time, didn't figure out what it was. They thought it was some normal pains, that it wasn't anything acute. Some days later it was found that it was acute. I think if I, who know

the person and am Sami, if they had come to me and I was the one in emergency care, I would have thought that I must examine this person very thoroughly, because they don't come here unless they really need to. That's one example. Some Sami are like that. Also, there was one time someone came with a broken leg, and they told me they didn't think it was broken. I said I was pretty sure it was, and asked if it didn't hurt. (The patient answered) 'Well, it's not painful, maybe a bit uncomfortable.' But I could see that they had a lot of pain and could hardly walk. So, it's like some Sami don't want to admit pain. But there are also some Sami speakers that come to the doctor's frequently, maybe for things that didn't warrant coming quite so early.

5.2.3 Avoidance and distrust of healthcare

A common comment was that Sami patients will wait longer before going to the doctor, to perhaps the frustration of some health professionals.

> P1: If one were to generalize a bit, maybe Sami people will wait a bit too long before contacting their doctor. Maybe Sami connected to reindeer husbandry will wait even a bit longer. They perhaps are used to waiting and seeing how it goes.

> P2: We often try to appeal to people that they don't have to be in mortal danger before calling (the emergency number). You can call if you have a fever and can't make it out of bed, and you are home alone. It's better that you call and tell us about your situation. If you can't walk from your bed to your car, you have the opportunity to have an ambulance come drive you to the doctor's office if you need to see a doctor. So that's a part of Sami I feel where 'there's no need to call (the emergency number), I'm not that sick.' That's very common among Sami, and 'what if the neighbors see the ambulance and they are startled and wonder what is going on here?' I've noticed that for a long time. That it has to be pretty severe before calling.'

> P3: And that goes for younger patients as well, and not only for ambulances but also for police and things like that. There is that skepticism: 'I'm not so ill that that's necessary.'

> P2: And it's been many times that we get a message from the doctor's office that we are to bring a patient to the hospital, and when I get there it's a seriously ill person.

Many times, I have asked them, 'how did you get to the doctor's office?' 'Well, I came by car,' and someone had brought them, and dragged them into the car somehow. I ask, 'where did you call first?' 'Well, I called the doctor's office.' I ask, 'well didn't they tell the ambulance to come?' 'Yes, they said ambulance could come, but I told them that wasn't necessary, that I'll get there myself.'

P3: They wait far too long before asking for help, and maybe they have become poorer than they would have been, had they come a long time ago. Maybe they don't want to be admitted, and many may fear that if they call for an ambulance that they are taken straight to the hospital. So yes, they wait too long, and accept more, they're in more pain, and in worse shape when they get here.

The trend is continued in Sami patients' skepticism of medications.

P3: What I experience, but which of course is not exclusive to Sami patients, is that many Sami patients are somewhat fearful of medicine, that they'd rather not have that, that it's the last option, that you'd have to be really sick before you would want that. They're skeptical of even paracetamol and all kinds of common medication. I see that in non-Sami patients as well, but then in men. Older men will be skeptical. In Sami, younger people too will be skeptical.

P2: Many times, a patient will tell me 'There's no point to that medicine, I'll let you give it to me, but it won't be of use, it won't save me.' But when I have given them the medication anyway, at the time it starts to work, they tell me, 'You were right about what you told me a while ago, that helped a lot, I feel like a different person now.'

This skepticism of conventional medicine can perhaps be explained partly by a common philosophy that is seen in Sami patients; the sense of fate taking its course.

P3: It's more that the Sami have larger sense of fate, that they believe that fate, what is destined to happen, will happen, that a person will die of something or other anyway, and their day (of death) has been predetermined. A common question of cancer patients is, 'how long do I have to live?' but Sami patients tend not to focus on that, but rather think, 'I guess this is what was meant to happen,' and that their days are predetermined. And maybe they think more that there is a Lord of their health somewhere who calls the shots. An example being code status. That 'what is meant to

be, will be,' that would perhaps be my experience. That also influences the fact that many patients don't consider that their symptoms can be relieved, that they are not meant to suffer though all kinds of pain, that there are many aids such as medication. I think many accept a lot more than what non-Sami would, because of that belief that 'what is meant to be, will be.' That can also be a nice attitude in my opinion, as it gives a sense of coping with their health and sickness, when it comes to serious illnesses. They get a really different sense of coping when they approach it with that worldview. On the other hand, there is a risk that they won't speak up about their experience because they believe that this is how they should live. I find in these cases that, because I have this understanding and I know that some people think like this, I can dig further and ask them 'are you having any pain? Are you sure? Are you sleeping well?' I have a different starting point for making these inquiries, and I might find that they are in fact in pain, that they lie awake at night thinking, and there's pain and anxiety, issues that can be helped.

P4: I think it's maybe that they don't really believe how important they are, the recommendations. How important they are for your health when you have type 2 diabetes. I think maybe it's more that they don't really believe that it's quite true that they themselves can do something for their own health. Maybe the thought is more that 'a disease is a disease, and it has come to me now.'

Encountering this belief in fate numerous times throughout their career, one health professional had developed their own strategy for calming and reassuring patients in life-threatening situations.

P2: It's very common when a person is panicked and ill, when there's a serious situation and the fear of death comes to the person who is ill. 'I'm going to die now, but I suppose I have lived my time,' is how they will speak, in a way that 'their minute and hour has now come.' For these patients that are truly fearful and keep thinking that death has now caught up to them, I tend to comfort them by saying, 'we'll try to treat you yet, and it was also written once that no one goes before their time, before their hour.' I need only say 'before their time,' every Sami patient understands. 'You're right about that, no one dies before their time,' they understand and accept that. I've never come across a Sami that doesn't understand what we're talking about.

I'll tell them, 'This might even go well, and the time we're talking about might not even have come,' and they will accept that, and we can move on from that.

Sami patients are described as less likely to ask questions during consultations. One health professional describes this as a paradoxical trust in the doctor, despite the distrust of medicine previously discussed. A different point of view might be that, due to lack of faith in medicine, Sami patients might feel that there is little point in discussing treatments as one will not be significantly more helpful that another anyway.

> P5: Norwegian patients, maybe, can be a bit more demanding, saying like 'is this correct?' or 'why like this and not like that?' Sami patients perhaps listen to me more, and everything I say seems alright with them.

> P3: What I maybe have experienced, is that Sami believe their doctor more than non-Sami. They have more trust when the doctor says this or that, they accept that. So you get a very important role in making a plan for that patient. For example, (with non-Sami patients) it's more that when you talk about diabetes they will ask, demand to know if they could try this because they heard this leads to weight loss and so on. That's not as common in my opinion in Sami patients, the times I've had diabetes-patients. Then it's more that you are the doctor, and you have to know what possibilities are out there, because the patients themselves have not researched through Google or anything. They are not ones to inquire, you have to present the opportunities for them. And even when you present them with these opportunities, 'should we try this or that, or what would you like?' They might say, 'well, what are your recommendations? What do you think is best?' So, they have more faith in the health care services, even if there is that skepticism we talked about earlier.

The guidelines from the Norwegian Directorate of Health strongly prioritize shared decision-making by doctors and patients. This was described as being more challenging with Sami patients, due to their reluctance to disagree with, or question, their doctor.

> P3: The shared decision-making doctors are trained for in their studies, it doesn't always work in practice in Sami society, because the patients themselves are not really as used to that. They start to think, 'Doesn't the doctor know? Why would they ask me to decide?' And so on. So yes, that's more of a challenge. Especially for the older population. Young people might want to decide more for themselves.

5.2.4 Difference between younger and older patients

Opposing opinions were expressed regarding differences between younger and older patients. Some had not experienced any significant differences, while others found younger patients to be more open. Mental health came up as an example of where differences in openness might especially differ.

> P1: I haven't really thought that (there is a difference), no. Maybe I've experienced that for mental illnesses, that the youth have more, well no, I haven't really thought that there is a difference, no.

> P5: Yes, I think younger people have an easier time (communicating) than older people. I have met many youth and young adults that speak quite openly about their mental health and such. I maybe hadn't expected that, and I got a bit surprised when I started working as a doctor here, that they are so open. Some are, and I think that's great.

> P4: There's not as big of a difference as you would expect. Of course, there is a slight difference in that younger patients are a bit more open. If you ask them if they have any pain, they might even say yes, they do! So, they might be a bit clearer when they speak about their symptoms and health… but there still seems to be the thought that they shouldn't bother the doctor.

> P6: (About differences between Sami and non-Sami patients) It's very different from person to person. I don't know that I can say that there are big differences between the younger people, but in older people there are larger differences. They are closer to nature, attached more to self-sufficiency, that you shouldn't speak about illness, and illness is comparable to weakness… There is really a lot more openness in younger people, but as soon as we touch on taboo topics such as mental illness or cancer, it is more secret, and they don't even want to speak about it to those closest to them

> P3: The thing with younger people is that they of course are more used to direct communication. They don't take offence if you ask question like that. For them the way we were taught in our medical studies works, so you don't need to spend as much time building your relationship in the first few minutes like I talked about before. But

most of the time when I have had younger patients, they have said how nice it is to be able to speak their mother tongue, and I think they get to explain in a totally different way why they have come to the doctor, and the experience is just completely different, I think. One patient told me that they felt that we were on the same level somehow, because we spoke the same language. Even if I was the doctor, they felt that they had less to fear somehow, that the power balance was smaller or something, and they felt safer speaking about their troubles.

P3 later elaborated:

P3: But if I were to compare younger Sami patients to non-Sami patients, then I still feel that non-Sami patients are more open than Sami.

5.2.5 The importance of language

All those interviewed pointed out the benefit and importance of patients being able to speak in Sami when communicating their problems to health care workers. Patients are able to give more detailed and accurate information when speaking in their mother tongue, and the process of anamnesis and diagnosis is much more efficient.

P1: It seems that most patients are very happy that there is a Sami speaking doctor, and that it feels safer. I like to make the comparison that, 'you can only become a great poet in your mother tongue'. You can explain more and create clearer pictures in your mother tongue. It can be difficult to explain your symptoms, and exactly what troubling you if not in your mother tongue… So, my experience is that Sami speaking patients, and really other patients as well, when they can use their mother tongue, they feel safer. So then it is also easier to get the correct information, and getting the information goes faster so we can diagnose the patient faster as well.

P3: My experience is that you get information from them easier if they can speak in their mother tongue, even if most people can manage in Norwegian. But you don't always get the deepest information if you have to explain it in your second language. So, you get a better conversation, and deeper information.

P2: When the worker speaks Sami with a Sami patient, the communication goes a lot smoother both ways. The patient understands you better, and the patient can explain

what they mean more profoundly, regarding pain and what is going on with their body just then. I have seen many times that when a Norwegian speaker questions a patient that is in pain, the communication doesn't go as smoothly.

P1: I know some colleagues that are not Sami-speaking have had some difficulties, which have cleared up quickly when I have spoken to the patients myself.

P6: Language can be a big problem if they meet with doctors that don't speak Sami, or understand Sami culture… They have not understood one another, and serious situations can arise that affect the patient if the patient has missed important information.

P5: For example, when patients call an ambulance, often I find that the information I receive from them (the dispatcher) is something completely different than what I get when I speak to the patient, because the patient has spoken in Norwegian to the dispatcher.

One health professional shared their experience when stepping in as an interpreter, finding themselves interpreting not only the language, but the culture as well.

P3: Your role as an interpreter is a bit special int that you are not just a regular interpreter, but also medium that has to interact with the patient in a way that, even if they say they don't have any pain, maybe you see that they do, that they're downplaying it and not telling it how it is. I've been an interpreter many times in the emergency room when it was completely necessary. But in the end, I was no longer the interpreter, but the one who assessed, because the others couldn't, due to not knowing the language. Yes, they heard the words that I interpreted, but what do those answers tell you when you're not seeing the patient in the context they're in? Culture might play a part there too.

Not only is there the psychological benefit, the feeling of safety, for the patient in being able to communicate in their mother tongue during stressful situations, one health care worker had observed physiological benefits. Namely that a person's level of stress will significantly decrease when encountering a fellow Sami speaking person, slowing their heart rate and lowering their blood pressure.

P2: And the other part is the physiological side. I've worked a lot in emergency care, and very often when we get there, we are the first to see the patient. They are distraught, there is fear, the patient has a high heart rate, high blood pressure. Immediately, when a Sami speaking worker comes, if the patient is Sami speaking, I've noticed that their heart rate goes down. Because the communication becomes such that the patient feels they are being understood. It becomes much safer for them when get to explain it in their mother tongue, their problem and what pains they have.

P2 expanded on this, and on the importance of language, with an experience that had stuck to their memory:

P2: I've experienced it once when I was working with a fellow that did not have Sami as their mother tongue… The situation was such that we had a very ill patient. We were driving them to a place, and they were being quickly sent to the hospital by air. When we were on our way to the landing field, my colleague asked me if I could come sit with the patient instead, because he felt that they weren't able to communicate well with each other anymore. He asked me to switch places with him, I was driving the car. I told him we could try that. When I got to the patient, they took my hand with both their hands and said how good it is that a Sami speaker has come. That they had given up and thought that they would demise because they felt unable to communicate any longer, that (the colleague) wasn't understanding them when they tried to explain in Sami, and they were unable to explain in Norwegian due to the pain. Even though they usually know Norwegian, they couldn't find the words, they couldn't even think of what word to use to explain in Norwegian. They gave up, figured they just had to accept that they no longer were able to communicate. They started to pray that they would make it, that it would go well. That has stayed in my memory since then, as the first time I truly experienced how important language is for the patient, communicating in their mother tongue. So, what happened with the patient is that their pain lessened just because they could communicate. Their blood pressure went down a bit, and their heart rate went down a bit.

One interview diverged to discuss the two words the Sami language has for diabetes, namely "diabetes" and "sohkárdávda" (literal translation: "sugar sickness"). One of the respondents thought the two terms were both completely neutral, but the other tended to avoid the second one.

P2: 'Sohkárdávda' is quite common. They know that we are talking about diabetes.

P3: I, on the other hand, would rather not use the term 'sohkárdávda', because to some it may seem stigmatizing. Because it's not that everyone that has diabetes has got it because they eat so much sugar. There's a lot of factors at play. For example, type 1 diabetes doesn't concern that at all. And young people are often the ones to get that. And, for type 2 diabetes, genetics play a large role in the disease, how disposed you are for getting that disease. So, I use 'diabetes' as often as possible. But if some older person starts the conversation by stating they have 'sohkárdávda', I might follow suit with 'sohkárdávda', and use the terminology they have chosen to use.

5.2.6 Particular challenges of Sami diabetes patients

When asked about what parts of type 2 diabetes might be particularly challenging for Sami patients, the lack of information about the disease, its complications, and medications in Sami was pointed out.

P5: Maybe that there are so many foreign words. When we explain what diabetes is, we use a lot of Norwegian words, and if you want to search about it on the internet, you only get Norwegian results. If you start a medication, the information is all in Norwegian.

P4: I think what can be difficult are first of all the recommendations you are given when you get your diabetes diagnosis, that you are supposed to follow in regard to what to eat and how much to exercise. I think, I don't know whether it's because we don't have a lot of that information in Sami, if that's the reason, but many don't really know what the recommendations are. I tell them, but it still seems like a lot of it is new to the patients.

Chapter 5.4 explores what high quality information is available about diabetes in Sami and affirms the interviewees' assessment in that it is lacking. This fact, if combined with only having a Norwegian-speaking doctor explain their condition and treatment plan to them, it seems that patients often can be less informed about these topics than would be ideal.

P1: Well, it can be pretty complicated for diabetes patients. First, you have the diabetes, and then there's the complications that come with diabetes such as heart

disease and so on. So, the treatment can be quite complex. So, it's very important that the patient understands the treatment, the plan. And it can be a challenge if the plan is explained in another language than the mother tongue. I have also experienced, at least with older patients, when they meet with Norwegian speaking doctors in the hospital, they will often say that they understand. Maybe it's a childhood trauma that if you didn't understand Norwegian you were considered stupid, that's just a theory. So, it's better to say you understand, even if you didn't. So, I have had a few patients, when I've spoken with them, and asked them if they understand the plan, they tell me that no, they didn't quite understand, and I have to explain it to them again in Sami.

On the topic of exercise, it was observed that there did not seem to be a culture of going to the gym. Many patients would use examples of daily chores and labor they do as examples of exercise, but there were some differing opinions amongst those interviewed on whether this type of activity truly was sufficient.

P4: Exercise, that's a bit difficult. It doesn't seem as common, at least in the older generation, to think that they should exercise. Often, I'll ask, and try to motivate them to exercise, but they'll say they do so much work outside, chopping wood and carrying stuff, and many such physical tasks. And, of course, if you work with reindeer husbandry or other primary industries, you have a lot of physical labor. Many think that's enough, that you have moved around enough, but that's not really the case. Really, they should start exercising 30 minutes every day.

P3: At least for older patients you have to explain that when they go chopping and working with wood in the forest, that's great. You can't just explain that it's important that they are 'physically active' with those words maybe. You have to tell them any movement, using everyday examples of what might benefit them. Here, it seems rare that people will go to a gym.

A healthy diet is a cornerstone of treating type 2 diabetes. Several doctors point out shortcomings in the dietary recommendations that are published by the Norwegian health authorities. The main critique is that the recommendations do not sufficiently mention the foods that are more commonly eaten in the Sami population, especially reindeer meat.

P4: Also, how much vegetables you are supposed to eat, like the plate model I think shows half of it should be vegetables preferably. I don't think that's widely used here,

and people maybe don't use as many vegetables when they cook, and don't quite know how to use them. And of course, for boiled reindeer meat and boiled salted meats, what are you supposed to do, make a salad? So that's a bit of a challenge.

P5: For example, if they say you shouldn't eat too much red meat, you have to consider that reindeer meat is different from the ground beef you buy at the store. Maybe the recommendations that are put out are not suited for Sami patients in that way. When considering the diet a person eats, it's perhaps better to use the things people eat here, like berries, things that are found here, and not start asking them to eat all these new fancy foods. You have to adapt it to the community.

For a Sami reindeer herder, a particular challenge is what foods to bring to a camp far from populated areas, traveling through a freezing climate.

P3: My experience is that maybe vegetables are not as big of a part of a Sami diet as that of a non-Sami. If you tell them to eat more vegetables, they'll ask 'So what, I'm supposed to starve?' It's also a challenge to tell a reindeer herder who has a 70 km trip to their camp, and that has to bring their food with them by snowmobile, that they should bring a salad, because it will be frozen by the time they get there. So I think diet recommendations are a bit challenging for Sami patients. What you can do is use their existing diet, by charting what they eat. Do they eat meat every day? What kind of meat? Then you can sneak things in. Can they eat fish instead that day? Try to use the foods that are in our area, many people fish themselves for example. To exploit that more, rather than expect them to start a whole new diet like advised by the Directorate of Health, when you know it's impossible that the patient will convert to that.

It seems it would be beneficial to create guidelines that specifically advise on how to include more vegetables and make healthier adjustments to a traditional Sami diet.

5.2.7 Taboo topics

Diet being a common struggle for Sami patients, it's perhaps not surprising that some patients would rather not go into detail on their eating habits during consultations.

P4: I think maybe it's a bit difficult to talk about food, what they really eat. Because, when they come to me, I'm the doctor and they know that I would want to hear that they eat a lot of vegetables. I think it can be hard to admit, how much vegetables they have eaten, but also to know how much they should eat.

Although their experience was that diet and weight could be a touchy subject, P4 was nonetheless positive to including weight registration in the application.

P4: Maybe if you register it yourself, you will get a larger feeling of ownership of your weight and lowering it. Some people care about that. It might be better if you register it yourself, and not have someone else asking you or weighing you at their office. I don't think that's pleasant, especially if you feel too heavy.

One health professional spoke about there not being enough focus on the many side effects that can arise when a person lives with diabetes for a longer period, especially those that relate to eyesight.

P2: They often speak a lot about heart and vein disease to diabetes patients, that arteries can get blockages, there's a lot of focus on that. What diabetes patients seem to hear less about is their eyes, their vision, because diabetes can damage your vision, even cause blindness.

P3 agreed with this opinion:

P3: Yes, these other complications like sores on your feet, erectile dysfunction, your eyes. There is maybe not enough focus on these complications, or maybe people don't want to talk about them, or the doctor doesn't know enough about it. I don't know what the reason may be.

Perhaps unsurprisingly, complications related to a patient's privates or sexual function can be quite difficult for patients to talk about.

P3: There are some complications that maybe they don't want to tell you. That's not only for Sami patients. Maybe especially those that concern your private parts. For example, if you are using medication which make you urinate sugar, you are more disposed to get fungal infections, UTIs and so on. So, diseases that affect your private

parts, maybe Sami don't speak about that as openly, but that of course applies to non-Sami as well. I can't say whether it's more like that for Sami.

P5: Talking about sexual function is maybe the hardest, I don't know. But we have to ask and see if the patient wants to talk about that. If they want to talk, we can talk more about it, but if they completely don't want to talk about that at all, then I move on.

P4: Talking about sexual function I think is really hard. I only have a couple patients that have ever mentioned that to me. So yes I think so. And I think I should be better about asking about that too. I think it's something patients never initiate a conversation about themselves.

P4 also brought up another difficulty in talking about sexual functions; the Sami language has a lack of neutral words for these body parts and processes.

P4: That's really difficult in the Sami language. In Sami there's not really any good words for that, good and neutral words. Not for your privates, and not for sexual functions. There are no neutral words. In Norwegian, and also in Latin, you have 'vagina' and 'penis,' but in Sami those are really loaded terms.

In Sami, the existing words relating to these topics are seen as perhaps too crude to be appropriate to use in the context of a visit with a doctor, creating another hindrance for open communication.

5.2.8 Explanations for differences

There is undoubtedly a complex web of reasons for these cultural differences. Those interviewed generally did not come with any definite reasons, but figured past traumas and experiences might play into it.

P3: There are a lot of factors that play into that. When it's always been doctors that speak Norwegian, or health care workers that speak Norwegian, maybe many people fear that they will not be understood, and they feel stupid for not being able to explain, and so it's best if they don't go at all.

P4: I think here, and in all of northern Norway probably, in the past it has been a bit like there is no use in whining. It's a long way to the doctor. It's not a certainty that there even is a doctor. So, if you are hurt in any way, there is little use in whining, and it's best to just treat yourself somehow, and it will probably be fine. I think that has shaped how people talk about it, disease and illness.

5.2.9 Suggestions for the application

All the participants were of the opinion that an application as described to them could be helpful to Sami patients. Many thought that it could be helpful for doctors as well. One health professional opined that it would be especially helpful to those newly diagnosed, as they tend to be more motivated to put in the effort and lowering their blood glucose levels.

Some respondents knew about patients using other health applications with success, such as apps for depression or headaches. None of the participants had heard of a similar application already existing.

P3 brought up potential a benefit of the application; that it creates a new way to bring up difficult subjects.

P3: Not everyone knows about the different complications, so an app could be a good medium for starting a conversation about something. Such as 'what does this mean on the app' and so on. It can make taboo subject seem less scary, and you might get a more natural way of starting a conversation about potential side effects that may affect private areas and such.

