

# ***msHelse*: a Self-Management Mobile Application for Persons with Multiple Sclerosis**

**Aleksander Nygård Tonheim**

*Supervisor*

Professor Ankica Babic



Master thesis for the degree of Master in Information Science  
at the Department of Information Science and Media Studies,  
University of Bergen

2018



# Acknowledgements

First of all, I would like to thank my supervisor Ankica Babic for her impeccable support, motivation and expertise, even at your own spare time.

I would like to express my gratitude for Professor Lars Bø, MD, Ph.D., and MS specialist nurse Anne Britt Rundhovde Skår, M.Sc., for contributing with their expertise during the development process.

*I am grateful to all the persons that have participated in this project: you have all made an important and valuable contribution to the research and for the future users.*

Lastly, I would like to thank my mother Laila, my boyfriend Tor Ragnar, my family and friends for endless motivation and support.



# Abstract

This master thesis presents the *msHelse* application for patient self-management within the field of Multiple Sclerosis (MS). This Design Science research project went through a user-centred design process that included nine persons with MS and two medical experts from the Norwegian competence centre of MS at the Haukeland University Hospital, Bergen. The development was comprised of four design iterations from low- to high-fidelity prototypes.

Resulting are four main modules; *Mobile diary*, *Summary statistics module*, *Stress management module* and a *To-do list*. Through these functionalities users are supported to monitor the course of the disease, to gain knowledge about the disease dynamics and to make adjustments to their lifestyle.

Useful in the development were suggestions from the users and medical experts. For example, the persons with MS suggested that the application should be personalised and automated to simplify data registration into the *Mobile diary*. The medical staff believed that a patient – physician consultation would benefit from using the collected data. Both the persons with MS and the medical experts have expressed their positive attitude throughout the development and evaluation, which resulted in high System Usability Scores.

The outcome of the usability testing with the ten IT experts was encouraging as well and they suggested that it would be a good idea to implement a user guide for new users and improve the navigation to enhance the user experience. The results have suggested that there is a place for IT based tools to support patient self-management, even as a part of the patient routine care. The future development would include testing the application in clinical trials to understand clinical outcomes for users. It would also be important to integrate the *msHelse* application with the Norwegian healthcare system in order to combine patient entered data with the rest of the patient record.



# Contents

<b>Acknowledgements</b>	<b>v</b>
<b>Abstract</b>	<b>v</b>
<b>1 Introduction</b>	<b>1</b>
1.1 Motivation . . . . .	2
1.2 Research questions . . . . .	2
<b>2 Research overview</b>	<b>3</b>
2.1 Medical informatics . . . . .	3
2.2 E-health . . . . .	4
2.3 Human-Computer interaction (HCI) . . . . .	4
2.3.1 User Experience (UX) . . . . .	4
2.3.2 Information visualisation . . . . .	4
2.4 Information design . . . . .	5
2.5 Summary statistics . . . . .	6
2.6 Related work . . . . .	6
2.6.1 Design by user preference . . . . .	6
2.6.2 Related selected applications . . . . .	7
2.7 Summary . . . . .	9

---

<b>3</b>	<b>Medical theory</b>	<b>11</b>
3.1	Autoimmune demyelinating disease . . . . .	11
3.2	Types of MS . . . . .	12
3.3	Symptoms . . . . .	12
3.4	Diagnosis of MS . . . . .	13
3.5	The immune <i>self attacks</i> . . . . .	13
3.6	Treatment of an attack at Haukeland University hospital . . . . .	14
3.6.1	Person with MS/family/next of kin . . . . .	15
3.6.2	Primary health care . . . . .	15
3.6.3	Specialist health services . . . . .	16
3.6.4	Medical treatment and rehabilitation . . . . .	16
3.7	Patient self-management . . . . .	16
<b>4</b>	<b>Methodology and methods</b>	<b>17</b>
4.1	Design Science Research . . . . .	17
4.1.1	Artifacts . . . . .	19
4.1.2	Class of Problems . . . . .	20
4.2	Methods . . . . .	20
4.2.1	Semi-structured interviews . . . . .	20
4.2.2	Case study . . . . .	21
4.2.3	Likert scale . . . . .	21
4.2.4	Measuring usability by user preference . . . . .	21
4.2.5	Conceptual design . . . . .	22
4.2.6	Design prototyping . . . . .	22
4.2.7	Interaction design lifecycle . . . . .	22