It may also be easier for the doctor to provide a more valuable consultation for the patient if the patient has prepared beforehand.

P3: You have a much better foundation for structuring their visit if the patient has prepared. For example, if they have written on a note all the questions that they have. That's great, because the doctor then can have a look at it at the beginning of the visit, pick out the most acute points and say, 'ok, if we don't get the time to look at the last two points, we can look at them next time.' So anything a patient can do to prepare is good.

All the respondents stressed the importance of the app being easy to use. Privacy, naturally, also was noted to be of high importance, and must be clearly explained to the users.

> P3: I think it's important that patients know that their information is not shared with whomever. They have to know where the information is going, and if anyone can see it. I think that is important.

What follows is a list of features that were suggested for the application by the respondents:

- Interface:
  - Easy to use, intuitive
  - Must be able to register new data quickly, using only a few touches
  - Not an overwhelming amount of information on pages with key features. More information could be added elsewhere on the application
  - Graphs that show the progression of health data
  - List of medications
  - Visual indicator of desired values for blood glucose
  - Registration of HbA1c
  - Information on a variety of subjects
- Language
  - Having the application in Sami will be more understandable and attractive to users
  - Some users may not be familiar with some Sami terms that relate to health, so the language should be simple
  - The app also being available in Norwegian would be an advantage
- Notifications
  - Weekly notifications to measure fasted blood glucose
  - Daily notifications to measure blood glucose, for instance in the afternoon
  - Reminders to exercise
  - Reminders of healthy habits and recommendations

5.2.10   How may these findings help shape the application?

Some of the major recurring themes that can help shape the design of the application are:

- Sami patients will prefer questions about more general topics before moving to details
- Sami patients are more reluctant to express pain or discomfort
- Sami patients are more reluctant to question or disagree with their doctor
- Sami patients dislike feeling rushed when answering questions
- Sami patients may not as readily consider that there may be solutions to their health problems
- Sami patients may lack faith in their own ability to affect their health positively
- Patients with Sami as their mother tongue will prefer to use Sami to communicate
- Patients will find it more difficult to speak about topics that are seen as embarrassing or taboo
- The word "Sohkárdávda" may seem stigmatizing to some
- There is a lack of information about diabetes available in the Sami language

From this, some design choices that could be made are:

- A patient would reflect on the general state of their health first, before going deeper into specifics
- Patients should be encouraged to be open and honest to their physician about any health problems
- Patients should be encouraged to question and voice dissatisfaction to their physician if needed
- Patients should be allowed as much time as they need to answer questions
- Patients should be assured that there are solutions available to their problems
- Patients should be assured that they have the power to take control over their own health
- The application should be available in Sami
- Topics that could be seen as more difficult to speak about should appear towards the end of the session
- The word "Diabetes" should be used instead of "Sohkárdávda"
- The application should include general information about diabetes.

5.3 Examining online access to high-quality diabetes information in Sami

5.3.1 Helsenorge

Helsenorge (https://www.helsenorge.no/) is the official government website for information about, and access to, health care services for residents of Norway [29]. Finding all available information in Sami is quite simple through a link in the main menu, which leads you to the Northern Sami site https://www.helsenorge.no/se/saami/. Unfortunately, the available information is limited, and there is no information about diabetes specifically.

5.3.2 Norsk Helseinformatikk

Norsk Helseinformatikk (NHI) (https://nhi.no/) is Norway's largest supplier of health information [30]. It also supplies the Norwegian Electronic Doctor's Manual [30]. The site does not supply information in any other languages besides Norwegian.

5.3.3 The Norwegian Institute of Public Health

The Norwegian Institute of Public Health (NIPH) (https://www.fhi.no/) is a government agency under the Ministry of Health and Care Services [31]. It states its mission as producing, summarizing, and disseminating knowledge to support good public health efforts and healthcare services [31]. Its main page has in it banner a link named "In English", that takes you to the English site. No similar link is available in Sami in the banner nor elsewhere. Searching the site with the keyword "sámi", "sámegiella" or "sámegillii" produces no results. Searching for "samisk" produces some results of publications such as information sheets, posters and pamphlets that have been translated to Sami. No results pertain to diabetes.

5.3.4 The Norwegian Directorate of Health

The Norwegian Directorate of Health (https://www.helsedirektoratet.no/) reports to the Ministry of Health and Care Services, and is tasked with implementing government policies and other responsibilities that are delegated by the ministry [32]. In the site's main menu, there is a link available named "In English", that takes you to the English site. No similar link is available in Sami. Searching the site with the keyword "samisk" brings up 129 results.

Some of the results are pdfs of publications such as information sheets, posters and pamphlets that have been translated to Sami. There is no way to narrow down the results, as adding for instance "diabetes" to the search field also brings up results pertaining just to diabetes and not Sami. Manually looking through the 129 results, no results appeared to be about diabetes.

5.3.5 The Norwegian Diabetes Association

The Norwegian Diabetes Association (https://www.diabetes.no/) is an independent interest group for those with diabetes, or others somehow affected by the disease [33]. The association works for better treatment, rights and support for all those that live with diabetes [33]. The main menu offers a link to information in several languages. The link sends you to the site https://www.diabetes.no/mer/pa-flere-sprak/innvandrere/ where one will find a link to information in Sami, among other languages. The URL translates to https://www.diabetes.no/more/in-more-languages/immigrants/ and has the header "Immigrants and diabetes" which could be considered a strange site to include Sami information in, as Sami certainly are not immigrants, but an indigenous people of Norway.

Further navigating to the Sami site, its contents are one brochure and one audio file about diabetes and physical activity. This amount is on the lower side for the site, as the languages Arabic, Dari, English, Farsi, Kurdish, Polish, Somali, Sorani, Tamil, Tigrinja, Turkish, Urdu and Vietnamese all contain between 7 and 30 links to resources in the respective language. The Spanish and Russian sites contain one link each.

5.3.6 Google search

No relevant, high-quality results were found.

5.3.7 Overall results

The overall results of the investigation must be classified as rather poor. It is clear that there is a need for information in Sami about diabetes, and that including this in the application would be an asset.

5.4 Related work

5.4.1 Karbo & Insulin

Karbo & Insulin is an app is developed by Norsk Diabetessenter, available for both iPhone and android [34]. The price for the app on Google Play in May of 2024 was 33,00 kr [34]. It acts as a library of carbohydrate content of common foods, and lets the user calculate the carbohydrate content of their meal [34]. The user may also add their own entries into the library of foods that they frequently eat [34]. The provided information is limited to only carbohydrate content, with no other nutritional information. The app does not include any tracking of health data, or connection to other devices.

5.4.2 mySugr

The MySugr app is described on its website as "the diabetes management app made for people with diabetes by people with diabetes" [35]. The app is a sophisticated blood glucose level tracker, with features such as report generation, estimated HbA1c, and motivational challenges. Other data and habits such as meals, activity and sleep can also be logged. A calculator that can aid in determining insulin dose for a meal is provided, though carbohydrate content must be calculated by the user themselves, as there is no functionality for this in the app. The app does not provide any general information about topics related to diabetes. Connection with blood glucose meters for automatic data importing is possible, though this is only for compatible devices. The app is free, but some features such as pdf-reports are only available with purchase of a subscription at the cost of 33,51 NOK/month, or 332,46 NOK/year.

5.4.3 Diabetesdagboka

Diabetesdagboka (translation: diabetes diary) is a flexible application with many options for tracking health data and habits. The app lets you log blood glucose measurements, workouts, carbohydrate/calorie intake, and bodyweight. The progression of blood glucose in shown in a graph. The user can select goal to work towards, such as exercising regularly or measuring blood glucose more frequently and the app will show the user how well they are progressing towards these goals by evaluating the logs. The app does not provide information about

carbohydrate content in foods, so the user must calculate this themselves. Neither does the app contain any other information related to diabetes. The Norwegian Centre for E-health Research developed the application, which is free of charge [36].

5.4.4 Freestyle Libre

The Freestyle Libre apps are intended to be used with the Freestyle Libre 2 and Freestyle Libre 3 sensors [37]. It offers real-time glucose information, as received by the sensor, and statistics such as time-in-range and estimated HbA1c. The sensor and app are connected through Bluetooth, so the smartphone must be nearby to the sensor to receive data. The readings are presented to the user in a graph, and the app offers alarms for low and high glucose levels [37]. A diary-like option is available to log events such as taking insulin, eating, or exercising. The app offers the user to share their data, in the shape of clinical reports, with a healthcare provider through a bespoke platform named LibreView [37]. No general information about diabetes is offered.

5.4.5 Overall results

None of the applications are available in a Sami language. The applications mainly provide the user with tools to help control and chart their blood glucose levels. Some also allow for charting of other health data such as bodyweight, exercise and nutrient intake. None of the applications offer any general information about diabetes. None have any functionality for preparing for a yearly control session beyond offering to share registered data with health care workers.

6 Requirement specification

The following deliberation of requirements and desired functionality of the application was based on the results found in the previous chapter.

6.1 Primary design considerations

The application is designed for users with average technical knowledge, and as such should be no more difficult to operate than other applications that a user makes use of daily. To increase ease-of-use and understandability the application should follow the common design principles and guidelines that are in place for smartphone applications and that will be familiar to a smartphone user. The application may be used on a daily basis, so commonly used functions should be quick to navigate to and complete. As personal health data is registered by users of the application, it is crucial that those data are not made available to unwanted parties. As many Sami people often find themselves in areas without internet access, it would be very beneficial that the application can function as normally even when not connected to the internet.

6.2 Device and OS

Common devices for health applications are PCs, smartphones and wearable devices. The application is meant to be used on a daily basis. As such, it should be available on a device that is easily on hand for the user, preferably also when away from home. It should also be on a device that is available for a wide range of people. PCs and smartphones are owned by a larger part of the population than wearable devices such as smartwatches. Smartphones are typically more readily available than a PC as a smartphone is typically carried around with the person as they move, as opposed to PCs which more often are stationed at a desk. Due to these reasons, the best choice for a device to implement the application was determined to be a smartphone. No statistic is available on types of phones owned by the Sami population. Due to the author's particular skillset and experience with Android development, it was determined to use the Android framework to achieve optimal results.

6.3 Sharing

One option for the application would be the opportunity for the user to share their registered data with others, such as their primary care physician. This was decided against due to the main priority for the application being to act as a safe space for the user. It is crucial that the user feels in total control of their data. Though sharing might only be implemented as an option, merely the option might make the user feel pressure to share their data, especially if asked to do so by, for instance, their physician or a family member. This might lead to the user choosing not to use the application or registering inaccurate data. Not having the option to share data eliminates any pressure on the user, and also eliminates any chance of the data being intercepted by a third party during sharing, increasing the sense of security for the user.

6.4 Language

As discussed in chapter 5.2.5, it's important that a person may use their first language to express themselves. The application should be made available in Sami, so a user feels that this application was designed with them in mind, and so that they feel more comfortable using it.

6.5 Registering health metrics

Managing blood glucose levels is an essential part of diabetes management. A user should be able to see the progression of their blood glucose level over time. Information about recommended blood glucose levels should also be available. Registering a new value should be quick and easy.

Letting the user manually choose the registration time was considered. Thereby the user would be able to register values from the past. This feature could be useful in cases where the user's phone is unavailable at the time of measuring their blood glucose level or weight. It was ultimately decided against due to the fact that such a situation seemed unlikely to occur on a frequent enough basis and that it would increase the complexity of the user interface, thereby creating more room for confusion or error.

Implementing an input and graph section similar to the daily blood glucose level tracker was considered for HbA1c. It was decided not to include this due to the risk that it might confuse the users, and also the fact that several months usually pass between each measurement, as the

measurement is taken by a health professional. One doctor expressed in an interview that it was somewhat common for their patients to confuse the meaning of daily blood glucose values and HbA1c values. The note section of the app is seen as a more suitable place for a user to note down their HbA1c values each time they are tested.

A person's bodyweight affects their blood glucose levels. Keeping a healthy weight will positively affect a person's ability to keep their blood glucose within recommended levels. Tracking one's weight can provide both motivation and accountability. As found in chapter 5.2.7, some patients might feel uncomfortable talking about their weight to their doctor. Including an option in the app for tracking bodyweight progression might give patient a greater sense of control and understanding of their bodyweight, leading to more openness and better communication with their physician. As with blood glucose, the user should be informed about recommended ranges. BMI is a widely used value for assessing a person's weight compared to their height. Though BMI has its shortcomings, it can still be useful in providing a baseline understanding of what constitutes a normal weight, and a starting point to further discussion with a physician.

6.6 Preparing the patient for consultation

The most important part of the application is preparing the user for a consultation with their doctor. The preparation should include the typical questions a patient might receive during a regular consultation. The guidelines from the Norwegian Directorate of Health will provide a solid starting point when deciding what topics should be included, but the process must be designed with Sami customs in mind. The questioning should start with more general questions first, before homing in on details. Question that are seen as more difficult should come later in the process. The user should be able to take the time that they need to go through the process. Reasonings for the questions should be provided such that the user understands the relevancy of the question. The user should be encouraged be forthcoming and speak their minds during their upcoming consultation, to ask questions of their doctor and speak up about things they may disagree with.

6.7 Providing information

As shown in chapter 5.3, there is little information easily available in Sami about type 2 diabetes. It seems natural that an application meant for Sami people with diabetes should provide such information. As the target audience of the application are laypeople without medical expertise, the information should be tailored to that level. As observed from the research in earlier chapters, Sami patients may struggle especially with opening up about their feelings about their diagnosis, and with keeping to a healthy diet and exercise routine. These topics would be especially important to target in the provided information.

7 Design and implementation

This chapter describes the design and implementation of the application that was presented to users for testing, as described in chapter 8. The application consists of five main parts: The blood glucose tracker, bodyweight tracker, chat, information, and notes. All these parts are accessed from a main menu screen.

7.1 Main menu

The main menu (Figure 5) is the first screen that is presented to the user upon opening the application. The main menu consists of five buttons, which lead the user to the five main functions of the app, namely tracking of blood glucose levels, tracking of body weight, chat, information, and notes. For ease of use and clarity, the buttons are large, have a clear separation, and are clearly labeled both with both words and unique icons.
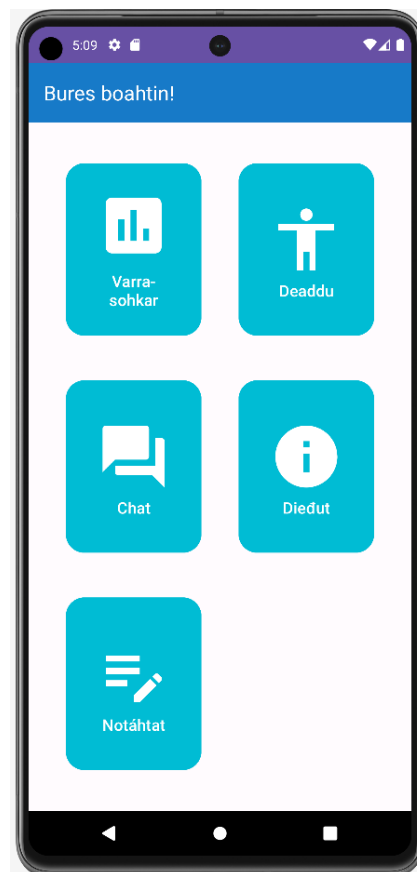
Figure 5: App screenshot, main menu.

Bures boahtin! = Welcome!, Varrasohkar = Blood glucose, Deaddu = Body weight,

Dieđut = Information, Notáhtat = Notes.

7.2 Blood glucose tracker

This page lets the user register and track their blood glucose level. A user is meant to measure their blood glucose level on a measuring device before manually entering the result into the app. The view (Figure 6) contains a graph of the registered values, with the x-value being the date and time of the measurement, and the y-value being the measured blood glucose level in mmol/L. The graph is color coded to reflect the recommended values for blood glucose, and can be scrolled horizontally.

Figure 6: App screenshot, registration and graph of blood glucose levels. The user is asked to input their blood glucose level and answer yes or no on whether they have eaten during the last two hours.

Varrasohkar = Blood glucose, Varrasohkarmihttu = Blood glucose measurement, Juo = Yes, In = No,

Seaste = Save.

Below the graph is a field for entering a new value measured in mmol/L. The user may also select whether they have eaten in the last two hours, as that affects what range of values is recommended for blood glucose. Upon saving the measurement by pressing the save-button lowest on the screen, the value will appear on the graph with the current time as the x-value.

The overflow menu presents the user with the option to delete the latest value in case of an accidental erroneous registration. Pressing the info-icon in the menu shows the user more information about blood glucose levels such as recommended values and suggestions on when to take measurements (Figure 7).
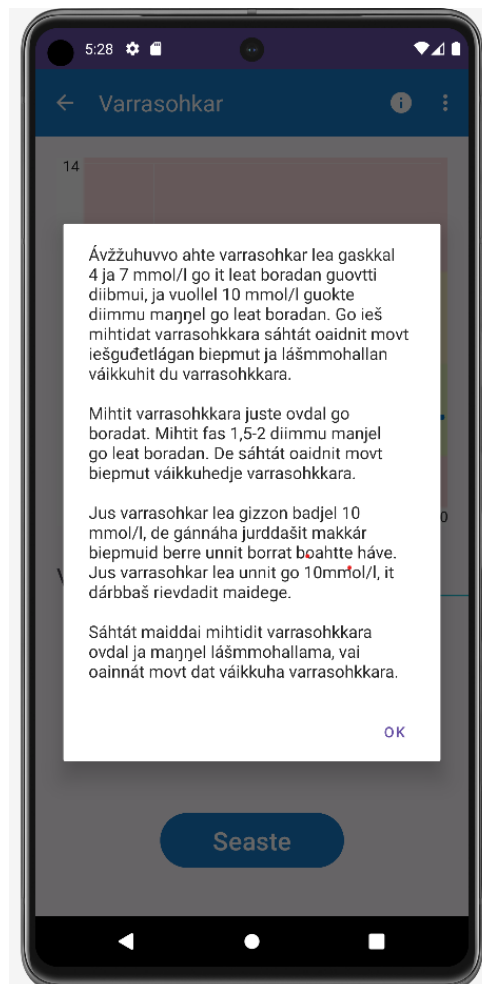
Figure 7: App screenshot, information about blood glucose. General information and recommendations are presented to the user upon tapping the information button.

7.3 Bodyweight tracker

The first time the user enters the bodyweight tracker, a dialog will show, asking the user to enter their height. When a height has been registered, the user may continue to the page. The main parts of the view (Figure 8) are a graph, a report of the user's BMI, a field to input a measurement, and a save button.

The graph presents the previously registered values, with the x-value being the date and time of the measurement, and the y-value being the measured weight in kg. The graph can be scrolled horizontally.
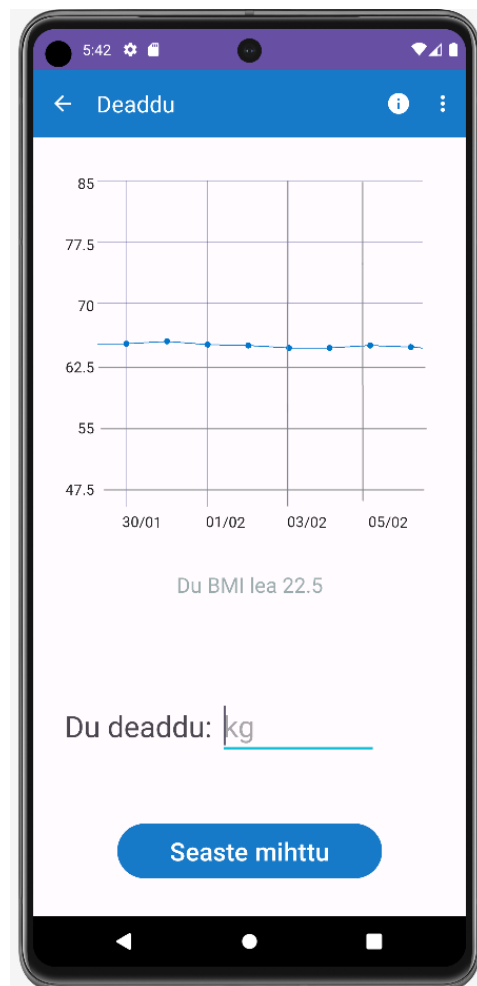
Figure 8: App screenshot, registration and graph of bodyweight.

Du deaddu = Your weight, Seaste mihttu = Save measurement.

When a user wishes to register a new value, they may simply input the measured weight in the input field and press the save-button. The new value will immediately show up in the graph with the current time. A short statement under the graph informs the user of their BMI, calculated on the basis of the last recorded weight, and the user's registered height.

The overflow menu presents the user with the option to delete the latest value in case of an accidental erroneous registration. Pressing the info-icon in the menu shows the user more information about weight management and BMI (Figure 9).
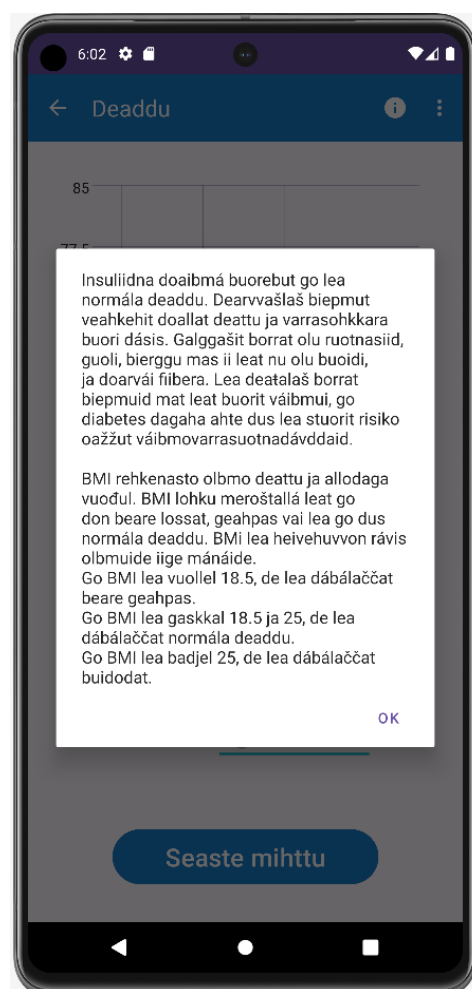

Figure 9: App screenshot, information about bodyweight. General information and recommendations are presented to the user upon tapping the information button.

7.4 Chat

The chat is created as a way for a person with diabetes to prepare themselves for a consultation with a medical practitioner. A typical example would be a yearly control session with their primary physician. The chat is implemented as a series of questions that are presented to the user. The user is given the option to answer these questions in the chat interface. Figure 10 shows the view the user is presented with when accessing the chat for the first time.
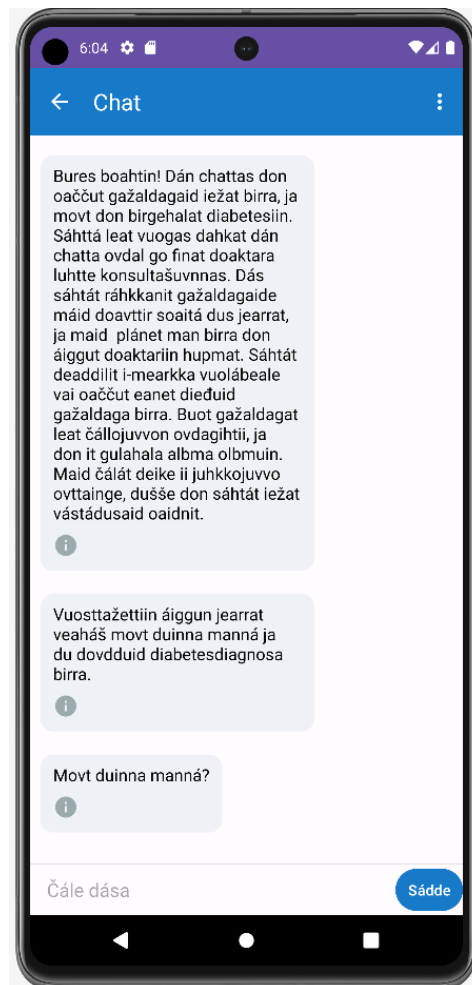

Figure 10: App screenshot, Chat startup. This is the initial page the user will encounter when starting a new chat. The text bubbles explain how the chat works, and the none of the users answers or information are available to others.

Pressing the input field at the bottom of the view will bring the phone's system keyboard into view, and the user may type an answer to the question (Figure 11).

Figure 11: App screenshot, user input to chat. The chat uses a typical chat interface, and input is made available through the system keyboard.

The questions are presented one by one, with the next question appearing when the user presses the "Sádde/Send" button (Figure 12). The next question will appear regardless of whether the user has written anything in the answer field, and thereby the user is given the option to skip over questions or write their answers on another medium. When the "Sádde/Send" button is pressed, the input of the user is saved. If the user chooses to leave the chat, they will see their previous answers, and be able to pick the chat up at the stage they left it when they return.

Figure 12: App screenshot, progression of chat. Once a user has submitted an answer to a question, the chat will continue with next question.

When the chat bubble of a question is tapped, the user is presented with a popup window with more information about the topic of the question (Figure 13). There might also be tips that help the user formulate an answer, or examples on what an answer might contain.
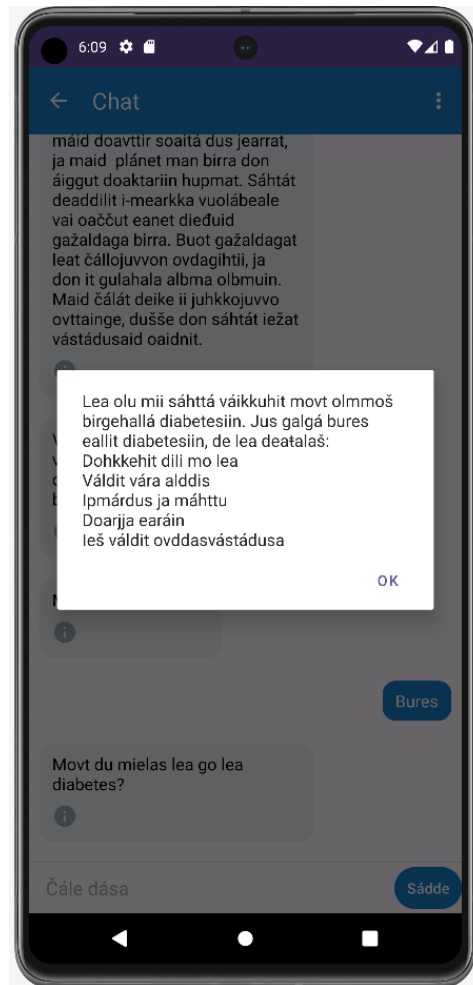
Figure 13: App screenshot, extra information and prompts. Upon tapping a question in the chat, supplemental information, explanation, prompts or example answers will appear.

7.4.1 Chat questions

The questions are modeled after the guidelines by Norwegian Directorate of Health, of a yearly control session for diabetes. These guidelines are presented in chapter 3.1.2. The questions are sectioned into four parts: Mental health, goals, blood glucose and weight management, and physical symptoms. Before each section, a short introduction is presented on what the next questions will be about.

Table 7 shows a full overview of the questions a user will receive in the chat, translated into English from Northern Sami. Some outputs are not questions, but information to the user that do not require input. These are marked by (info) in the first column.

Some questions are dependent what has been registered in the blood glucose and bodyweight trackers. The questions are marked by letters a, b, c, … in the first column. When the chat

opens, linear regression is performed on registered weights in the bodyweight tracker to determine whether the user's weight has been increasing or decreasing during the latest month. Also, the percentage of registered blood glucose values that are within the recommended range is calculated.

Table 7: Chat output. Some questions will change based on registered blood glucose or bodyweight measurements. Alternative questions are marked by letters a, b, c, ...

Nr.	Output:	Extra information:
1 (info)	Welcome! In this chat you will receive questions about yourself, and how you are managing your diabetes. It can be beneficial to go through this chat before you visit with your doctor for a consultation. Here you can prepare for the questions that the doctor might ask you, and plan for what you might want to discuss with your doctor. You can tap the i-icon below to receive more information about the question. All the questions have been prepared beforehand, and you are not communicating with a real person. What you write will not be shared with anyone, only you can see your answers.	Each question has additional information. If you want to know more about a topic, tap the i-icon, like you just did. What you write is saved to your phone and is not sent anywhere. If you'd like, you can write your answers on paper, or just think about your answer. You can progress by tapping the send button. In the upper right corner are three dots. If you tap on these, you find the option to erase the chat, or erase just your last answer. Use these if you want to start over or change your answer.
2 (info)	Firstly, I'd like to ask about how you are doing, and about your feelings about your diabetes diagnosis.	There's a lot that can affect how a person manages with their diabetes. If one is to live well with diabetes, important factors are: • Accepting the situation as it is • Taking care of oneself • Knowledge and skills • Support from others • Taking responsibility
3	How are you doing?	There's a lot that can affect how a person manages with their diabetes. If one is to live well with diabetes, important factors are: • Accepting the situation as it is • Taking care of oneself • Knowledge and skills • Support from others • Taking responsibility
4	How do you feel about having diabetes?	Many people will experience difficult feelings when they get diabetes. Often, it's hardest just after getting the diagnosis.
5	What is going well for you?	Positive feeling can provide motivation to make good changes. What are you succeeding with?
6	What is not going that well?	When the doctor asks you to make lifestyle changes, you're not expected to succeed in two minutes. It can take time to make changes to lifestyle and thought patterns, and to see that the

		changes are helping. Remember that small changes can make a big impact, and that you don't have to learn everything at once.
7	Is there anything that worries or bothers you? Do you think your blood glucose is affected when you worry?	Your feelings and worries also can affect your blood glucose. Speak up if something bothers you, there may be a solution!
8	Do you receive support from those close to you?	When getting diabetes, your and your loved ones' feelings about the diagnosis are also important. Maybe you feel alone in in your illness.
9	Are you sleeping well?	Both thoughts and bodily symptoms can affect your sleep.
10 (info)	Now I'd like to ask about how you are doing in keeping your blood glucose at good values, and how your bodyweight has progressed. If you have registered data about this in the app, we'll look at that as well.	Making lifestyle changes is an important part of diabetes treatment. Healthy foods and exercise are very helpful. Many can become symptom free.
11	Are you able to keep to healthy eating habits?	Healthy foods help keep your blood glucose to in a good range. You should eat a lot of vegetables, fish, low fat meats, and enough fiber. It's important to eat heart friendly foods, as diabetes makes you more at risk to develop heart disease.
12	What are your biggest challenges in keeping healthy eating habits?	Examples may be: • You get very hungry • You don't know what to eat • You don't get support from those close to you • Others offer you unhealthy foods • You don't know how to eat healthy when in the wilderness • You don't believe healthy eating will be of any use
13	Are you following good routines when it comes to exercise?	Exercise makes it so that sugar in your blood can be more easily used by your body, and your blood glucose level decreases. You also burn the energy that you get from food, so your bodyweight stays stable.
14a	Are you able to keep your blood glucose level within a good range most of the time?	The recommended values for blood glucose are between 4 and 7 mmol/L when you have not eaten in two hours, and under 10 mmol/L up to two hours after eating.
14b	From the points you have registered in the app, (X)% are at recommended values. You seem to be keeping your blood glucose at good values quite well. How do you feel that you are doing?	The recommended values for blood glucose are between 4 and 7 mmol/L when you have not eaten in two hours, and under 10 mmol/L up to two hours after eating.
14c	From the points you have registered in the app, (X)% are at recommended values. What are your greatest challenges in keeping good blood glucose levels?	The recommended values for blood glucose are between 4 and 7 mmol/L when you have not eaten in two hours, and under 10 mmol/L up to two hours after eating.

15a	Are you happy with your bodyweight? Have you gained or lost weight since you last visited with your doctor?	If a person is overweight, losing weight is good for lowering blood glucose. That's because insulin works better in a normal weight body. A smaller body also requires less insulin. Losing 5 to 10 percent of their current weight will have a positive impact on blood glucose.
15b	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is over 25, usually the person is overweight. The data show that you have lost weight in the last month. Well done! Why do you think you have succeeded in losing weight? What are your biggest challenges?	If a person is overweight, losing weight is good for lowering blood glucose. That's because insulin works better in a normal weight body. A smaller body also requires less insulin. Losing 5 to 10 percent of their current weight will have a positive impact on blood glucose.
15c	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is over 25, usually the person is overweight. The data show that you are about the same weight now as you were a month ago. What are your biggest challenges in reaching a healthy weight?	If a person is overweight, losing weight is good for lowering blood glucose. That's because insulin works better in a normal weight body. A smaller body also requires less insulin. Losing 5 to 10 percent of their current weight will have a positive impact on blood glucose.
15d	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is over 25, usually the person is overweight. The data show that you have gained weight in the last month. What do you think is the reason for this?	If a person is overweight, losing weight is good for lowering blood glucose. That's because insulin works better in a normal weight body. A smaller body also requires less insulin. Losing 5 to 10 percent of their current weight will have a positive impact on blood glucose.
15e	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is between 18.5 and 25, usually the person is normal weight. Great! The data show that you have lost weight in the last month. You seem to be normal weight, so it seems you don't need to lose more weight. Are you happy with your current weight?	Insulin works better in normal weight bodies. Healthy foods help keep your blood glucose to in a good range. You should eat a lot of vegetables, fish, low fat meats, and enough fiber. It's important to eat heart friendly foods, as diabetes makes you more at risk to develop heart disease. Exercise makes it so that the sugar in your blood can be more easily used by your body, and your blood glucose level decreases. You also burn the energy that you get from food, so your bodyweight stays stable.
15f	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is between 18.5 and 25, usually the person is normal weight. Great! The data show that you are about the same weight now as you were a month ago. Why do you think	Insulin works better in normal weight bodies. Healthy foods help keep your blood glucose to in a good range. You should eat a lot of vegetables, fish, low fat meats, and enough fiber. It's important to eat heart friendly foods, as diabetes makes you more at risk to develop heart disease. Exercise makes it so that the sugar in your blood can be more easily used by your body, and your blood glucose level decreases. You also burn the energy that you get from food, so your bodyweight stays stable.

	you are succeeding in keeping a healthy weight?	
15g	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is between 18.5 and 25, usually the person is normal weight. Great! The data show that you have gained weight in the last month. What do you think is the reason for this?	Insulin works better in normal weight bodies. Healthy foods help keep your blood glucose to in a good range. You should eat a lot of vegetables, fish, low fat meats, and enough fiber. It's important to eat heart friendly foods, as diabetes makes you more at risk to develop heart disease. Exercise makes it so that the sugar in your blood can be more easily used by your body, and your blood glucose level decreases. You also burn the energy that you get from food, so your bodyweight stays stable.
15h	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is less than 18.5, usually the person is underweight. The data show that you have lost weight in the last month. What do you think is the reason for this?	Insulin works better in normal weight bodies. Healthy foods help keep your blood glucose to in a good range. You should eat a lot of vegetables, fish, low fat meats, and enough fiber. It's important to eat heart friendly foods, as diabetes makes you more at risk to develop heart disease. Exercise makes it so that the sugar in your blood can be more easily used by your body.
15i	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is less than 18.5, usually the person is underweight. The data show that you are about the same weight now as you were a month ago. Have you tried gaining weight during this time?	Insulin works better in normal weight bodies. Healthy foods help keep your blood glucose to in a good range. You should eat a lot of vegetables, fish, low fat meats, and enough fiber. It's important to eat heart friendly foods, as diabetes makes you more at risk to develop heart disease. Exercise makes it so that the sugar in your blood can be more easily used by your body.
15j	The last weight you registered was (X) kg. This means that your BMI is (Y). When BMI is less than 18.5, usually the person is underweight. The data show that you have gained weight in the last month. What are your biggest challenges in reaching a healthy weight?	Insulin works better in normal weight bodies. Healthy foods help keep your blood glucose to in a good range. You should eat a lot of vegetables, fish, low fat meats, and enough fiber. It's important to eat heart friendly foods, as diabetes makes you more at risk to develop heart disease. Exercise makes it so that the sugar in your blood can be more easily used by your body.
16 (info)	Now I'd like to ask you about your goals. It's important to create specific goals, so that you get motivated to reach them	Write down what your thoughts and hopes are and try to figure out what your most important goal is. To stay motivated, you should find a goal that is important to you.
17	What do you think your goals of diabetes treatment should be?	These questions can help you find goals: - What is the most important part of your treatment plan? - What is realistic for you on a daily basis? - What might be obstacles for reaching your goals? It can be useful to split your goals into daily goals and long-term goals. Examples: - Daily goal: That diabetes affects you as little as possible on a daily basis.

		• Long-term goal: That you don't get any severe complications. • Daily goal: Go for a bike ride every day. • Long-term goal: Losing 5 kilos in 6 months.
18	What goal will be the most difficult to reach?	A piece of advice is to make small changes at a time, so you can better maintain them. Remember that you are not treating an illness short-term, rather you should maintain these changes for as long as you live.
19	How can your doctor help you, so you can reach your goals easier?	You and your doctor should create goals and find solutions together. Speak up if you disagree!
20 (info)	In the last part I'd like to ask you some questions about complications that may arise with diabetes.	When you have type two diabetes, your blood glucose level is too high. The goal of treatment is to lower blood glucose to normal levels, so you don't experience symptoms that affect your body.
21	Do you smoke?	Smoking stops insulin from working as well as it should. It also increases the risk of getting complications that affect the veins. Quitting smoking would be very good for your health, and especially for treating diabetes. Your doctor can help you if you wish to stop smoking. There are both medications and other aids available.
22	How are your feet? Do they feel the same as before? Do you have any wounds?	Diabetes can affect your feet, such that you lose feeling or get wounds. The doctor may want to examine your feet.
23	How is your eyesight? Is it the same as before, or have you noticed any difference?	Many will notice a worsening of their eyesight while as their blood glucose is high. It's not dangerous as long as it's just occasional, but if your blood glucose is too high for too long, your eyes can be affected.
24	When did you last visit with an eye doctor?	It's important to have regular examinations by an eye doctor so any problems are discovered early.
25	Do you use insulin? How are you managing in injecting it?	The doctor may want to examine the injection site.
26	Have you noticed any difference in your memory or thinking?	Have you noticed, for example, that: • You tire faster when having to do difficult tasks? • You don't remember important information or appointments? • You don't understand what you hear or read as well as before? • You are less able to control your feelings and actions?
27	Do you have other conditions that may affect your diabetes, such as illnesses or pregnancy?	It's important to let your doctor know if you have other illnesses or are pregnant. Your doctor can explain how these conditions can affect diabetes and give you advice.
28	Diabetes can sometimes affect your private parts and sexual function. Have you noticed any changes in these areas?	Diabetes can make it so that you get urinary tract infections more easily, and you may also experience urinary incontinence. Your private areas are also more disposed to get infections. Diabetes can also cause erectile dysfunction in men, and vaginal dryness in women. You should let your doctor know if you are experiencing any problems, even if it may seem embarrassing. There may solutions to your problems. Remember that anything you tell your doctor is confidential, and your doctor is not allowed to share it with anyone.

29 (info)	Those were all the questions. Hopefully you feel more prepared for your next consultation. If you thought of something that you want to discuss with your doctor, it's a good idea to note it on a piece of paper and take it with you so you remember. This chat is also saved until you choose to erase it. The option to erase it appears when you tap the three dots in the upper right corner.	If you want to start a new chat, tap the three dots in the upper right corner and tap "Erase all". Talk to you later!

7.5 Information

Upon tapping the information-button in the main menu, the user is taken to a list of topics (Figure 14). The user may then tap on a desired topic to access information about it on a new page (Figure 15).
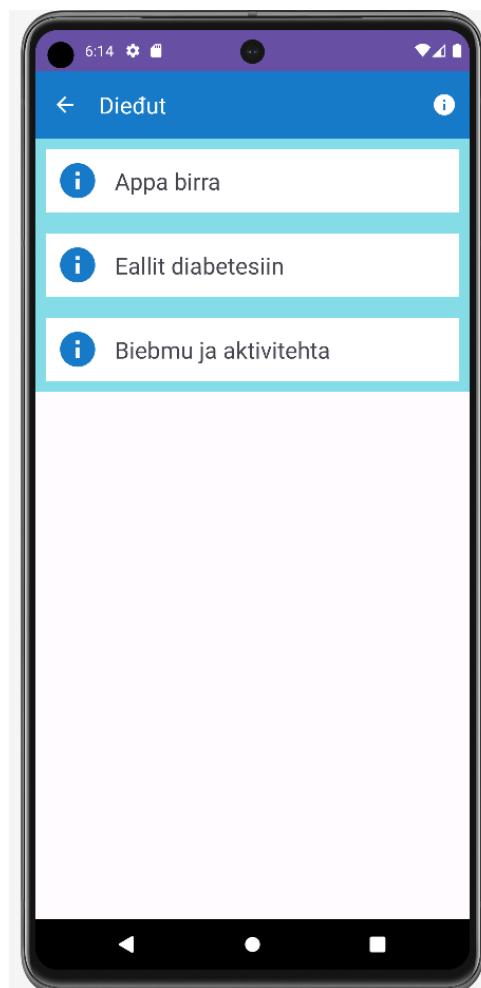
Figure 14: App screenshot, index of information. Here, a user may select a topic to read more about.

Appa birra = About the app, Eallit diabetesiin = Living with diabetes, Biebmu ja aktivitehta = Food and exercise.
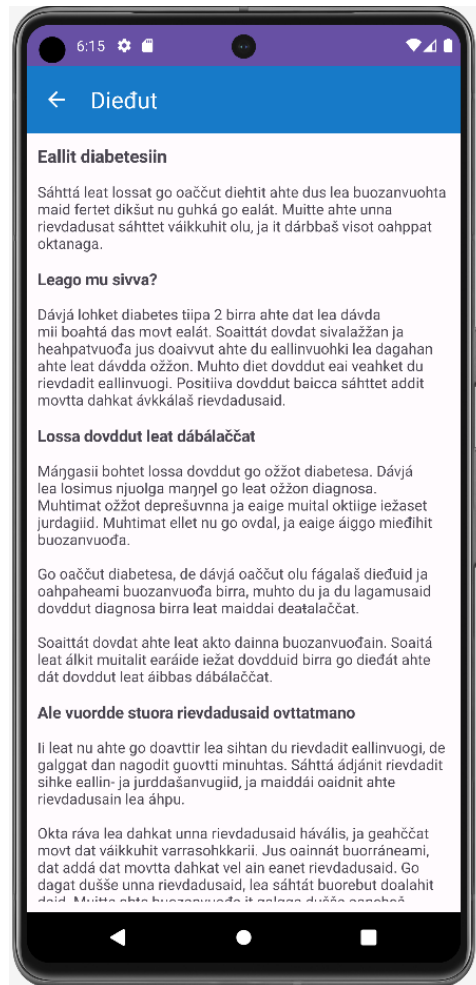
Figure 15: App screenshot, information about selected topic.

The first topic is concerning the app itself. On this page, the app-creators name and contact information is given. The users are also informed that the app is not connected to the internet, and that none of their information is shared outside their phone.

The second topic is on living with diabetes, and on feelings and challenges that may arise due to the diagnosis. The information is meant to be uplifting to those with negative feelings about their diagnosis and encourages speaking about thoughts and feelings. The information originates from the Norwegian Diabetes Association [38] and was translated into Northern Sami.

The third topic is on healthy foods and exercise. Contained on this page is advice on how to maintain a healthy lifestyle, based on the recommendations from the Norwegian health

officials. The source of the information is the Norwegian Diabetes Association [39], and it was translated into northern Sami.

7.6 Notes

This part of the application lets the user create their own notes on whatever topic they may choose. The application suggests examples such as making a list of medications the user may use, or making notes of information received from their doctor. The notes are meant as a simple way for a user to jot down any information they would like to keep track of. A note consists of a title and a text. A list displays each note by title (Figure 16), and a user may tap on a list item to see and edit the text contained in that note (Figure 17).
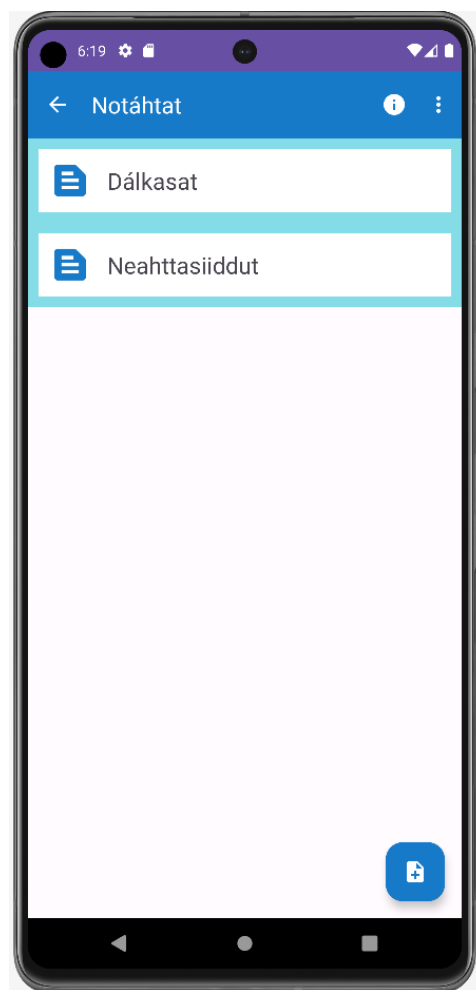
Figure 16: Index over user-created notes. A user may tap on a note to read it or create a new note from this page.