---

4.2.8	Usability goals . . . . .	23
4.2.9	System Usability Scale (SUS) . . . . .	24
4.2.10	Usability testing . . . . .	24
<b>5</b>	<b>Establishing requirements</b>	<b>27</b>
5.1	Design iteration one . . . . .	27
5.1.1	Case study . . . . .	27
5.1.2	Selecting study subjects . . . . .	28
5.1.3	Information acquirement . . . . .	28
5.1.4	Results from information acquirement . . . . .	29
5.1.5	Discussion of the information acquirement . . . . .	31
5.1.6	User evaluation of MS applications . . . . .	32
<b>6</b>	<b>The application <i>msHelse</i></b>	<b>35</b>
6.1	Diary module . . . . .	35
6.2	Summary statistics module . . . . .	36
6.3	Stress management module . . . . .	37
6.4	To-do list . . . . .	37
6.5	<i>msHelse</i> as a self-management system . . . . .	38
<b>7</b>	<b>Prototype development</b>	<b>39</b>
7.1	Development tools . . . . .	39
7.1.1	NativeScript . . . . .	39
7.1.2	SourceTree . . . . .	39
7.1.3	Trello . . . . .	40
7.1.4	SQLite database . . . . .	40

---

7.1.5	Adobe XD . . . . .	40
7.2	Development . . . . .	41
7.2.1	Developing conceptual design with pen and paper . . . . .	41
7.2.2	Developing mixed-fidelity prototype in NativeScript . . . . .	42
7.3	Design iteration two . . . . .	42
7.3.1	Medical expert knowledge acquisition . . . . .	43
7.3.2	Results from the medical expert knowledge acquisition . . . . .	43
7.3.3	Feedback from the medical experts . . . . .	46
7.3.4	Discussion of the medical expert acquisition . . . . .	46
7.3.5	Adjusting new functionalities in Adobe XD . . . . .	47
7.3.6	Implementing functionalities in NativeScript . . . . .	48
<b>8</b>	<b>Evaluation</b>	<b>51</b>
8.1	Design iteration three . . . . .	51
8.1.1	Evaluating the prototype with medical experts . . . . .	51
8.1.2	Feedback from medical experts . . . . .	52
8.1.3	Results of semi-structured interviews with the medical experts . . . . .	53
8.1.4	Semi-structured interviews with persons with MS . . . . .	54
8.1.5	Feedback from the study group . . . . .	54
8.1.6	Results of the evaluation with persons with MS . . . . .	57
8.1.7	Feedback from persons with MS and the medical experts . . . . .	58
8.2	Design iteration four . . . . .	60
8.2.1	Usability evaluation with IT experts . . . . .	61
8.2.2	Usability testing results . . . . .	61
8.2.3	Recording time spent on a task . . . . .	64

---

8.2.4	Application demonstration with usability evaluation . . . . .	67
<b>9</b>	<b>Discussion</b>	<b>71</b>
9.1	Semi-structured interviews . . . . .	71
9.2	Applying for ethical approval . . . . .	72
9.3	Recruiting study subjects . . . . .	72
9.4	Likert scale to measure usability by user preference . . . . .	73
9.5	SUS . . . . .	74
9.6	Prototyping . . . . .	75
9.7	Usability evaluation . . . . .	75
9.8	The self-assessment process . . . . .	77
9.9	Shared decision making . . . . .	77
9.10	Generalising the prototype . . . . .	78
9.11	Certification of a mobile application . . . . .	78
9.12	The Design Science Research . . . . .	79
9.13	Research questions . . . . .	81
<b>10</b>	<b>Conclusions</b>	<b>83</b>
10.1	Conclusions . . . . .	83
10.2	Future work . . . . .	84
<b>A</b>	<b>Related publications</b>	<b>87</b>
<b>B</b>	<b>NSD</b>	<b>105</b>
	<b>Bibliography</b>	<b>109</b>