Dálkasat = Medication, Neahttasiiddut = Websites.
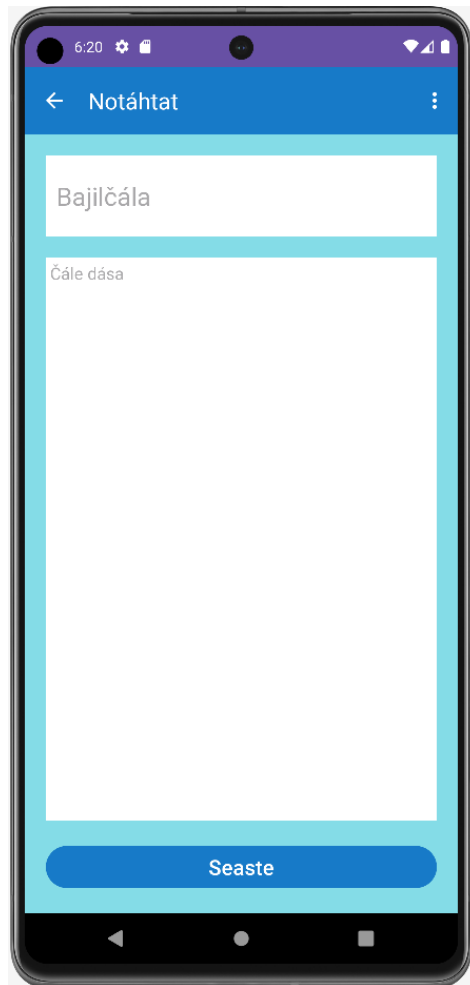
Figure 17: App screenshot, new personal note. A user is asker to select a title that will appear on the index, and offered a large input field for the details.

Bajilčála = Title, Čále dása = Write here, Seaste = Save.

8 Testing

8.1 Assessment and process

To test the application, Sami-speaking individuals that have been diagnosed with type 2 diabetes were recruited to use the application for some time, and then fill out a questionnaire about how they experienced using the different parts of the application.

The testing process was approved by both The Regional Committee for Medical and Health Research Ethics (REK), and Sikt. Consent forms were created and translated into northern Sami and signed by the participants. Sami and Norwegian consent forms can be found in appendices F and G.

8.2 Recruitment

Some participants were contacted directly. Posts were also published on public Facebook groups, explaining the project, and asking those who might be interested in participating to contact the author directly. Participants were also asked if they could provide information about others that might be interested in participating.

In total, four people were willing to participate in testing the application. Each participant was met with individually and the application was installed onto their personal phone with them present. The participants were guided through each part of the application, and the different functionalities were explained and demonstrated. The participants were then left to test the application by themselves for some weeks. The participants were then contacted again and were provided with a URL to the survey, asking them their opinion on the different parts of the application.

8.3 Survey

The survey was built using the webtool "Nettskjema" [40], which was built by the University of Oslo to act as a versatile and secure method of administering surveys and is widely used within academic research. The survey was made available to participants by providing them with the URL. Participants were not required to use any method of login, and uniquely identifying information such as name or e-mail address was not collected. At the beginning of

the survey, the participants were informed that they had the option to skip any question that they did not wish to answer. Table 8 describes the structure of the survey, what questions were asked, and what method of input was available for each question.

Table 8: Structure of questionnaire with questions and input method.

Question	Input method
How long have you had the diagnosis of type 2 diabetes?	Four alternatives: • Less than 2 years • Between 2 and 5 years • Between 5 and 10 years • Longer than 10 years
How well did you think the blood glucose tracker worked?	Rate from 0 to 10 where 0 is very poorly and 10 is very well
How easy was it for you to use the blood glucose tracker?	Rate from 0 to 10 where 0 is very difficult and 10 is very easy
How useful was the blood glucose tracker for you?	Rate from 0 to 10 where 0 is not useful and 10 is very useful
Was there anything that could be improved in the blood glucose tracker?	Free written input
How well did you think the bodyweight tracker worked?	Rate from 0 to 10 where 0 is very poorly and 10 is very well
How easy was it for you to use the bodyweight tracker?	Rate from 0 to 10 where 0 is very difficult and 10 is very easy
How useful was the bodyweight tracker for you?	Rate from 0 to 10 where 0 is not useful and 10 is very useful
Was there anything that could be improved in the bodyweight tracker?	Free written input
How well did you think the chat worked?	Rate from 0 to 10 where 0 is very poorly and 10 is very well
How easy was it for you to use the chat?	Rate from 0 to 10 where 0 is very difficult and 10 is very easy
How easy was it for you to understand the questions?	Rate from 0 to 10 where 0 is very difficult and 10 is very easy

How useful was the extra information you got when tapping the info-button on the different question?	Rate from 0 to 10 where 0 is not useful and 10 is very useful
Do you think the app will be useful to you for preparing for a doctor's appointment?	Yes/No
Were there questions that you did not like, or that you did not see as relevant? In what way?	Free written input
How did you like the order of the questions? Would you have preferred a different order? Why?	Free written input
Was there anything that could be improved in the chat?	Free written input
(Regarding the information part of the app) How easy was it for you to understand the information?	Rate from 0 to 10 where 0 is very difficult and 10 is very easy
(Regarding the information part of the app) How relevant do you feel the information was for you?	Rate from 0 to 10 where 0 is not relevant and 10 is very relevant
(Regarding the information part of the app) Was there any information you feel was lacking, or anything else that could be improved?	Free written input
How well did you think the notes worked?	Rate from 0 to 10 where 0 is very poorly and 10 is very well
How easy was it for you to use the notes?	Rate from 0 to 10 where 0 is very difficult and 10 is very easy
How useful do you feel the notes were?	Rate from 0 to 10 where 0 is not useful and 10 is very useful
Was there anything that could be improved in the notes?	Free written input
Is there anything else you would like to mention or suggest for the app?	Free written input

9 Results of user testing

What follows are the main results of the test survey. Some questions have been omitted from this chapter as they had no answers, or the answers were less relevant. The full results can be found in appendix E.

In total, four participants tested the application and filled out the survey. All the participants answered having the diagnosis type 2 diabetes for longer than 10 years.

9.1 Blood glucose tracker

The blood glucose tracker was generally well received by the participants. Figure 18 shows most participants thought the tracker worked well, giving the rating 8 or 9. One participant gave a mid-level rating at 6.
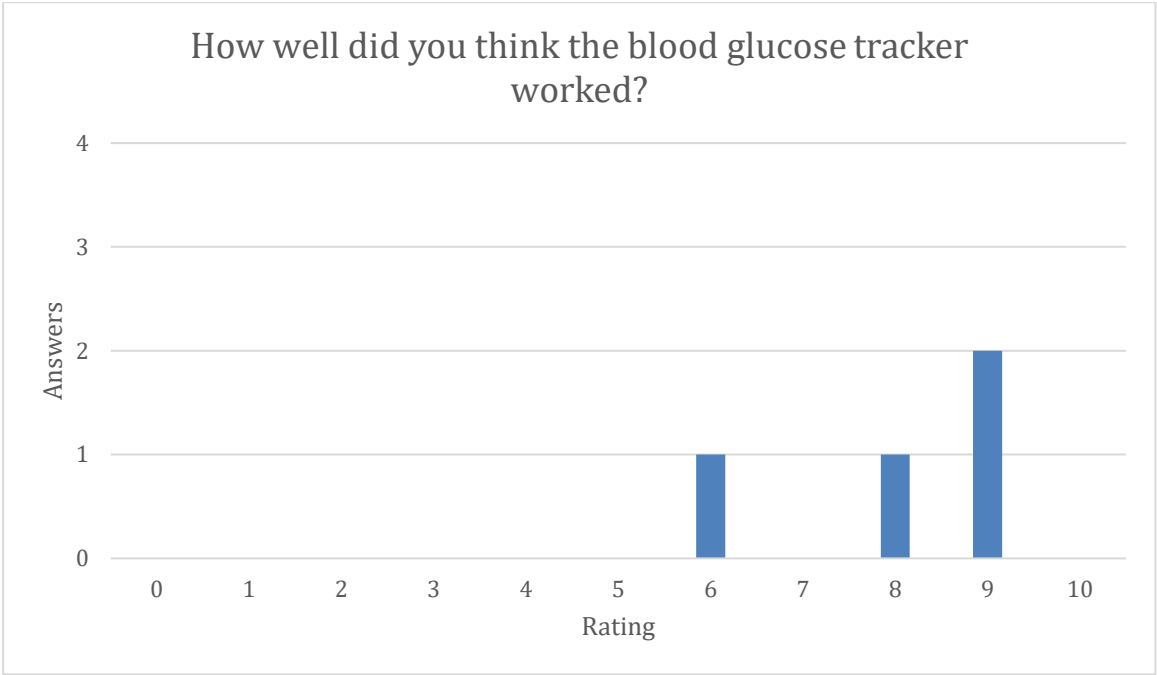
Figure 18: Result of survey showing mid-to-high rating of how well the blood glucose registration worked.

Figure 19 shows that all participants thought the blood glucose tracker was very easy to use, as three participants rated the ease of use at 10, and one at 9.
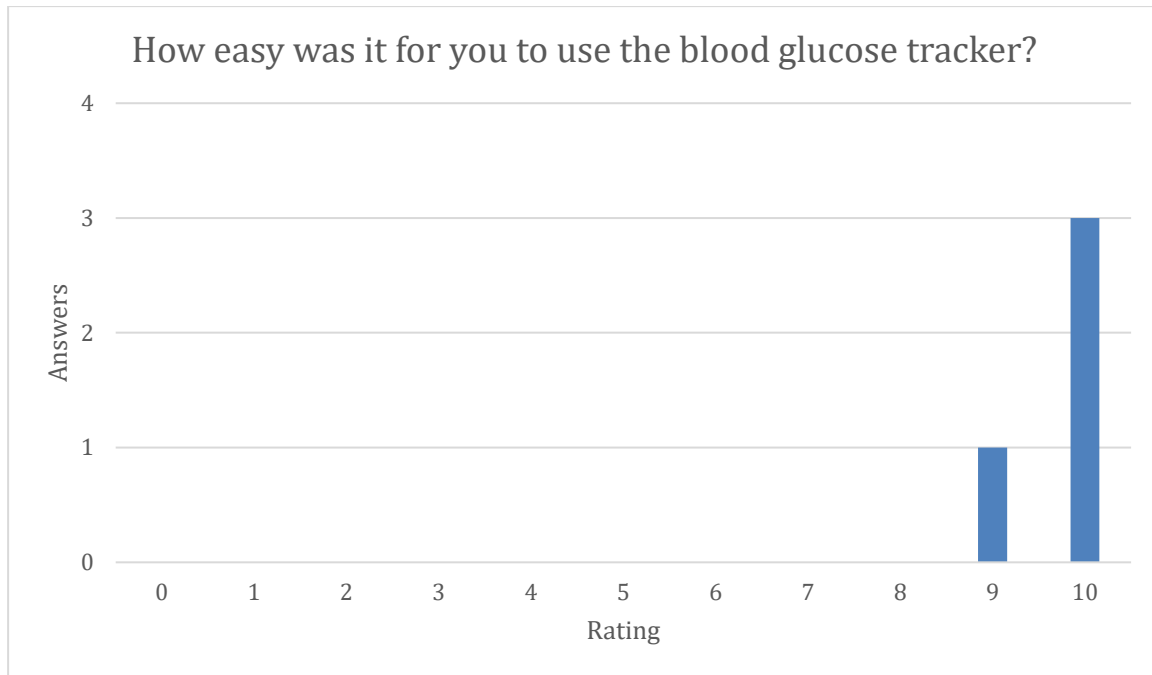
Figure 19: Survey showed all participants found the blood glucose registration easy to use.

All the participants also found the blood glucose tracker to be very useful, given the ratings 9 and 10 as shown in Figure 20.
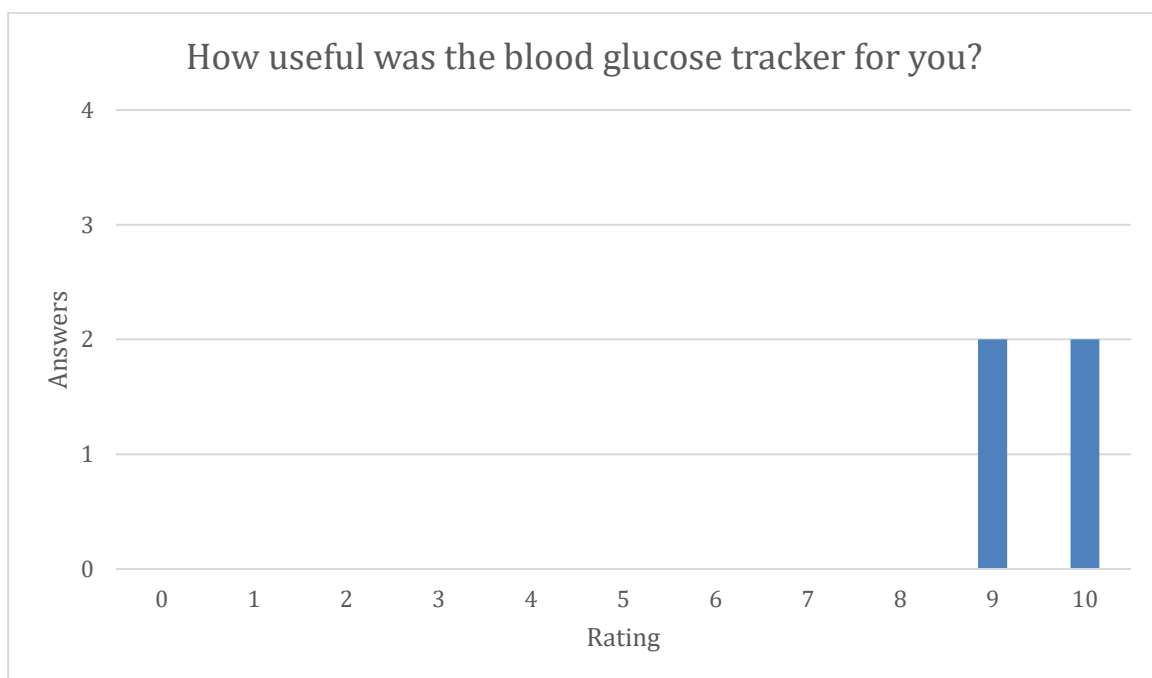
Figure 20: Survey showed all participants found the blood glucose tracker to be useful.

On the question of whether there was anything that could be improved in the blood glucose tracker, on participant commented on not being able to register part values: "I don't always have my phone with me, and so I couldn't always register my values. You should be able to register past values to the graph."

9.2 Bodyweight tracker

The participants were seemingly happy with the tracker as Figure 21, Figure 22 and Figure 23 show that how well the tracker worked, its ease of use and usefulness were all rated highly, from 8 to 10.
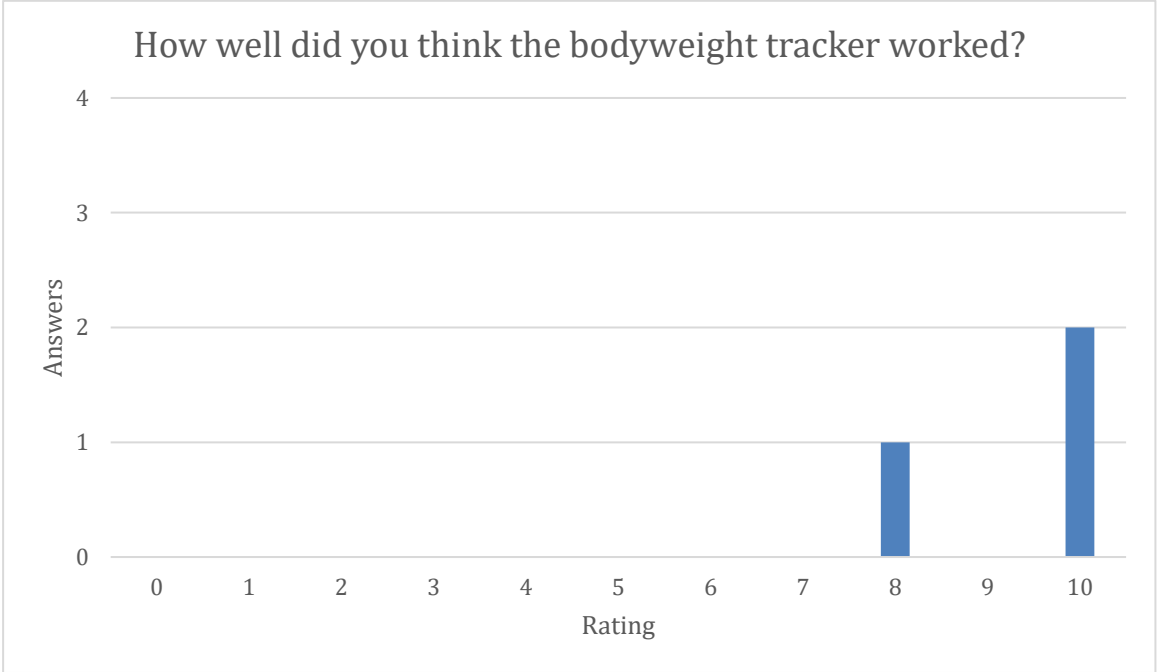
Figure 21: Survey shows participants were generally happy with how the bodyweight tracker worked. One participant chose not to answer.
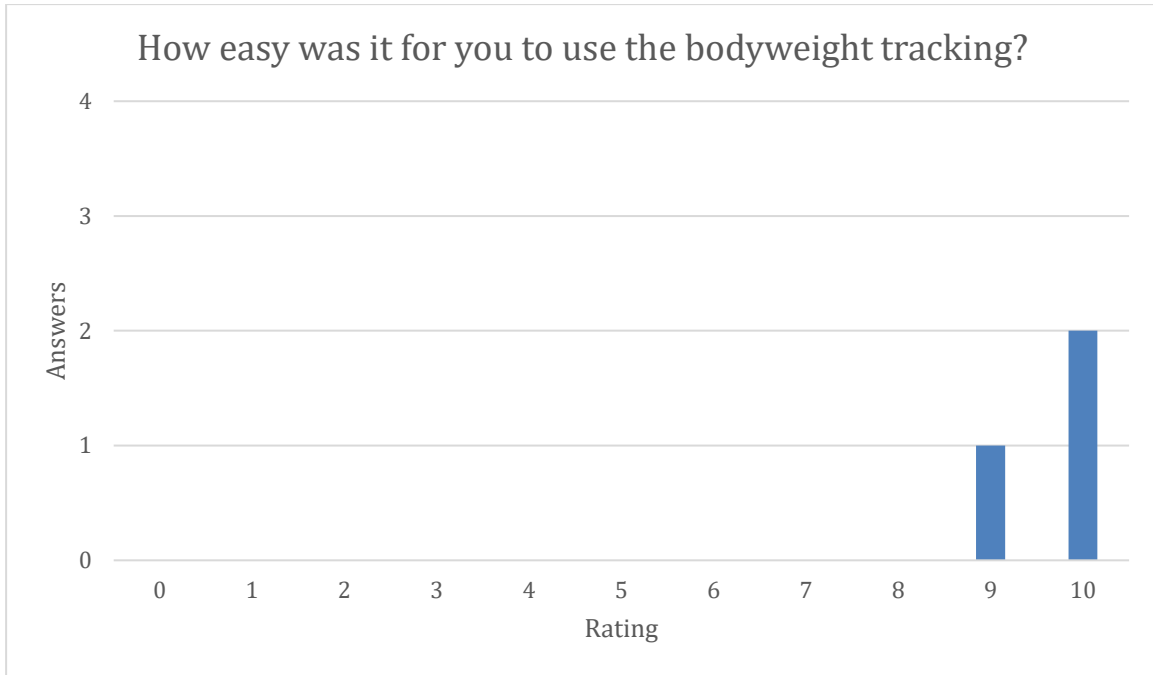
Figure 22: Survey shows participants found the bodyweight tracker easy to use. One participant chose not to answer.
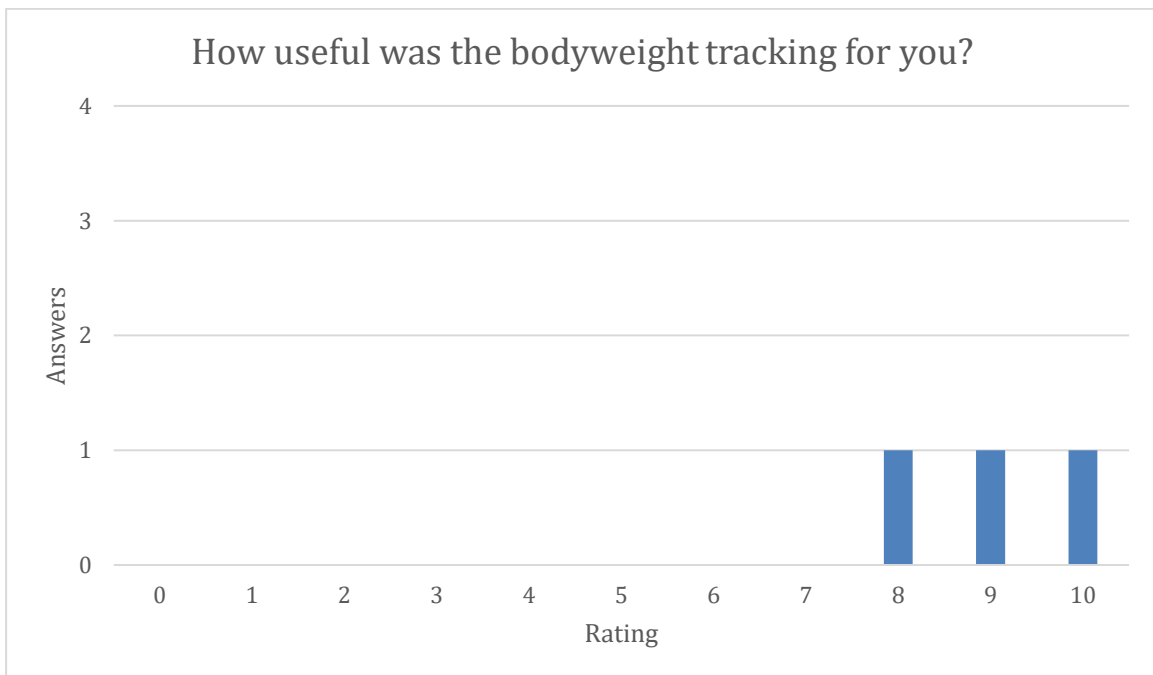

Figure 23: Survey shows participants generally thought the bodyweight tracker was useful. One participant chose not to answer.

The comment about being able to register past values reoccurred for the bodyweight tracker, as one participant wrote: "Here too you should be able to register past values with correct date and time."

9.3 Chat

The participants thought that the chat worked well, with ratings being 8 and 9 as shown in Figure 24.
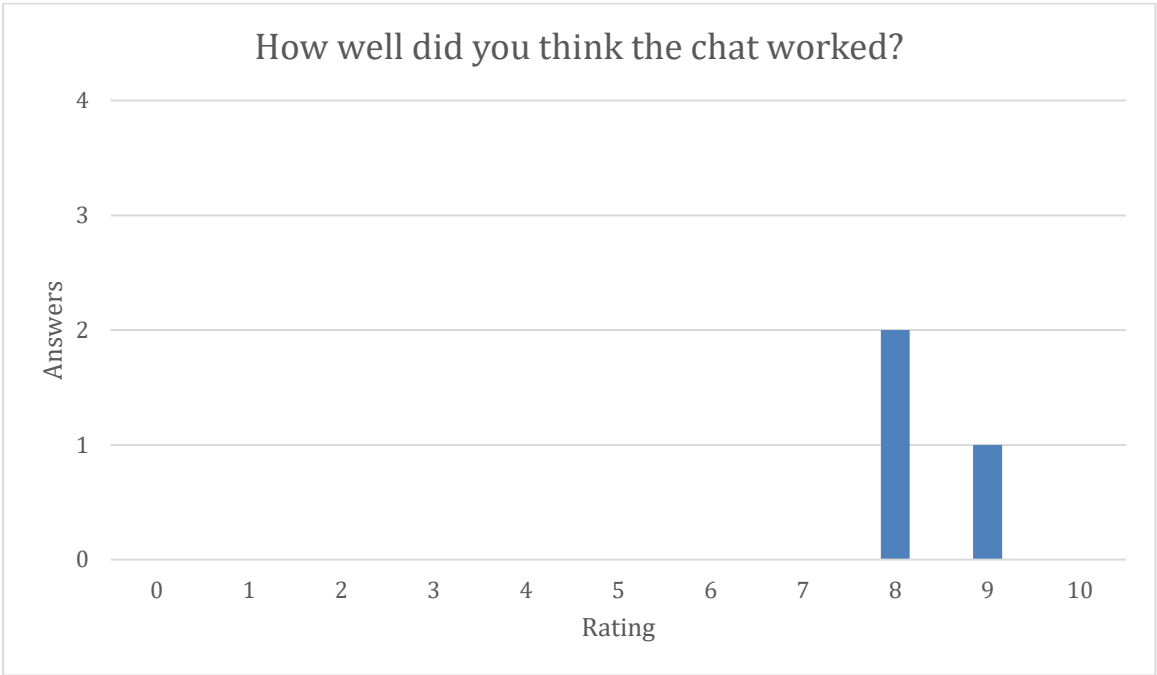
Figure 24: Survey shows the participants thought the chat worked quite well. One participant chose not to answer.

The ease-of-use of the chat received mid-to-high ratings, with two participants being a bit less satisfied, giving the ratings 6 and 7, as opposed to the 9 and 10 received by the other two participants, as shown by Figure 25
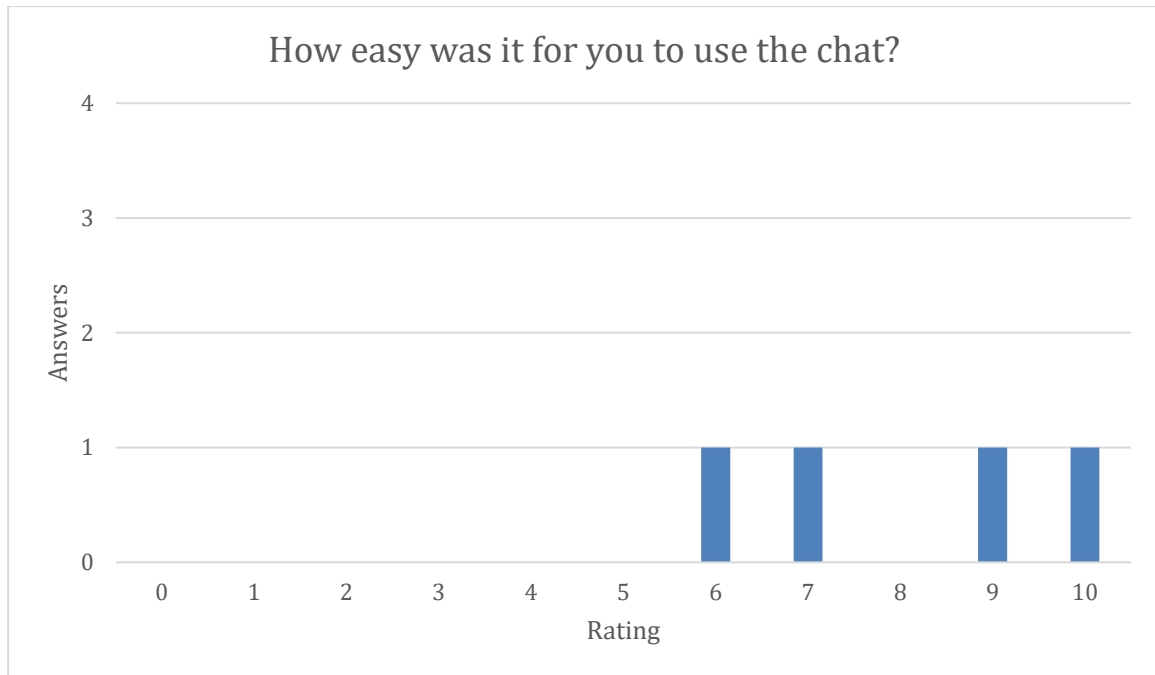
Figure 25: Survey shows varying opinions on the chat's ease of use.

Figure 26 shows the same mid-to-high trend for the understandability of the chat questions. Two participants found the chat questions very easy to understand, rating it a 10, while two participants gave the ratings 6 and 7.
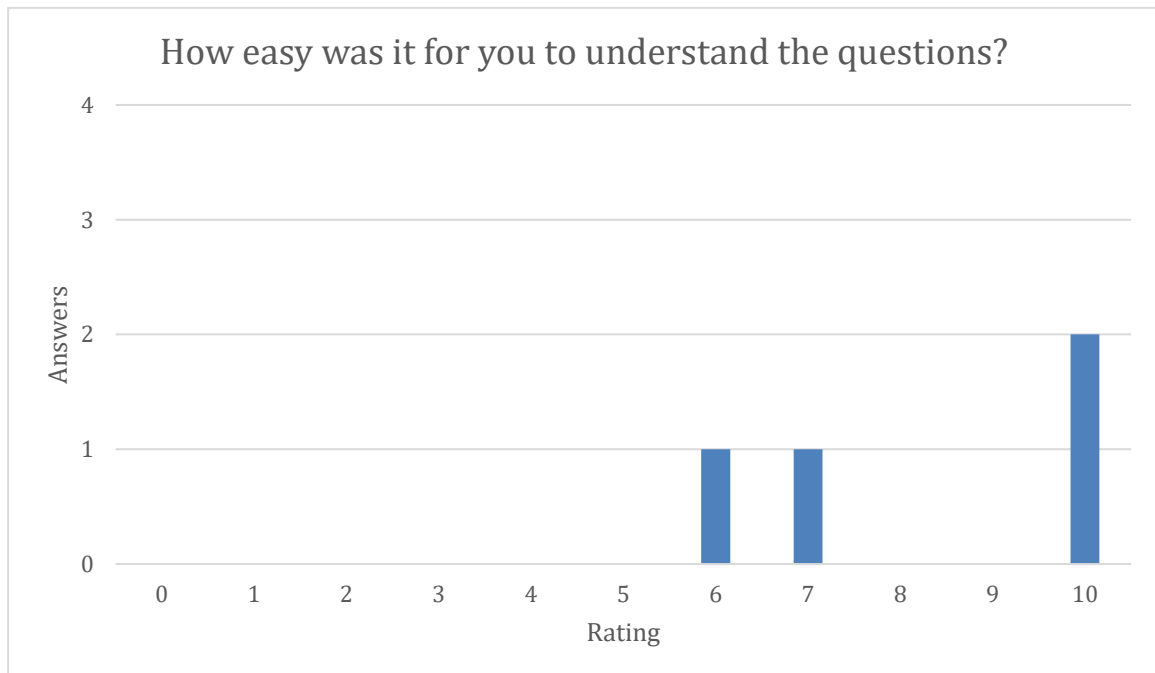

Figure 26: Survey shows varying opinions on how easy the chat's questions were to understand.

Figure 27 shows that the participants were somewhat less satisfied with the supplemental information that is available for the individual chat questions. One rated the usefulness of information as 5, while the other ratings were in the 7-8 range. Unfortunately, no feedback was received on what could be improved in this regard.
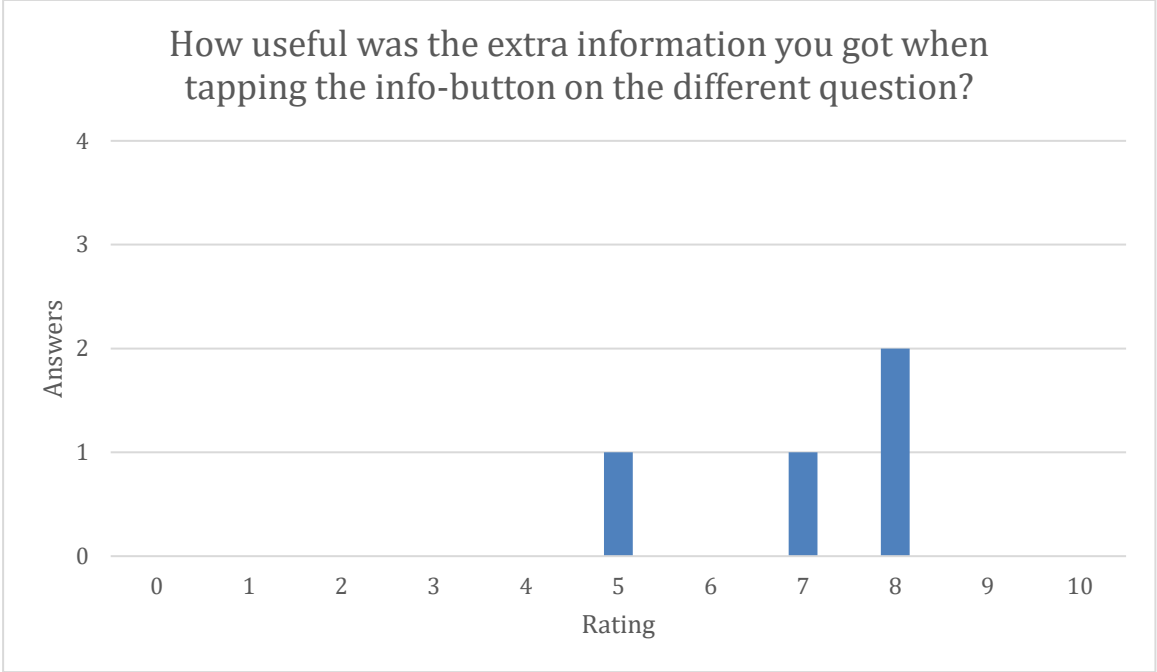

Figure 27: Survey shows that the participants thought the chat's supplemental information was somewhat less useful.

Figure 28 shows that all the participants believed the app to be a useful tool in preparing for a doctor's appointment.

Do you think the app will be useful to you for preparing for a doctor's appointment?
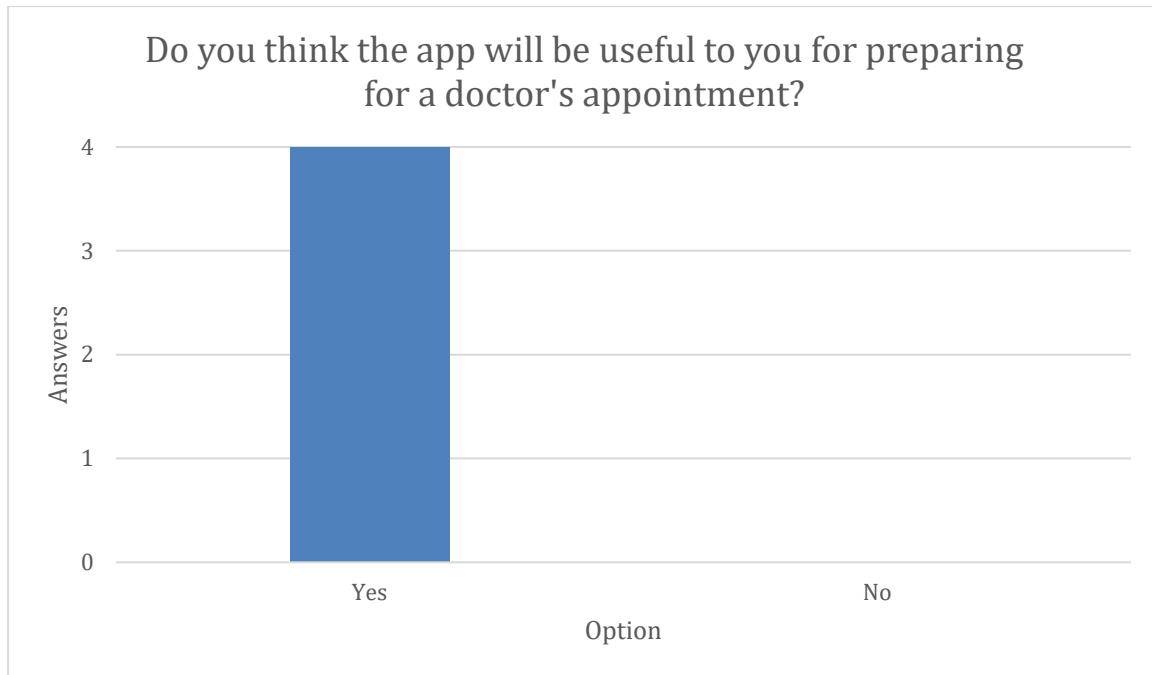
Figure 28: Survey shows that all participants felt the app would be useful in preparation for a doctor's appointment.

9.4 Information

The participants generally thought that the information presented in the information-part of the application was easy to understand as shown in Figure 29, but there were mixed reviews on the relevancy of the information. Figure 30 shows the lowest rating the of relevancy at 5, and the highest at 10.
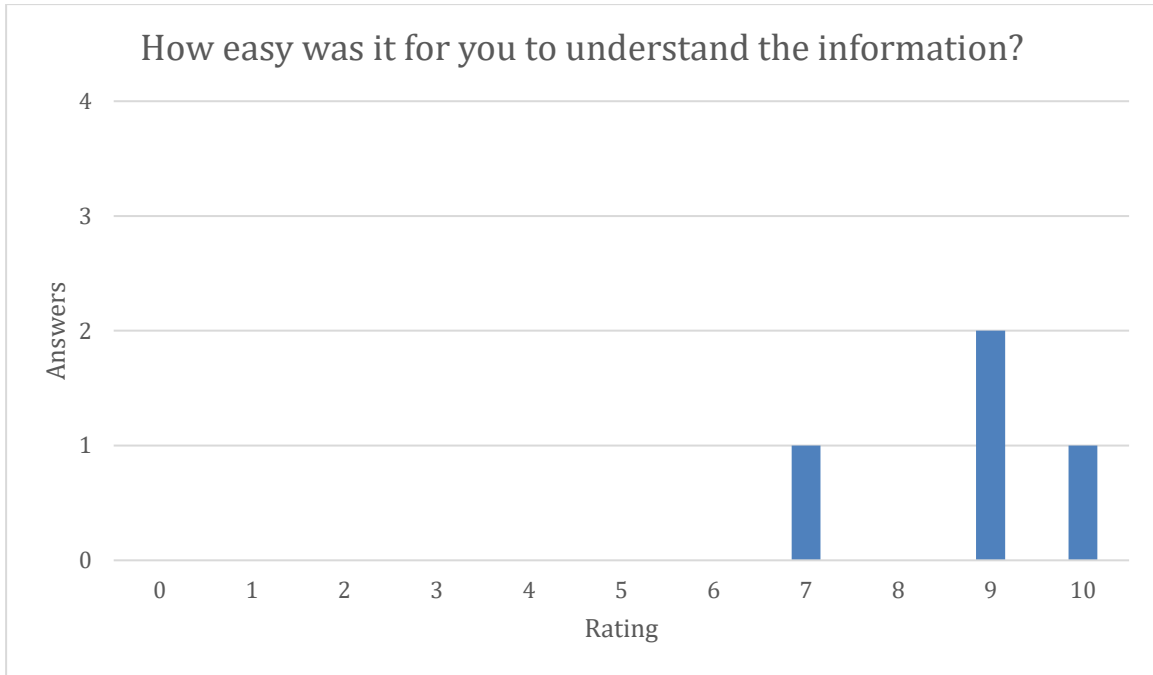
Figure 29: Study shows that participants generally found the information easy to understand.
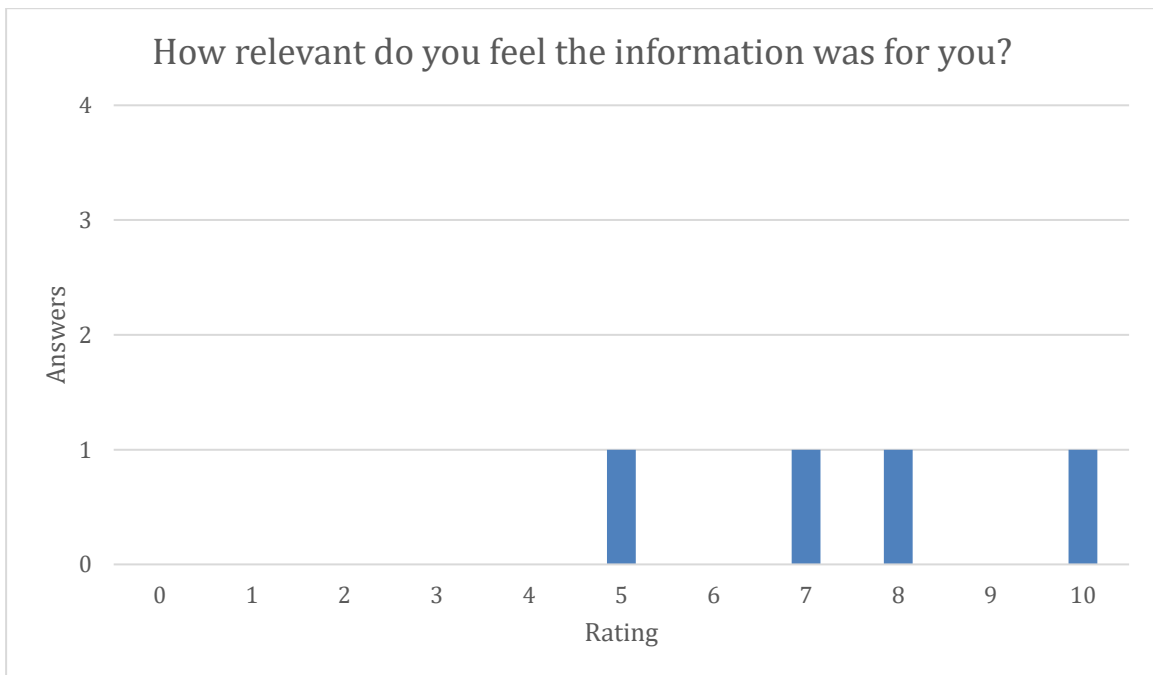

Figure 30: Study shows varying results in how relevant the participants felt the information provided was.

9.5 Notes

The majority of the ratings for the note functionality are in the 9-10 range, while one rating in each of the figures is in the 4-5 range. Unfortunately, no comment was left on what might be improved.
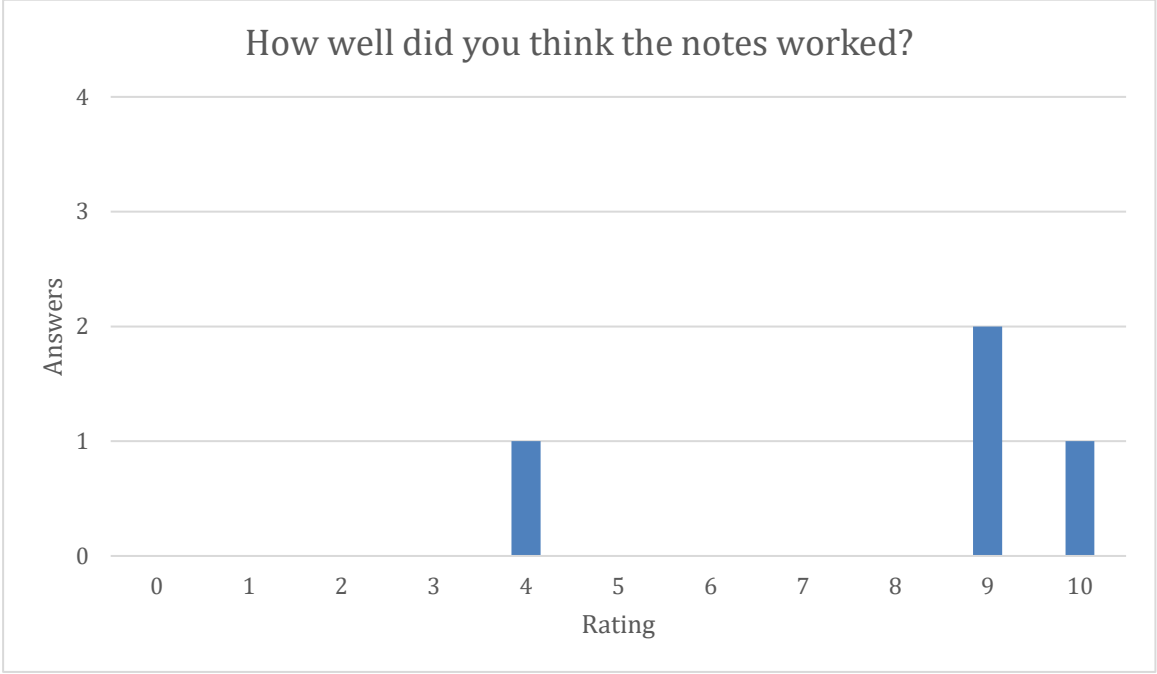