# List of Figures

2.1	The three selected applications; A) SymTrac, B) MS Self, C) My MS Manager.	7
3.1	The course of treatment of an attack at Haukeland University Hospital [1]. . .	14
4.1	The Design Science Research model [2]. . . . .	18
4.2	Seven criterias for conducting the Design Science research [2]. . . . .	19
4.3	The interaction design lifecycle model [3]. . . . .	23
4.4	The SUS scores and how they can be interpreted [4]. . . . .	24
5.1	User evaluation of SymTrac. . . . .	32
5.2	User evaluation of MS Self. . . . .	33
5.3	User evaluation of My MS Manager. . . . .	34
6.1	The time-frame of the <i>Summary statistics module</i> . . . . .	36
7.1	A selection of four wireframes of the low-fidelity prototype. . . . .	41
7.2	The mixed-fidelity prototype. . . . .	42
7.3	Three wireframes based on feedback from medical experts. . . . .	45
7.4	Mock-up in Adobe XD. . . . .	47
7.5	Implemented in NativeScript. . . . .	48
8.1	Four selected wireframes of the prototype used in the evaluation with persons with MS and medical experts. . . . .	52

---

8.2	The SUS Scores from the evaluation of the prototype with four persons with MS.	57
8.3	Suggested functionality of the symptom registration in the diary module. . . .	58
8.4	Feedback from persons with MS on automation and the <i>Summary statistics</i> . .	60
8.5	Three screenshots from the latest version of the high-fidelity prototype. . . .	61
8.6	The SUS scores from the usability evaluation with ten IT experts. . . . .	64
8.7	The average time spent on filling out the diary was 01:04 minutes. . . . .	65
8.8	The average time spent on locating the detailed graph overview of symptoms was 00:36 seconds. . . . .	66
8.9	SUS Score from the demonstration with IT master students. . . . .	68

# Chapter 1

## Introduction

Multiple Sclerosis (MS) is a chronic demyelinating disease in the central nervous system. There are three types of MS; relapsing-remitting, secondary progressive and primary progressive MS [5]. In Norway, it is estimated to be 11 000 persons living with MS. Every year it is estimated that 350-400 persons receive the diagnosis, in Norway alone [6]. In Norway, it is estimated to be 11 000 persons living with MS. Every year it is estimated that 350-400 persons receive the diagnosis, in Norway alone.

IT technology has been used to support users in managing their disease development in other countries such as US [7],[8] and Spain and among European countries [9], but in Norway the usage of IT technology to support self-management has not been fully utilized [10]. Surprisingly, medical experts in Norway does not practice the use of mobile applications to collect knowledge to monitor the disease development [11]. However, there is a need for applications that can support patient self-management and to assist in a patient – physician consultation. The goal of this research has been to utilize IT technology to support users in managing and monitoring their disease and to provide useful information regarding the symptoms and activities. The tool should be used to collect, summarize and represent data in a way that is easily understandable and helpful to users to manage their lives better.

## 1.1 Motivation

Rationale for the research project is both personal motivation and interest in developing IT tools. Two persons within close family are suffering from relapse-remitting MS and they tried to manage their conditions in their own way, sometimes feeling helpless and sometimes feeling optimistic. For them and any persons living with MS, it takes time to understand symptoms and economise their energy. My understanding is that IT tools could help and make this process easier for newly diagnosed persons who are already used to many different treatments and mobile technologies.

## 1.2 Research questions

1. *How can a mobile application be designed to help persons with MS support to self-manage the disease?*
2. *How can a mobile application detect disease related changes of symptoms and help prevent an MS attack?*
3. *How can a mobile application be designed to facilitate a patient – physician consultation?*
4. *How can a mobile application support persons with MS to control symptoms and extract useful information from the collected data?*



# Chapter 2

## Research overview

This chapter will introduce relevant fields this master thesis touches upon. Medical informatics, E-Health, Human-computer interaction with interactive information visualisation, iterative design, User Experience, and Summary statistics.