Figure 31: Study showed one participant being less happy with how well the notes worked than the others.
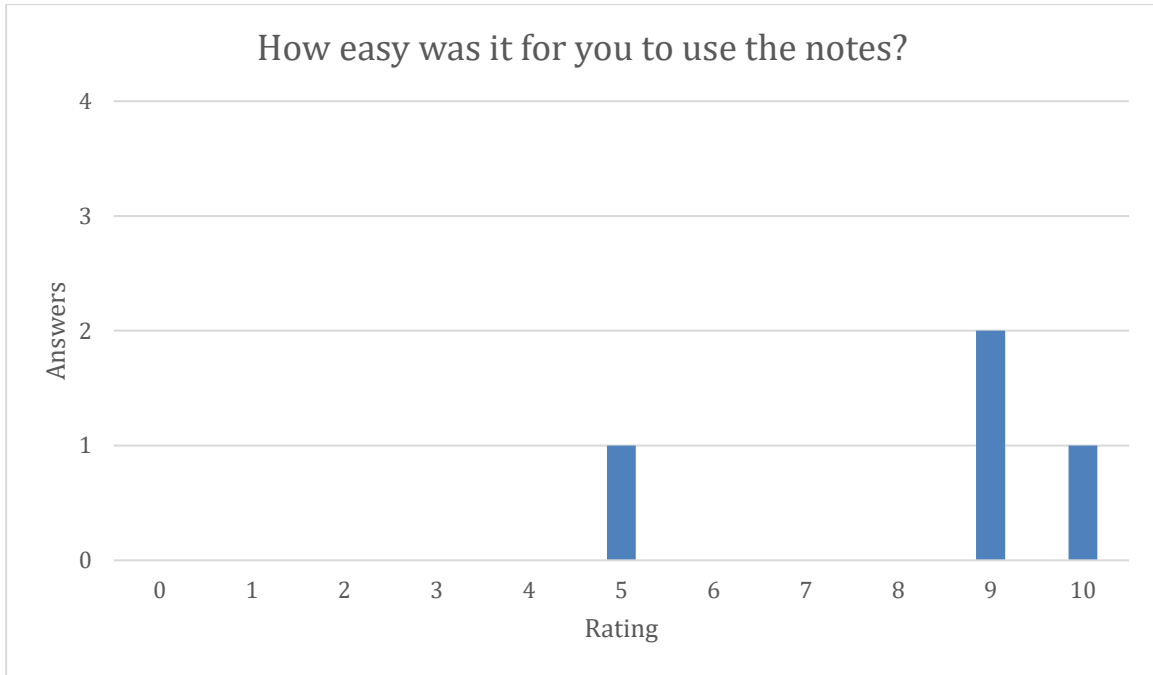
Figure 32: Study shows mid-to-high ease of use for the note functionality.
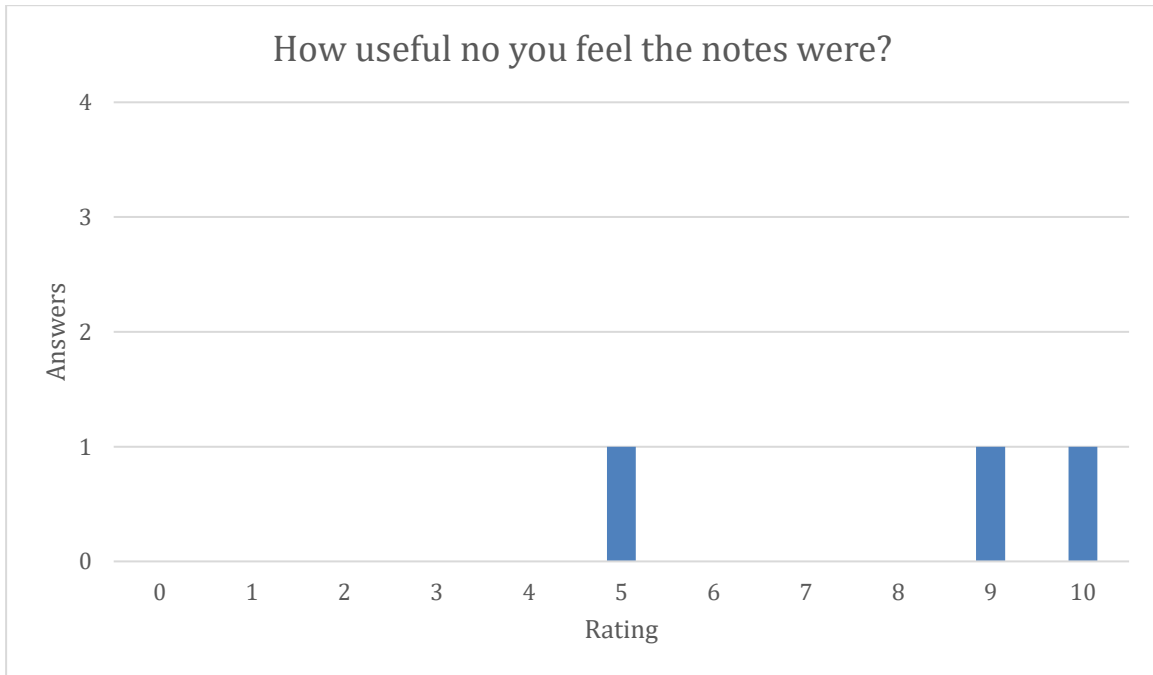

Figure 33: Study found the participants ranked the notes mid-to-high in usefulness. One participant chose not to answer.

10 Discussion

This chapter will discuss the development of the application outlined in chapter 7, and how the preliminary investigations such as the literature review and interviews influenced its design. The user test survey results will be discussed, and an estimation of how many people the application may be relevant to is calculated. Potential points of improvement for the application are listed, and the potential to create similar applications for other health conditions is discussed. Lastly, the authors experiences from attending the 2024 ATTD conference, and the importance of making technology accessible for diverse populations is discussed.

10.1 Project management

The work generally progressed well throughout the project, and the project was completed in the designated time. To a significant extent information was gathered from people outside the project, meaning the interviews and user testing. As meeting with interviewees and test participants naturally had to be determined along with the participating individuals, timing for these meetings could not be strictly scheduled at the beginning of the project. It was generally decided to remain very flexible with timing and meet with individuals at whatever time suited them, and schedule other work around that. Applications to Sikt and REK also required processing time, which further added to the need for flexibility. As such, a strict Waterfall development process could not be maintained, rather a more flexible approach was required. This was solved by having some overlap in scheduling for different phases of the project, and alternating what was worked on by what was possible and convenient. Figure 34 shows an overview of how the project was organized into phases, and the state of the project as of May 13, 2024.

The development tools that were chosen worked well for the project, and implementation of the application went smoothly, without significant delays or problems. The application code generally follows standard best practices of Android development, minimizing the risk of problems or bugs occurring.

Milestone description	Category	Assigned to	Progress	Start	Days
PRE-PROJECT	Mål		100 %	01.08.2023	120
Literature review	I rute		100 %	01.08.2023	60
Analyze available information in Sami on the internet	I rute		100 %	01.10.2023	7
Create interview guide and contact DPO and Sikt	I rute		100 %	19.09.2023	11
Conduct interviews	I rute		100 %	15.11.2023	60
Transcribe interviews	I rute		100 %	01.01.2024	30
Write interview chapter	I rute		100 %	01.01.2024	30
Finish pre-project	Milepæl		100 %	01.02.2024	1
DEVELOPMENT	Mål		100 %	01.12.2023	60
Development	I rute		100 %	01.12.2023	60
App ready for testing	Milepæl		100 %	01.02.2024	1
TESTING	Mål		100 %	01.01.2024	60
Contact Sikt and REK	I rute		100 %	01.01.2024	30
Testing	I rute		100 %	01.01.2024	90
Collect results	I rute		100 %	01.04.2024	14
Testing complete	Milepæl		100 %	14.04.2024	1
FINISH REPORT	Mål		82 %	15.04.2024	30
Abstract	I rute		100 %	15.04.2024	30
1. Introduction	I rute		90 %	15.04.2024	30
2. Background	I rute		100 %	15.04.2024	30
3. Theoretical framework	I rute		90 %	15.04.2024	30
4. Methods	I rute		90 %	15.04.2024	30
5. Theoretical results	I rute		100 %	15.04.2024	30
6. Requirement specification	I rute		100 %	15.04.2024	30
7. Design and implementation	I rute		100 %	15.04.2024	30
8. Testing	I rute		100 %	15.04.2024	30
9. Results	I rute		100 %	15.04.2024	30
10. Discussion	I rute		80 %	15.04.2024	30
11. Conclusion	I rute		80 %	15.04.2024	30
Appendix	I rute		100 %	15.04.2024	30
Deliver report	Milepæl		0 %	15.05.2024	1

Figure 34: Project organization.

10.2 Application design

Chapter 4 and 5 presented a range of investigations into Sami health culture and accessibility of information and tools in the Sami language. The following chapter will present how the findings from these investigations gave rise to the design of the application.

10.2.1   Encouraging interaction

From the literature review and interviews with health professionals it was found that, when communicating about issues regarding health and illness, Sami patients tend to:

- be more reluctant to express pain or discomfort
- avoid voicing complaints
- be more reluctant to question or disagree with their doctor

Engaging patients and facilitating open communication during visits with their doctor is important, as patients will gain more understanding of their condition and treatment options. Shared decision-making with their doctor will also result in a better treatment plan and increase adherence, leading to better health results. In addition, by speaking up about new symptoms, treatments and interventions can be started at an early stage, before the problem progresses.

The application aims to empower active engagement by encouraging the user to speak up about issues they are having, and reminding the user that the doctor and patient should work together to find the best treatment plan. Preparing for their visit by carefully considering how they are managing and if they have noticed any changes in their body can also help patients approach their appointment with the mindset of having a productive conversation with their doctor. Preparing questions and topics they would like to discuss can help the user make the most of their limited time with the doctor, increasing the value they receive from the consultation.

Reinforcement theory tells us that a positive experience will make a behavior more likely to occur in the future. The goal of the application is to act as a catalyst for a more empowered, productive and positive healthcare experience, thereby increasing the likelihood for further collaboration with the healthcare services and combatting the avoidance behavior that was commented on in the interviews and found in literature.

10.2.2　Empowering the patient

The results from the literature review and interviews with health care providers showed that Sami patients tend to feel disempowered when it comes to their health, in that they:

- lack faith in their own ability to affect their health positively
- will not as readily consider that there may be solutions to their health problems

As was discussed in chapter 3.3.1 about cognitive psychology, someone's attitudes about a topic will influence how they process new information about the topic. A person with the attitude of "I don't have much power to change my health", is more likely to reject information about healthy habits. To someone with type 2 diabetes, this attitude is not very helpful, as a large part of type 2 diabetes management is adopting lifestyle changes like a healthier diet and regular exercise.

The application addresses this attitude by often ensuring the users that they do not have to make drastic changes to their lifestyle all at once and need not become experts immediately, but rather that it's okay to learn bit-by-bit, and that even small changes can have a meaningful impact. The application also emphasizes the importance of setting smaller, realistic goals that can be achieved, as this will improve confidence and build motivation. This approach of slowly building confidence and setting achievable goals will help users gain a sense of empowerment over their health and increasing the likelihood that they will adopt healthy and sustainable lifestyle changes.

10.2.3　Taking culture into account

Sami patients have a way of communicating that is described indirect, and values subtlety and non-confrontation. In the literature review and interviews with health care providers it came forth that Sami patients:

- need time to open up, and dislike feeling rushed during consultations
- prefer discussing more general topics before moving to details
- find it more difficult to speak about topics that are seen as embarrassing or taboo

The application is designed to be a safe space for users to think about their health and diabetes management. As such it takes Sami communication culture into account to promote a comfortable experience.

In the application, the user may take whatever time they need going through the chat and may take a break and come back to it at any point without feeling rushed or pressured. The aim is that considering these questions beforehand will make a consultation with their doctor feel less stressful, as the patient will have had the time at home to prepare their thoughts.

To conform better with Sami communication culture, the chat opens with more general questions about the user's life and how they are managing before moving on to more specific details about topics such as weight management and bodily symptoms. Topics that are seen as more embarrassing are addressed at the very end of the chat, allowing the user to build up to considering those topics.

While keeping a neutral and respectful tone, the application still prioritizes providing accurate information to the user and not sugarcoat the realities of type 2 diabetes.

10.2.4   Providing information

From the results that were presented in chapter 5, we know that:

- there is a lack of information about diabetes available in the Sami language
- explaining to a patient the reason why certain questions are asked during a consultation will provide reassurance and facilitate dialogue

Knowledge also builds confidence, and so the application makes sure to provide information about type 2 diabetes, both in general and in the context of the questions that arise in chat. Understanding the reason for questions asked during a consultation will help build the foundation for further discussion with their doctor, promoting shared decision-making and adherence to treatment plans.

Understanding the nature of their own disease can empower the user to take responsibility of their own health and make informed decisions regarding their lifestyle. Awareness of complications that can arise from type 2 diabetes makes it more likely that symptoms are noticed at an early stage, and interventions can be put into place early.

10.3 User test survey results

The survey shows that the application was generally well received, and that the participants found it to be useful.

The questions regarding the bodyweight tracker only received three answers each, so it may seem that one participant has chosen not to answer these questions. One participant left a comment that they had not tried the bodyweight tracker, which makes the theory seem more likely.

Comments were left on the survey requesting the ability to register past health data measurements. As discussed in chapter 6.5, this functionality was considered, but ultimately decided against, as it seemed unlikely that it would be needed frequently. This decision seems ultimately to have been a mistake, and the ability to manually set the time and date for measurements of blood glucose and bodyweight should be included in the application after all.

One participant ranked the general information about type 2 diabetes available in the app as only moderately relevant. As we know from the survey, all of the participants have had type 2 diabetes for over 10 years, and as such it seems likely that they would already know much of the information that was presented in that part of the application. Some of the information also pertains especially to those newly diagnosed and would as such be less relevant to these participants.

Overall, it can seem that one participant was clearly less happy than the others with the note functionality of the application. While we don't know which individual has given each rating, one rating seems to stand out for each of the questions relating to the topic, as described in Figure 31, Figure 32 and Figure 33. Unfortunately, no comment was left on what in particular could be improved, in the participant's opinion.

Ultimately, one of the most important findings of the survey was that all the participants selected "Yes" as the answer to whether the app would be useful in preparation for a consultation with their doctor. As this was the most important goal of the project, it is exciting to see that the application was successful in this regard.

10.3.1 Participation

A general weakness of the study is the rather small number of participants. As installing an application outside of sites such as Google Play is a multi-step process that can be difficult for those without that particular technical knowledge, it seemed best to meet the participants in person to aid them through the process. With limited time and budget, this need to meet in person created restrictions to the geographical regions participants could be recruited from.

As we learnt from the literature review and interviews in chapter 5, Sami tend to also be private in matters relating to their health, and so are less likely to seek to participate in research projects related to the topic. Having a larger number of participants would have lent the results greater credibility and quality. In particular, having more participants that had been more recently diagnosed with type 2 diabetes would have been beneficial.

A person that has had the diagnosis of type 2 diabetes for a long time will have a lot of experience managing their disease, and will likely know a great deal about the topic. They will also have gone through a number of consultations with their doctor, and therefore be familiar with what the session will look like and what questions are likely to arise. Having seen their doctor many times, more trust would have been established between them, and the person would be more comfortable talking with their doctor about health issues.

It is likely that the application would be even more useful for someone who was newly diagnosed, as they would have less knowledge of the disease and what lifestyle changes are recommended. They would also be less accustomed to consultations with their doctor, and so would see more benefit of preparing for it in a deliberate and systematic way. Comparing survey responses of newly diagnosed participants with responses from those more experienced with the disease would have been valuable, to see if the responses would support this theory.

10.4 Number of potential users

Possible users of the application would be people who speak Northern Sami and who have type 2 diabetes and are aware of that.

In the SAMINOR 2 study, 9.6% of Sami men and 6.9% of Sami women self-reported having type 2 diabetes [5]. It seems reasonable to use these numbers to estimate how many Sami

people have type 2 diabetes and are aware that they do. An estimated 25 000 people speak Northern Sami [13], which can reasonably be split evenly into 12 500 men and 12 500 women.

9.6% of 12 500 = 1200. An estimated 1200 Sami-speaking men have diabetes and are aware of the fact.

6.9% of 12 500 = 863. An estimated 863 Sami-speaking women have diabetes and are aware of the fact.

By these estimations, there may be around 2000 people that would be in the target group for the application in its current state. This number would increase with the translation of the application into other languages spoken by Sami. As the prevalence of type 2 diabetes is unfortunately increasing worldwide [8], so the number of potential users is also likely to increase in the future.

10.5 Future work

The following list names some points of potential future improvement for the application, based on the results from the preliminary investigations and application test survey:

- Adding the possibility of setting a date and time manually for health measurements
- Adding more information about type 2 diabetes in Sami, especially information that is more relevant for those that have had the diagnosis for a longer time
- Modify the supplemental information in the chat to be more relevant and easier to understand
- Optimize the chat and personal notes for ease-of-use
- Translate the application into other languages spoken by Sami
- Adding notifications and reminders to, for instance, measure blood glucose or exercise

It seems likely that this application could act as a blueprint for developing similar applications for other diseases and health conditions. This applies not only to physical conditions, but also to mental health struggles. From research done by Dagsvold [27, 28], as covered by the literature review, we know that the same communication culture exists for mental health as for physical health. Research has shown that mental health issues are slightly more prevalent

in the Sami population than in the Norwegian majority population [41]. It seems therefore that developing a similar application to empower conversations about mental health would be of great benefit.

10.6 ATTD conference and publication

In September 2023, an abstract (appendix H) describing the project was submitted to the 17th International Conference on Advanced Technologies & Treatments for Diabetes (ATTD 2024). The abstract was accepted, and along came the offer to display an e-poster at the conference. A poster (appendix I) was submitted and accepted by the conference in February. I traveled to Florence for the conference and attended several interesting lectures about the newest ideas and technologies related to diabetes treatment. The trip was sponsored by The Faculty of Science and Technology at UiT.

During the ATTD conference Professor Melanie J. Davies held the opening lecture, focusing on treatment of type 2 diabetes [42]. A key point of her talk was the importance of using a holistic and person-centered approach to diabetes management [42], as illustrated by Figure 35. The figure stems from a consensus report by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD) [43]. From the figure we can tell how a holistic approach to diabetes treatment will take into account social determinants of health and psychosocial factors. The report further explains how a patient with type 2 diabetes must be considered as an individual with their own specific preferences, values and social determinants of health, and how these factors must be considered when providing treatment [43].

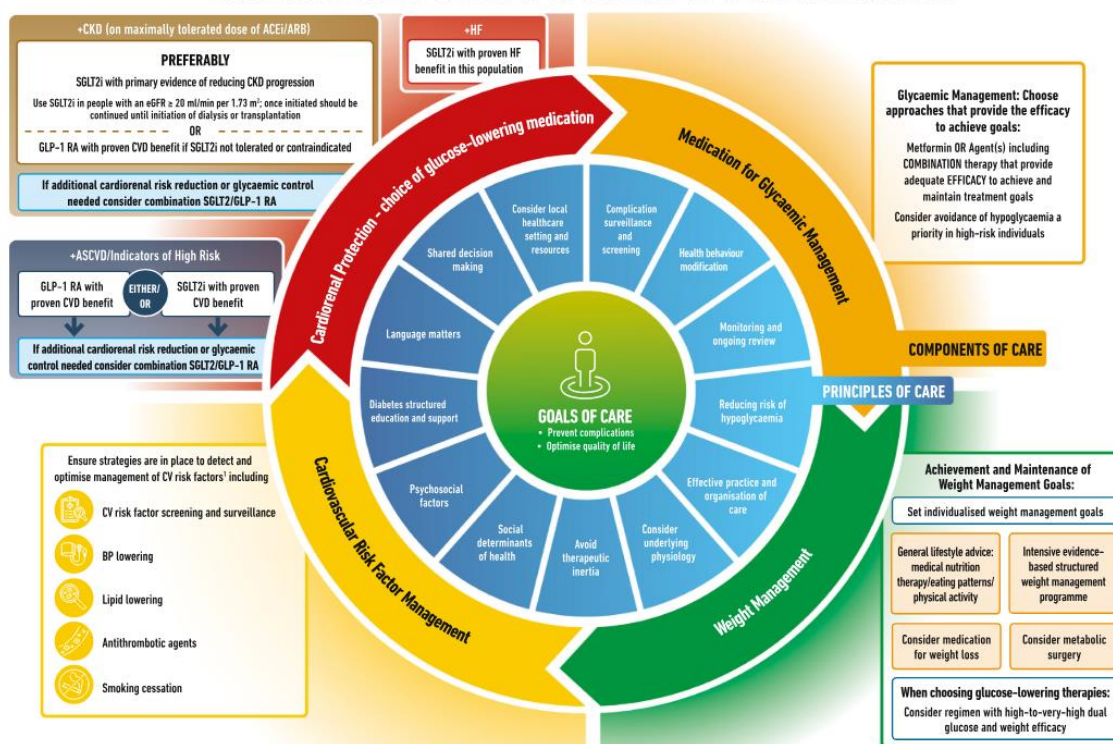HOLISTIC PERSON-CENTRED APPROACH TO T2DM MANAGEMENT

Figure 35: Figure from consensus report from ADA and EASD describing a holistic and person-centered approach to type 2 diabetes management [43].

The report describes diabetes self-management education and support (DSMES) as very important interventions, and that technologies such as mobile apps and other digital self-management tools can be used to deliver DSMES, thereby reaching a broader population [43].

Dr. Emma Wilmot held a lecture exploring technology supported behavior interventions for type 2 diabetes [44]. Her opinion was that while different technologies have come to play a major role in managing type 1 diabetes, we are not making the most of the opportunities to utilize technology in type 2 diabetes management [44]. She pointed to the standards of care from the American Diabetes Association (ADA) which state that technologies such as mobile apps, digital coaching and digital self-management interventions can be effective methods to deliver DSMES and can be beneficial for diabetes prevention and management [45]. Dr. Wilmot stressed the importance of taking into account demographic characteristics such as ethnic and cultural background when providing these services [44].

My experience from the conference was that there was an increased focus on the potential of digital tools and technologies for type 2 diabetes management. Though there can be great benefit in introducing new technologies to the field, it is important that these solutions become accessible for diverse populations and take their needs and preferences into account. At the very least the technologies should be made available with user interfaces and user manuals in the populations' native languages in order to promote accessibility and prevent a greater "digital divide". Health disparities already exist between ethnic groups [45], and it is crucial that these disparities are not exacerbated by the introduction of new technologies, but rather serve to improve health outcomes for everyone.

The application that has been the focus of this project addresses the need for digital DSMES tools that are adapted for a unique social and cultural context, and the problems which are faced by the target population.

11 Conclusion

The research problem defined in this thesis' introduction was as follows:

> "How can a mobile application be created to empower Sami people with type 2 diabetes to communicate with more confidence and openness with their primary care physician?"

During this project, a mobile application was created to address the need defined in the problem. The groundwork for understanding Sami culture of communicating about health and the requirements of the application was laid by conducting a literature review on the topic, and by gathering insights from health care workers though interviews. From the insights gained, the mobile application was designed and implemented with functionality to track health metrics, access information in the north Sami language, and empower Sami people with type 2 diabetes to confidently discuss their diabetes management with their primary care physician.

The most important contribution of the project was the implementation of a novel chat-like interface for people with type 2 diabetes to prepare for a consultation with their health care provider. The chat presents question to the user that are likely to come up during the consultation. The questions are based on the official guidelines by the Norwegian Directorate of Health and are adapted to better fit Sami norms of communication. By going through the questions ahead of time, the user can feel more empowered and confident in discussing and asking questions about their diabetes treatment during the actual consultation. The application acts as a safe space for users to consider their diabetes management, as it allows them to explore their thoughts, feelings and experiences without the pressure that comes with a face-to-face interaction with limited time.

The application was well-received by the Sami participants during the user testing phase, and all the participants agreed that the app would be a useful tool for them to prepare for their next doctor's appointment. The application has the potential to improve the quality of care and health outcomes for Sami people with type 2 diabetes by acting as a catalyst for more open and valuable conversations with their healthcare providers.

While significant literature exists on Sami health culture and the communication challenges Sami patients face in health care settings, not much has been done to address the problem

beyond bringing attention to it. This thesis brings forth a novel approach to the problem, and designs and implements a practical tool to empower Sami people with type 2 diabetes to confidently engage with health professionals.

There also exists the promising opportunity to develop similar applications for other health conditions in the future. This includes not only physical conditions, but mental health issues as well, such as anxiety and depression.

Bibliography

[1] M. Hedlund and A. Moe, "De forstår ikke hva som er viktig for oss: Helsetjenester og sørsamer," Nord-Trøndelagsforskning, 2000. [Online]. Available: http://hdl.handle.net/11250/2444863

[2] B. A. Bongo, "Samer snakker ikke om helse og sykdom: Samisk forståelseshorisont og kommunikasjon om helse og sykdom. En kvalitativ undersøkelse i samisk kultur.," Doctoral thesis, Universitetet i Tromsø, 2012. [Online]. Available: https://hdl.handle.net/10037/5458

[3] G. Mehus, B. A. Bongo, and P. Moffitt, "Important factors when communicating with Sami patients about health, illness and care issues," *Nordisk sygeplejeforskning,* vol. 8, no. 4, pp. 288-301, 2018, doi: doi:10.18261/issn1892-2686-2018-04-04.

[4] A. Naseribafrouei, B. M. Eliassen, M. Melhus, and A. R. Broderstad, "Ethnic difference in the prevalence of pre-diabetes and diabetes mellitus in regions with Sami and non-Sami populations in Norway - the SAMINOR1 study," *Int J Circumpolar Health,* vol. 75, p. 31697, 2016, doi: 10.3402/ijch.v75.31697.

[5] A. Naseribafrouei, B. M. Eliassen, M. Melhus, J. Svartberg, and A. R. Broderstad, "Prevalence of pre-diabetes and type 2 diabetes mellitus among Sami and non-Sami men and women in Northern Norway - The SAMINOR 2 Clinical Survey," *Int J Circumpolar Health,* vol. 77, no. 1, p. 1463786, Dec 2018, doi: 10.1080/22423982.2018.1463786.

[6] L. C. Stene, H. L. Gulseth, C. Berg, and P. L. D. Ruiz. "Folkehelserapporten - Helsetilstanden i Norge: Diabetes i Norge." Folkehelseinstituttet. https://www.fhi.no/he/folkehelserapporten/ikke-smittsomme/diabetes/?term= (accessed August 16, 2023).

[7] Helsedirektoratet. "Nasjonal faglig retningslinje for diabetes." Helsedirektoratet. https://www.helsedirektoratet.no/retningslinjer/diabetes (accessed November 14, 2023).

[8] N. H. Cho *et al.*, "IDF Diabetes Atlas: Global estimates of diabetes prevalence for 2017 and projections for 2045," (in eng), *Diabetes Res Clin Pract,* vol. 138, pp. 271-281, Apr 2018, doi: 10.1016/j.diabres.2018.02.023.

[9] Diabetesforbundet. "Komplikasjoner ved diabetes." https://www.diabetes.no/felles/komplikasjoner/ (accessed August 16, 2023).

[10] Helsenorge. "Diabetes Type 1." Helsedirektoratet. https://www.helsenorge.no/sykdom/diabetes/diabetes-type-1/ (accessed August 16, 2023).

[11] Helsenorge. "Diabetes type 2." Helsedirektoratet. https://www.helsenorge.no/sykdom/diabetes/diabetes-type-2/ (accessed August 16, 2023).

[12] M. Berg-Nordlie and H. Gaski. "Samer." Store Norske Leksikon. https://snl.no/samer (accessed August 21, 2023).

[13] BUFDIR. "Samisk kultur, historie og befolkning." https://www.bufdir.no/nasak/samisk-kultur-historie-og-befolkning/ (accessed August 21 2023, 2023).

[14] SAMINOR. "SAMINOR." UiT The arctic university of Norway. https://uit.no/research/saminor_en (accessed August 17, 2023).

[15] A. Naseribafrouei, B. M. Eliassen, M. Melhus, J. Svartberg, and A. R. Broderstad, "Estimated 8-year cumulative incidence of diabetes mellitus among Sami and non-Sami inhabitants of Northern Norway - The SAMINOR Study," *BMC Endocr Disord,* vol. 19, no. 1, p. 66, Jun 24 2019, doi: 10.1186/s12902-019-0399-7.

[16]   R. Sherman, *Business Intelligence Guidebook - From Data Integration to Analytics*. MA, USA: Morgan Kaufmann, 2015.

[17]   B. Simons-Morton and M. G. Lodyga, *Behavior Theory in Public Health Practice and Research*. Jones & Bartlett Learning, 2022.

[18]   E. T. Hall, *The Silent Language*. Garden City, New York: Doubleday & Company, 1959.

[19]   J. N. Martin and T. K. Nakayama, *Intercultural communication in contexts*. Mountain View, California: Mayfield Publishing Company, 2000.

[20]   F. L. Wiig. "Kan mobilapper gi deg en bedre diabeteshverdag?" Diabetesforbundet. https://www.diabetes.no/mer/nyheter-om-diabetes/nyheter-2020/mobilapper/ (accessed April 29, 2024).

[21]   jjoe64, "GraphView, v.3.1." [Online]. Available: https://github.com/jjoe64/GraphView

[22]   A. Preston. "Android chat tutorial: How to build a messaging UI." Sendbird. https://sendbird.com/developer/tutorials/android-chat-tutorial-building-a-messaging-ui (accessed May 13, 2024).

[23]   NOU 1995:6, "Plan for helse- og sosialtjenester til den samiske befolkning i Norge," 1995. [Online]. Available: https://www.regjeringen.no/no/dokumenter/nou-1995-6/id139873/

[24]   I. Dagsvold, "'In gille huma, De tause rommene i samtalen : samiske fortellinger om kreft," Master thesis, Universitetet i Tromsø, 2006. [Online]. Available: https://hdl.handle.net/10037/1603

[25]   T. M. Ness and M. C. Munkejord, ""All I expect is that they accept that I am a Sami" an analysis of experiences of healthcare encounters and expectations for future care services among older South Sami in Norway," *International Journal of Circumpolar Health,* vol. 81, no. 1, p. 2078472, 2022/12/31 2022, doi: 10.1080/22423982.2022.2078472.

[26]   J. I. Engnes, N. Sivertsen, B. A. Bongo, and G. Mehus, "Sámi and Norwegian nurses' perspectives on nursing care of Sámi patients: a focus group study on culturally safe nursing," *International Journal of Circumpolar Health,* vol. 80, no. 1, p. 1948246, 2021/01/01 2021, doi: 10.1080/22423982.2021.1948246.

[27]   I. Dagsvold, S. Møllersen, and V. Stordahl, "What can we talk about, in which language, in what way and with whom? Sami patients' experiences of language choice and cultural norms in mental health treatment," *International Journal of Circumpolar Health,* vol. 74, no. 1, p. 26952, 2015/01/31 2015, doi: 10.3402/ijch.v74.26952.

[28]   I. Dagsvold, S. Møllersen, and B. H. Blix, "Clinicians' assumptions about Sami culture and experience providing mental health services to Indigenous patients in Norway," (in eng), *Transcult Psychiatry,* vol. 57, no. 2, pp. 363-374, Apr 2020, doi: 10.1177/1363461520903123.

[29]   Helsenorge. "About Helsenorge." https://www.helsenorge.no/en/about-helsenorge/ (accessed April 29, 2024).

[30]   N. Helseinformatikk. "Norsk Helseinformatikk." https://norskhelseinformatikk.no/ (accessed April 29, 2024).

[31]   T. N. I. o. P. Health. "Social mission of the Norwegian Institute of Public Health." https://www.fhi.no/en/ab/niph/fhis-organisasjon-og-visjon/ (accessed April 29, 2024).

[32]   T. N. D. o. Health. "About the Norwegian Directorate of Health." The Norwegian Directorate of Health. https://www.helsedirektoratet.no/english/about-the-norwegian-directorate-of-health (accessed April 29, 2024).

[33]   Diabetesforbundet. "Om Diabetesforbundet." https://www.diabetes.no/om-oss/ (accessed April 29, 2024).

[34] "Karbo & Insulin." https://play.google.com/store/apps/details?id=no.webstep.karbopremium&hl=no&gl= US (accessed May 1, 2024).

[35] mySugr. "The mySugr app." https://www.mysugr.com/en/diabetes-app (accessed May 1, 2024).

[36] "Diabetesdagboka." Google Play. https://play.google.com/store/apps/details?id=no.telemed.diabetesdiary&hl=no&gl=U S (accessed May 1, 2024).

[37] F. Libre. "FreeStyle Libre." https://www.freestyle.abbott/us-en/products/freestyle-libre-app.html (accessed May 1, 2024).

[38] Diabetesforbundet. "Å mestre diagnosen." https://www.diabetes.no/diabetes-type-2/behandling/a-mestre-diagnosen/ (accessed May 9, 2024).

[39] Diabetesforbundet. "Sunt kosthold og aktivitet." https://www.diabetes.no/diabetes-type-2/behandling/sunt-kosthold-og-aktivitet/ (accessed May 9, 2024).

[40] Nettskjema. "Nettskjema." https://nettskjema.no/ (accessed April 29, 2024).

[41] L. E. Torheim *et al.*, "Folkehelserapporten - Helsetilstanden i Norge: Helse og levekår i den samiske befolkningen," Folkehelseinstituttet, Oslo, 2024. [Online]. Available: https://www.fhi.no/he/folkehelserapporten/grupper/helse-i-den-samiske-befolkningen/?term=#psykisk-helse

[42] M. J. Davies, "A new era in the management of T2DM and obesity – Scanning what's on the horizon," ed: 17th International Conference on Advanced Technologies & Treatments for Diabetes. Florence, Italy, 2024.

[43] M. J. Davies *et al.*, "Management of hyperglycaemia in type 2 diabetes, 2022. A consensus report by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD)," *Diabetologia,* vol. 65, no. 12, pp. 1925-1966, 2022/12/01 2022, doi: 10.1007/s00125-022-05787-2.

[44] E. Wilmot, "Technology-supported behavior intervention in T2DM," ed: 17th International Conference on Advanced Technologies & Treatments for Diabetes. Florence, Italy, 2024.

[45] N. A. ElSayed *et al.*, "Standards of Care in Diabetes-2023," (in eng), *Diabetes Care,* vol. 46, no. Suppl 1, Jan 1 2023.

List of appendices

Appendix A: Interview consent form in northern Sami

Háliidat go oassálastit dutkanprošektii

"An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes"?

Dá lea jearaldat dutnje searvat dutkanprošektii mas ulbmil lea ráhkadit applikašuvnna mii sáhttá veahkehit sámi diabetespasieanttaid gulahallat buorebut dearvvašvuoðabargiiguin. Ja earenomážit fástadoavttirin go leat konsultašuvnnas. Dán čállosis oaččut dieðuid prošeavtta ulbmiliid birra, ja maid mearkkaša dutnje oassálastit.

Ulbmil
Prošeakta lea mastergrádabargu UiT Norgga árktalaš universitehta bokte. Máŋga jearahallama lea čájehan ahte sámi pasieanttain dávjá leat váttisvuoðat muitalit ráhpásit iežaset dearvvašvuoða ja buozanvuoða birra doaktárii. Dasa sáhttet leat máŋga ákka, dego kulturerohusat dahje historjjálaš traumat vealaheami dihte. Dán prošeavtta ulbmil lea iskat sáhttá go digitála applikašuvdna veahkehit sámi pasieanttaid geain lea diabetes tiipa 2 dovdat eanet oadjebassan go leat doaktára luhtte, ja gulahallat buorebut doaktáriin.

Gean ovddasvástádus lea dutkanprošeakta?
Ovddasvástádus dutkanprošektii lea luonddudiehtaga ja teknologiija fakultehta, informatihka instituhtta UiT Norgga árktalaš universitehta bokte.

Manne oaččut don jearaldaga oassálastit?
Jearahallan lea oaivvilduvvon fástadoaktáriidda, buohccidivššáriidda dahje eará dearvvašvuoðabargiide geain lea duogáš dálkkodit sámi pasieanttaid. Don oaččut jearaldaga oassálastit go dus lea dát duogáš.

Maid sisttisdoallá dutnje oassálastit?
Jus válljet oassálastit prošeavttas, dat mielddisbuktá ahte don oassálasttát semi-strukturerejuvvon jearahallamis. Jearahallamis oaččut gažaldagaid mat gusket du oainnuide sámi kultuvrra birra, sámi kommunikašuvnna dearvvašvuoða birra, ja lea go sámis kultuvra mii hehtte rabasvuoða dearvvašvuoða birra. Mii maiddai jearrat dovddat go iežat sápmelažžan, du oahpu birra, ja makkár duogáš dus lea sámi pasieanttaid dikšuma oktavuoðas. Jearahallan bistá sullii diimmu. Jearahallan báddejuvvo.

Lea eaktodáhtolaš searvat.
Lea eaktodáhtolaš searvat prošektii. Don sáhtát vaikko goas ja almmá makkárge čilgehusa haga geassádit guorahallama oassálastimis. Buot du persovnnalaš dieðut dasto sihkkojuvvojit. Eai leat makkárge váikkuhusat dutnje jus it áiggo searvat dahje maŋŋel válljet geassádit.

Du personsuodjalus – movt mii vurket ja adnit du dieðuid
Mii adnit dieðuid du birra dušše daidda ulbmiliidda mat dán čállosis leat čilgejuvvon. Mii meannudit dieðuid luhtolaččat ja čuovvut personsuodjalusnjuolggadusaid.

Jearahallan báddejuvvo off-line diktafuvdnii. Báttit vurkojuvvojit lássejuvvon skuffas gitta leat transkriberejuvvon, ja maŋŋil báttit sihkkojuvvojit. Čohkkejuvvon dieđut transkriberejuvvojit off-line PC:i, ja dalle eret-identifiserejuvvojit. Dušše studeanta (Karianne Aho) ja su bagadeaddjit (Gunnar Hartvigsen, Eirik Årsand ja Tina Rishaug) sáhttet gieđahallat báttiid.

Čohkkejuvvon dieđut leat eret-identifiserejuvvon gárvvis prošeavttas. Koda čatná du nammii ja dieđuide nammalisttu bokte, ja nammalistu vurkojuvvo sierra sajis.

Mii geavvá du persondieđuiguin go dutkanprošeakta loahpahuvvo?
Prošeakta loahpahuvvo plána mielde go bargu sáddejuvvo sisa 15. Miessemánu 2024. Jus leat báhcán jietnabáttit, dat dalle sihkkojuvvojit.

Mii addá midjiide rievtti meannudit persondieđuid du birra?
Mii meannudit dieđuid du birra du miehtama vuođul.

Bargogohččumis UiT Norgga árktalaš universitehtas lea Sikt – Kunnskapssektorens tjenesteleverandør árvvoštallan ahte persondieđuid meannudeapmi dán prošeavttas čuvvot personsuodjalusnjuolggadusaid.

Du rievttit
Nu guhka go du sáhttá identifiseret diehtomateriálas, lea dus riekti:
- oaidnit makkár dieđuid mii gieđahallat du birra, ja oaččut kopiija daid dieđuin
- divvut dieđuid du birra mat leat boastut dahje eai muital riekta
- gáibidit ahte persondieđut du birra sihkkojuvvojit
- sáddet váidalusa Datatilsynet:ii du persondieđuid gieđahallama birra

Jus dus lea gažaldagat prošektii, dahje siđat eambbo dieđuid dahje áiggut geavahit iežat rivttiid, váldde oktavuođa:
- Informatihka instituhtta, UiT Norgga árktalaš universitehta:
  - Karianne Aho, kah005@uit.no, +4748075178 (Studeanta)
  - Gunnar Hartvigsen, gunnar.hartvigsen@uit.no, +4777644049 (Váldobagadeaddji)

- Min personsuodjalusain: Annikken Steinbakk, personvernombud@uit.no

Jus dus leat gažaldagat mat gusket Sikt personsuodjalusbálvalusa árvvoštallamii, sáhtát váldit oktavuođa:
- Epoasta: personverntjenester@sikt.no dahje telefovdna: 73 98 40 40.

Dearvvuođaiguin

Gunnar Hartvigsen   Karianne Aho
(Bagadeaddji)   (Studeanta)

Miehtancealkámuš

Mun lean ožžon ja ipmirdan dieđuid *"An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes"* prošeavtta birra, ja lean beassan jearrat gažaldagaid. Mun mieđan:

- ☐ oassálastit jearahallamii
- ☐ ahte jearahallan báddejuvvo

Mun mieđan dasa ahte mu dieđut meannuduvvojit gitta prošeavtta lohppii

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(Vuolláičállojuvvon prošeaktaoasseválddis, dáhton)

Appendix B: Interview consent form in Norwegian

Vil du delta i forskningsprosjektet

"An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes"?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å utvikle en applikasjon som kan hjelpe diabetespasienter med samisk bakgrunn å kommunisere åpent med helsepersonell, da spesielt med legen sin ved en konsultasjon. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet er en mastergradsoppgave ved UiT Norges arktiske universitet. Flere studier har belyst at pasienter med samisk bakgrunn ofte kan ha vanskeligheter med å snakke åpent og direkte om helse og sykdom med legen sin. Det kan være ulike grunner til dette, og alt fra kulturforskjeller til generasjonstraumer fra diskriminering kan spille en rolle. Prosjektet har som formål å undersøke om en digital applikasjon kan få samiske pasienter med diabetes type 2 til å føle seg tryggere ved et legebesøk, og kommunisere mer effektivt med legen sin.

Hvem er ansvarlig for forskningsprosjektet?

Fakultetet for naturvitenskap og teknologi, institutt for informatikk ved UiT Norges arktiske universitet er ansvarlig for prosjektet.

Hvorfor får du spørsmål om å delta?

Intervjuet er rettet mot fastleger, sykepleiere eller annet helsepersonell som har erfaring med å behandle samiske pasienter. Du får spørsmål om å delta fordi du passer disse kriteriene.

Hva innebærer det for deg å delta?

Hvis du velger å delta i prosjektet, innebærer det at du deltar i et semi-strukturert intervju. Under intervjuet vil du bli stilt spørsmål som omhandler din oppfatning om samers kultur og kommunikasjon rundt helse, og om du tror det fins kulturelle normer som hindrer åpenhet rundt helseproblemer. Du vil også bli spurt om du selv oppfatter deg som samisk, om din utdanning, og om din erfaring med behandling av pasienter med samisk bakgrunn. Intervjuet vil vare i rundt én time. Det vil bli tatt lydopptak av intervjuet.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Intervjuet vil bli tatt opp på en off-line diktafon. Lydopptakene vil bli oppbevart i en låst skuff til de er transkribert, deretter vil opptakene bli slettet. Innhentet informasjon vil transkriberes på en off-line

PC, og vil da de-identifiseres. Kun studenten (Karianne Aho) og hennes veiledere (Gunnar Hartvigsen, Eirik Årsand og Tina Rishaug) vil ha tilgang til opptakene.

Innhentet informasjon vil være de-identifisert i det ferdige prosjektet. Navnet og kontaktopplysningene dine vil bli erstattet med en kode som lagres på egen navneliste adskilt fra øvrige data

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?
Prosjektet vil etter planen avsluttes når oppgaven leveres 15. mai 2024. Eventuelle lydopptak vil da bli slettet.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra UiT Norges arktiske universitet har Sikt – Kunnskapssektorens tjenesteleverandør vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:
- innsyn i hvilke opplysninger vi behandler om deg, og å få utlevert en kopi av opplysningene
- å få rettet opplysninger om deg som er feil eller misvisende
- å få slettet personopplysninger om deg
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger

Hvis du har spørsmål til studien, eller ønsker å vite mer om eller benytte deg av dine rettigheter, ta kontakt med:
- Institutt for Informatikk ved UiT Norges arktiske universitet:
  - Karianne Aho, kah005@uit.no, +4748075178 (Student)
  - Gunnar Hartvigsen, gunnar.hartvigsen@uit.no, +4777644049 (Hovedveileder)

- Vårt personvernombud: Annikken Steinbakk, personvernombud@uit.no

Hvis du har spørsmål knyttet til vurderingen som er gjort av personverntjenestene fra Sikt, kan du ta kontakt via:
- Epost: personverntjenester@sikt.no eller telefon: 73 98 40 40.

Med vennlig hilsen

Gunnar Hartvigsen   Karianne Aho
(Veileder)   (Student)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *"An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes"*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i intervju
☐ at det blir tatt lydopptak av intervjuet

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

----
(Signert av prosjektdeltaker, dato)

Appendix C: Interview guide in northern Sami

Jearahallan - Sámi kultuvra ja kommunikašuvdna dearvvašvuođa birra

Álggahus

Muitaluvvo oassálasttiide prošeavtta birra, sin rivttiid birra, ja man guhka jearahallan ádjána. Jus leat gažaldagat, dat vástiduvvojit.

Oassálastit čállet vuollai miehtancealkámuša.

Muitaluvvo oassálastiide ahte jietnabádden álgá.

Duogášgažaldagat

Makkár oahppu dus lea?

Dovddat go iežat sápmelažžan?

Makkár duogáš dus lea sámi pasieanttaid dikšuma oktavuođas?

Kommunikašuvdna sámi pasieanttaiguin

Movt govvidivččet iežat vásáhusaid sámi pasieanttaiguin?

Dovddat go ahte sápmelaččaiguin lea eará kultuvra dahje rabasvuohta dearvvašvuođa birra go dážaiguin? Makkár ládje? Leat go dus ovdamearkkat?

Deaivvadettiin sámi pasieanttaiguin, leat go vásihan hástalusaid kommunikašuvnnain giela dihte?

Deaivvadettiin sámi pasieanttaiguin, leat go vásihan hástalusaid kommunikašuvnnain kultuvrra dihte?

Doaivvut go ahte gávdnojit oasit diabetesbuozanvuođain mat leat earenomážit hástalussan sámi pasieanttaide?

Doaivvut go ahte gávdnojit oasit diabetesbuozanvuođain man birra lea earenomáš váttis sámi pasieanttaide hupmat?

Applikašuvdna

Lea plánejuvvon ráhkadit applikašuvnna mii galggašii veahkehit sámi pasieanttaid geain lea diabetes tiipa 2 gulahallat buorebut iežaset doavttirin. Pasieanta galgá sáhttit registreret iežas dearvvašvuođadieđuid applikašuvdnii, dego varrasohkarmihttu ja deattu. Daid dieđuid bokte applikašuvdna galgá čájehit pasientii fáttaid man birra doavttir soaitá áigu hupmat boahtte konsultašuvnnas, dahje fáttáid maid birra pasieanta soaitá ieš áiggošii hupmat.

Doaivvut go ahte dákkár applikašuvdna sáhtašii veahkehit pasieanta gulahallat buorebut doavttirin?

Dieđát go gávdno go jo dákkár sullasaš applikašuvdna?

Maid doaivvut lea deatalaš váldit vuhtii go galgá ráhkadit applikašuvnna mii galggašii veahkehit pasieanta gulahallat buorebut iežas doavttirin?

Loahpahus

Lea go mihkke ear: maid áiggut dadjat dahje lasihit?

Leat go makkárge gažaldagat maid ledjet vuordán ahte mun jearan, maid in leat jearran?

Sáhtašin go fas váldit oktavuođa jus šaddá dárbbašlaš?

Appendix D: Interview guide in Norwegian

Intervjuguide – Samisk kultur og kommunikasjon om helse

Innledning

Respondentene blir informert om prosjektet, sine rettigheter, hvor lang tid intervjuet vil ta, og eventuelle spørsmål besvares.

Samtykkeskjema underskrives av respondentene.

Det blir opplyst om at lydopptakeren startes.

Bakgrunnsspørsmål

Hva er din utdanning?

Oppfatter du deg selv som samisk?

Forstår du samisk?

Hvilken bakgrunn har du i forhold til behandling av samiske pasienter?

Kommunikasjon med samiske pasienter

Hvordan vil du beskrive dine erfaringer i møte med samiske pasienter?

Oppfatter du at samer har en annen type kultur eller åpenhet rundt helse enn ikke-samer? På hvilken måte? Har du noen eksempler?

Har du selv, i møte med samiske pasienter, opplevd utfordringer i kommunikasjon på grunn av språk?

Har du selv, i møte med samiske pasienter, opplevd utfordringer i kommunikasjon på grunn av kultur?

Er det noen aspekter ved sykdommen diabetes som du tror samiske pasienter har større utfordringer med enn ikke-samiske pasienter?

Tror du det er noen aspekter ved sykdommen diabetes som samiske pasienter vil synes det er spesielt vanskelig å snakke om?

Applikasjon

Det skal utvikles en applikasjon som har som mål å hjelpe samiske pasienter med diabetes type 2 å kommunisere åpent med legen sin. Pasienten skal kunne registrere sine helsedata på applikasjonen, for eksempel blodsukker og vekt. På bakgrunn av de registrerte dataene skal pasienten kunne få opp forslag til temaer som legen kanskje vil ta opp ved neste konsultasjon, og temaer som pasienten selv kan ta opp om de ønsker.

Tror du en applikasjon som beskrevet kan hjelpe en pasient med å kommunisere bedre med legen sin?

Vet du selv om applikasjoner som likner den som er blitt beskrevet?

Hva tenker du vil være viktig å ta hensyn til i en applikasjon som skal hjelpe en pasient med å kommunisere bedre med legen sin?

Avslutning
Er det noe mer du vil si eller legge til?

Er det noe du hadde forventet å bli spurt om som jeg ikke spurte om?

Kan jeg kontakte deg igjen hvis det blir aktuelt?

Appendix E: Survey results from user testing

Jearahallanskovvi - DiaVeahkki

Oppdatert: 27. april 2024 kl. 16:14

Bures boahtin jearahallanskovvái

Don leat maŋemus áiggiid geahččalan applikašuvnna mii lea ráhkaduvvon sápmelaččaide geain lea diabetes tiipa 2. Dán jearahallanskovis jearrat movt du mielas lei atnit iešguđetlágan osiid applikašuvnnas. Jus lea juoga masa it háliit vástidit, sáhtát njuiket dan gažaldaga badjel.

Man guhka dus lea leamaš diabetes tiipa 2 diagnosa?

Antall svar: **4**

Svar	Antall	% av svar	
Vuollel 2 jagi	0	0%	0%
Gaskkal 2 ja 5 jagi	0	0%	0%
Gaskkal 5 ja 10 jagi	0	0%	0%
Guhkit go 10 jagi	4	100%	100%

Varrasohkarmihtideapmi

Ovtta oasis applikašuvnnas sáhttet registreret varrasohkarmihtidemiid, ja oaidnit daid gráfas. Boahttevaš gažaldagat leat dien applikašuvdnaoasi birra.

Man bures du mielas doaimmai oassi varrasohkarmihtidemiid birra?

Antall svar: **4**   Snitt: **8.00**   Median: **8.5**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	1	25%	25%
7	0	0%	0%
8	1	25%	25%
9	2	50%	50%
10	0	0%	0%

Man álki lei dutnje atnit dien oasi appas?

Antall svar: **4**   Snitt: **9.75**   Median: **10**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	0	0%	0%
7	0	0%	0%
8	0	0%	0%
9	1	25%	25%
10	3	75%	75%

Man ávkkálaš lei du mielas diet oassi appas?

Antall svar: **4**   Snitt: **9.00**   Median: **9**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	0	0%	0%
7	0	0%	0%
8	2	50%	50%
9	0	0%	0%
10	2	50%	50%

Lea go mihkkege maid dien appa oasis sáhttá buoridit?

Antall svar: **1**

- olbmos ii leat alot tlf das lahkosin go mihdidan varrasohkkara ja de ii beasa registreret varrasohkkar mihtuid dakkaviđe, galggaši nu aht sahtta registreret mannjil ja de beassa oaidnit grafa

Deaddu

Ovtta oasis applikašuvnnas sáhttet registreret deattu, ja oaidnit daid gráfas. Boahttevaš gažaldagat leat dien applikašuvdnaoasi birra.

Man bures du mielas doaimmai oassi deattu birra?

Antall svar: **3**   Snitt: **9.33**   Median: **10**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	0	0%	0%
7	0	0%	0%
8	1	33.3%	33.3%
9	0	0%	0%
10	2	66.7%	66.7%

Man álki lei dutnje atnit dien oasi appas?

Antall svar: **3**   Snitt: **9.67**   Median: **10**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	0	0%	0%
7	0	0%	0%
8	0	0%	0%
9	1	33.3%	33.3%
10	2	66.7%	66.7%

Man ávkkálaš lei du mielas diet oassi appas?

Antall svar: **3**   Snitt: **9.00**   Median: **9**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	0	0%	0%
7	0	0%	0%
8	1	33.3%	33.3%
9	1	33.3%	33.3%
10	1	33.3%	33.3%

Lea go mihkkege maid dien appa oasis sáhttá buoridit?

Antall svar: **1**

- Das maid galggaši sahttit registeret mannjel deattu ja beassat biddjat rievtes dahtona ja aigemeari

Chat

Ovtta oasis appas lei chatta mii jearahallá du dearvvašvuođa birra. Boahttevaš gažaldagat leat dien applikašuvdnaoasi birra.

Man bures du mielas doaimmai chatta?

Antall svar: **3**   Snitt: **8.33**   Median: **8**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	0	0%	0%
7	0	0%	0%
8	2	66.7%	66.7%
9	1	33.3%	33.3%
10	0	0%	0%

Man álki lei dutnje atnit chatta?

Antall svar: **4**   Snitt: **8.00**   Median: **8**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	1	25%	25%
7	1	25%	25%
8	0	0%	0%
9	1	25%	25%
10	1	25%	25%

Man álki lei dutnje ipmirdit gažaldagaid?

Antall svar: **4**   Snitt: **8.25**   Median: **8.5**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	1	25%	25%
7	1	25%	25%
8	0	0%	0%
9	0	0%	0%
10	2	50%	50%

Man ávkkálaččat ledje liige dieđut mat ihte go deaddilit info-boalu iešguđetge gažaldagain?

Antall svar: **4**   Snitt: **7.00**   Median: **7.5**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	1	25%	25%
6	0	0%	0%
7	1	25%	25%
8	2	50%	50%
9	0	0%	0%
10	0	0%	0%

Orui go du mielas appa ávkkálaš go galggat ráhkkanit doaktárdiibmui?

Antall svar: **4**

Svar	Antall	% av svar	
Juo	4	100%	100%
Ii	0	0%	0%

Ledje go du mielas doppe gažaldagat maidda it liikon dahje mat eai lean relevánta? Guđe ládje?

Antall svar: **1**

· in leat geahzzalan deaddo oasi.

Movt du mielas lei gažaldagaid ortnetvuorru? Livččet go háliidan eará vuoru mielde oaidnit gažaldagaid? Manne?

Antall svar: **1**

· buorre

Lea go mihkkege eará chattas maid sáhttá buoridit?

Antall svar: **0**

Dette spørsmålet har ingen svar

Dieđut

Ovtta oasis applikašuvnnas sáhttet lohkat dieđuid diabetes tiipa 2 ja appa birra. Boahttevaš gažaldagat leat dien applikašuvdnaoasi birra.

Man álki lei dutnje ipmirdit dieđuid?

Antall svar: **4**   Snitt: **8.75**   Median: **9**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	0	0%	0%
6	0	0%	0%
7	1	25%	25%
8	0	0%	0%
9	2	50%	50%
10	1	25%	25%

Man relevánta ledje du mielas dieđut dutnje?

Antall svar: **4**   Snitt: **7.50**   Median: **7.5**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	1	25%	25%
6	0	0%	0%
7	1	25%	25%
8	1	25%	25%
9	0	0%	0%
10	1	25%	25%

Ledje go dieđut maid don váillahit, dahje juoga maid sáhttá buoridit dien appa oasis?

Antall svar: **0**

Dette spørsmålet har ingen svar

Notáhtat

Ovtta oasis applikašuvnnas sáhttet čállit iežat notáhtaid. Boahttevaš gažaldagat leat dien applikašuvdnaoasi birra.

Man bures du mielas doibme notáhtat?

Antall svar: **4**　　Snitt: **8.00**　　Median: **9**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	1	25%	25%
5	0	0%	0%
6	0	0%	0%
7	0	0%	0%
8	0	0%	0%
9	2	50%	50%
10	1	25%	25%

Man álki lei dutnje atnit notáhtaid?

Antall svar: **4**   Snitt: **8.25**   Median: **9**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	1	25%	25%
6	0	0%	0%
7	0	0%	0%
8	0	0%	0%
9	2	50%	50%
10	1	25%	25%

Man ávkkálaš lei du mielas diet oassi appas?

Antall svar: **3**   Snitt: **8.00**   Median: **9**

Svar	Antall	% av svar	
0	0	0%	0%
1	0	0%	0%
2	0	0%	0%
3	0	0%	0%
4	0	0%	0%
5	1	33.3%	33.3%
6	0	0%	0%
7	0	0%	0%
8	0	0%	0%
9	1	33.3%	33.3%
10	1	33.3%	33.3%

Lea go mihkkege maid dien appa oasis sáhttá buoridit?

Antall svar: **0**

Dette spørsmålet har ingen svar

Obbalaččat appa birra

Lea go eará maid áiggut namuhit dahje evttohit mii guoská appai?

Antall svar: **3**

- Appa lea buorre veahkki

- ferten atnit eanet aiggi geahzzalit appa.

- Mun in saddan nu ollu geavahit go oččon sensora maid lean geahččalan ovta aiggi

Appendix F: Survey consent form in northern Sami

Háliidat go oassálastit dutkanprošektii

"An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes"?

Dá lea jearaldat dutnje searvat dutkanprošektii mas ulbmil lea ráhkadit applikašuvnna mii sáhttá veahkehit sámi diabetespasieanttaid gulahallat buorebut dearvvašvuođabargiiguin. Ja earenomážit fástadoavttirin go leat konsultašuvnnas. Dán čállosis oačču dieđuid prošeavtta ulbmiliid birra, ja maid mearkkaša dutnje oassálastit.

Ulbmil
Prošeakta lea mastergrádabargu UiT Norgga árktalaš universitehta bokte. Máŋga jearahallama lea čájehan ahte sámi pasieanttain dávjá leat váttisvuođat muitalit ráhpásit iežaset dearvvašvuođa ja buozanvuođa birra doaktárii. Dasa sáhttet leat máŋga ákka, dego kulturerohusat dahje historjjálaš traumat vealaheami dihte. Dán prošeavtta ulbmil lea iskat sáhttá go digitála applikašuvdna veahkehit sámi pasieanttaid geain lea diabetes tiipa 2 dovdat eanet oadjebassan go leat doaktára luhtte, ja gulahallat buorebut doaktáriin.

Gean ovddasvástádus lea dutkanprošeakta?
Ovddasvástádus dutkanprošektii lea luonddudiehtaga ja teknologiija fakultehta, informatihka instituhtta UiT Norgga árktalaš universitehta bokte.

Manne oaččut don jearaldaga oassálastit?
Applikašuvdna lea oaivvilduvvon olbmuide geain lea diabetes tiipa 2, ja geain lea sámi duogáš.

Maid sisttisdoallá dutnje oassálastit?
Jus válljet oassálastit prošeavttas, dat mielddisbuktá ahte don geahččalat atnit applikašuvnna, ja deavddát jearahallanskovi. Skovvi jearrá dus movt du mielas doibme iešguđetlágan oasit applikašuvnnas, ja man guhkká dus lea leamaš diabetes tiipa 2 diagnosa

Lea eaktodáhtolaš searvat.
Lea eaktodáhtolaš searvat prošektii. Don sáhtát vaikko goas ja almmá makkárge čilgehusa haga geassádit guorahallama oassálastimis. Buot du persovnnalaš dieđut dasto sihkkojuvvojit. Eai leat makkárge váikkuhusat dutnje jus it áiggo searvat dahje maŋŋel válljet geassádit.

Du personsuodjalus – movt mii vurket ja adnit du dieđuid
Mii adnit dieđuid du birra dušše daidda ulbmiliidda mat dán čállosis leat čilgejuvvon. Mii meannudit dieđuid luhtolaččat ja čuovvut personsuodjalusnjuolggadusaid.

Dušše studeanta (Karianne Aho) ja su bagadeaddjit (Gunnar Hartvigsen, Eirik Årsand ja Tina Rishaug) sáhttet oaidnit vástádusaid jearahallanskovis.

Čohkkejuvvon dieđut leat eret-identifiserejuvvon gárvvis prošeavttas.

Mii geavvá du persondieđuiguin go dutkanprošeakta loahpahuvvo?
Prošeakta loahpahuvvo plána mielde go bargu sáddejuvvo sisa miessemánu 15. beaivvi 2024.
Vástádusat jearahallanskovis sihkkojuvvojit dalle.

Mii addá midjiide rievtti meannudit persondieđuid du birra?
Mii meannudit dieđuid du birra du miehtama vuođul.

Bargogohččumis UiT Norgga árktalaš universitehtas lea Sikt – Kunnskapssektorens
tjenesteleverandør árvvoštallan ahte persondieđuid meannudeapmi dán prošeavttas čuvvot
personsuodjalusnjuolggadusaid.

Du rievttit
Nu guhka go du sáhttá identifiseret diehtomateriálas, lea dus riekti:
- oaidnit makkár dieđuid mii gieđahallat du birra, ja oažžut kopiija daid dieđuin
- divvut dieđuid du birra mat leat boastut dahje eai muital riekta
- gáibidit ahte persondieđut du birra sihkkojuvvojit
- sáddet váidalusa Datatilsynet:ii du persondieđuid gieđahallama birra

Jus dus lea gažaldagat prošektii, dahje siđat eambbo dieđuid dahje áiggut geavahit iežat
rivttiid, váldde oktavuođa:
- Informatihka instituhtta, UiT Norgga árktalaš universitehta:
  - Karianne Aho, kah005@uit.no, +4748075178 (Studeanta)
  - Gunnar Hartvigsen, gunnar.hartvigsen@uit.no, +4777644049
    (Váldobagadeaddji)

- Min personsuodjalusain: Annikken Steinbakk, personvernombud@uit.no

Jus dus leat gažaldagat mat gusket Sikt personsuodjalusbálvalusa árvvoštallamii, sáhtát váldit
oktavuođa:
- Epoasta: personverntjenester@sikt.no dahje telefovdna: 73 98 40 40.

Dearvvuođaiguin

Gunnar Hartvigsen   Karianne Aho
(Bagadeaddji)   (Studeanta)

Appendix G: Survey consent form in Norwegian

Vil du delta i forskningsprosjektet

"An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes"?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å utvikle en applikasjon som kan hjelpe diabetespasienter med samisk bakgrunn å kommunisere åpent med helsepersonell, da spesielt med legen sin ved en konsultasjon. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål
Prosjektet er en mastergradsoppgave ved UiT Norges arktiske universitet. Flere studier har belyst at pasienter med samisk bakgrunn ofte kan ha vanskeligheter med å snakke åpent og direkte om helse og sykdom med legen sin. Det kan være ulike grunner til dette, og alt fra kulturforskjeller til generasjonstraumer fra diskriminering kan spille en rolle. Prosjektet har som formål å undersøke om en digital applikasjon kan få samiske pasienter med diabetes type 2 til å føle seg tryggere ved et legebesøk, og kommunisere mer effektivt med legen sin.

Hvem er ansvarlig for forskningsprosjektet?
Fakultetet for naturvitenskap og teknologi, institutt for informatikk ved UiT Norges arktiske universitet er ansvarlig for prosjektet.

Hvorfor får du spørsmål om å delta?
Applikasjonen er rettet mot personer med samisk bakgrunn som har diabetes type 2.

Hva innebærer det for deg å delta?
Hvis du velger å delta i prosjektet, innebærer det at du tester en mobilapplikasjon og fyller ut et spørreskjema. Spørreskjemaet vil spørre deg om hvordan du opplevde å bruke de ulike delene av applikasjonen, og hvor lenge du har hatt diagnosen diabetes type 2.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Kun studenten (Karianne Aho) og hennes veiledere (Gunnar Hartvigsen, Eirik Årsand og Tina Rishaug) vil ha tilgang til svarene fra spørreskjemaet.

Innhentet informasjon vil være de-identifisert i det ferdige prosjektet.

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?
Prosjektet vil etter planen avsluttes når oppgaven leveres 15. mai 2024. Svarene fra spørreskjemaet vil da slettes.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra UiT Norges arktiske universitet har Sikt – Kunnskapssektorens tjenesteleverandør vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:
- innsyn i hvilke opplysninger vi behandler om deg, og å få utlevert en kopi av opplysningene
- å få rettet opplysninger om deg som er feil eller misvisende
- å få slettet personopplysninger om deg
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger

Hvis du har spørsmål til studien, eller ønsker å vite mer om eller benytte deg av dine rettigheter, ta kontakt med:
- Institutt for Informatikk ved UiT Norges arktiske universitet:
    - Karianne Aho, kah005@uit.no, +4748075178 (Student)
    - Gunnar Hartvigsen, gunnar.hartvigsen@uit.no, +4777644049 (Hovedveileder)

- Vårt personvernombud: Annikken Steinbakk, personvernombud@uit.no

Hvis du har spørsmål knyttet til vurderingen som er gjort av personverntjenestene fra Sikt, kan du ta kontakt via:
- Epost: personverntjenester@sikt.no eller telefon: 73 98 40 40.

Med vennlig hilsen

Gunnar Hartvigsen   Karianne Aho
(Veileder)   (Student)

Appendix H: ATTD abstract

An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes.

Background

Research conducted on the indigenous Sami population in Norway, as part of the SAMINOR study, has shown a high prevalence of type 2 diabetes within this community.

Studies have also illuminated that Sami individuals often encounter greater challenges in engaging in open and effective communication with their healthcare providers, compared to their non-Sami counterparts. This issue is rooted in disparities related to cultural norms and language usage and, in some cases, historical distrust stemming from past cultural conflicts and intergenerational trauma.

To foster an environment where Sami patients feel encouraged to engage in open dialogue during healthcare consultations, the implementation of a dedicated application represents a promising solution.

Methods

An application designed for Sami individuals should inherently reflect Sami cultural norms and traditions. The groundwork for understanding the dynamics of the patient-clinician relationship and application requirements will be laid through scientific studies, interviews, and focus groups

Results

We will create a patient model using the gathered information. Users will have the capability to input their personal health data into the app, allowing them to track the evolution of their diabetes management. Using this data, the user will receive personalized recommendations for potential discussion points during their patient-clinician appointments. These recommendations aim to empower the patient, foster a sense of control, and encourage open communication.

Conclusion

The application will empower Sami patients, enabling them to feel more in control and fostering open communication during their consultations, ultimately enhancing the value derived from these appointments.

Appendix I: ATTD poster

An mHealth tool designed to empower and enhance communication between healthcare providers and Sami patients with type 2 diabetes

Karianne Aho, Eirik Årsand, Tina Rishaug, Gunnar Hartvigsen
Department of Computer Science, UiT The Arctic University of Norway, Tromsø, Norway

Background and aims

Research conducted on the indigenous Sami population in Norway, as part of the SAMINOR study, has shown a high prevalence of type 2 diabetes within this community.[1,2]

Studies have also illuminated that Sami individuals often encounter greater challenges in engaging in open and effective communication with their healthcare providers, compared to their non-Sami counterparts.[3] This issue is rooted in disparities related to cultural norms and language usage and, in some cases, historical distrust stemming from past cultural conflicts and intergenerational trauma.[3]

To foster an environment where Sami patients feel encouraged to engage in open dialogue during healthcare consultations, the implementation of a dedicated application represents a promising solution.

The application will empower Sami patients, enabling them to feel more in control and fostering open communication during their consultations, ultimately enhancing the value derived from these appointments.

Methods

An application designed for Sami individuals should inherently reflect Sami cultural norms and traditions. The groundwork for understanding the dynamics of the patient-clinician relationship and application requirements is being laid through scientific studies, interviews with Sami speaking clinicians and patients, and focus groups.

We are creating a patient model using the gathered information. Users will have the capability to input their personal health data into the app, allowing them to track the evolution of their diabetes management. Using this data, the user will receive personalized recommendations for potential discussion points during their patient-clinician appointments. These recommendations aim to empower the patient, foster a sense of control, and encourage open communication.

To the right: Example screenshots of the app. Tapping the chat bubble will provide more information. The original app is in the Sami language.
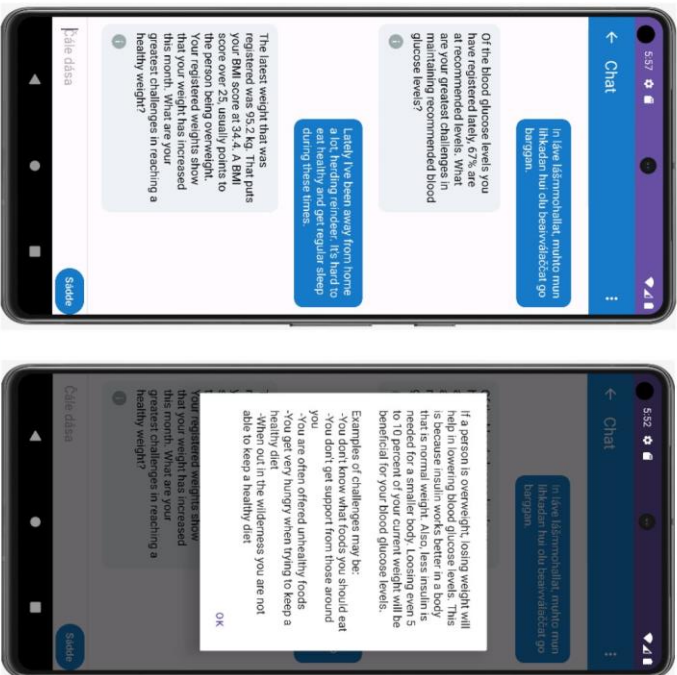
[1] Naseribafrouei et al (2016) "Ethnic difference in the prevalence of pre-diabetes and diabetes mellitus in regions with Sami and non-Sami populations in Norway - the SAMINOR study"

[2] Naseribafrouei et al (2018) "Prevalence of pre-diabetes and type 2 diabetes mellitus among Sami and non-Sami men and women in Northern Norway - The SAMINOR 2 Clinical Survey"

[3] Mehus et al. (2018) "Important factors when communicating with Sami patients about health, illness and care issues"

UiT The Arctic University of Norway