### 2.1 Medical informatics

The study and application of methods to improve the management of patient data, medical knowledge, population data and other information relevant to patient care and community health [12]. The field has played an important role in providing information systems for patients, hospitals and organisations combining efforts of IT and medical experts. This research wants to make use of development of applications utilizing the knowledge and experiences in which patient collected data is used for development of decision support. Patient self-management has been evolving with the rise and availability of mobile technology to the level where applications are available for practically any medical condition possible.

## 2.2 E-health

The use of internet technology by the public, health workers, and other to access health and lifestyle information and support [12]. Essential to this is a combination of web and mobile technologies, as well as mobile technologies alone. In this work mobile solutions have been prioritised, but eventually the results could be integrated into patient electronic record system.

## 2.3 Human-Computer interaction (HCI)

HCI is an interdisciplinary field, where the main objective is to investigate how humans interact with computers. HCI emerged in the 1980s, and it draws upon interests and expertise in disciplines such as psychology, sociology, anthropology, cognitive science, computer science and linguistics [13]. In this research, it was interesting to understand needs of a wider spectre of users and apply principles resulting in a tool that would be appealing, understandable and easy to use for any user. The field also offers a diversity of interactions techniques applicable for this project.

### 2.3.1 User Experience (UX)

UX is a field within HCI where the experience of a system is in centre. UX encompasses all aspects of the end-user's interaction with the company, its services and its products [14]. This dimension of HCI has emerged with evermore focus on the user and incorporating user preferences in the design and interaction.

### 2.3.2 Information visualisation

Interactive information visualisation is a field within HCI where data can be explored [15]. The literature presents the personal health information and clinical health information as two of three domains for Health 2.0 [16]. Through the design iterations and user evaluation, the

project aimed to deliver a solution for graphically presenting and summarizing patient entered data.

**Personal health information** Individuals will increasingly collect information about their own health practices, while body monitors and sensors will enable them to better understand their strengths and weaknesses. Health informatics services empower patients by allowing them to monitor their evolving health so as to assess their treatment plans or to understand their struggles to adhere to diet or exercise plans [15]. The content of this project would be also used to build upon a new type of services where patient and other clinical data would be combined. For example, patient entered data are unique to the patient and could be a part of a patient – physician consultation, as well as a part of the electronic patient record that would allow monitoring of a medical condition, even outside of the hospital.

**Clinical health information** As Electronic Health Record (EHR) systems become pervasive, patient care could improve, and secondary use of these data will provide valuable insights about treatment patterns. Physician training continues to improve but the vast knowledge of specialised conditions, numerous medications, and professional guidelines emerging from research make it very difficult for physicians to know all that they need to know. Interactive visualisations are starting to help clinicians and patient safety managers query EHR databases to understand the patterns of use [15].

## 2.4 Information design

The science data or knowledge used by human and computer agents to reduce uncertainty, take decisions, and guide actions [12]. This research combines clinical and other user information in the form adjusted in first-hand the self-assessment tool. Eventually the application could be adjusted to a decision support system and as a part of EHR.

## 2.5 Summary statistics

Summary statistics is a simple way of presenting larger amounts of data in this context. Users may feel rewarded by understanding what data they have collected, they can get a quick and direct insight into their symptoms and summarize their well-being in an efficient way. This research collects certain amount of data from the user and making them aware helps patient self-monitoring and even self-assessment if one is recording physical activities.

## 2.6 Related work

### 2.6.1 Design by user preference

There are already many applications available through iOS app store via free download. The choice of a proper application might be difficult for a user and that is why we conducted a case study with a person living with MS for 12 years. The study focused on three different applications that offered different functionalities, user interfaces and to some extent had different content. During this pre-study stage, three different applications were selected for further consideration and those are namely SymTrac, MS Self and My MS Manager, see the Figure 2.1.

**SymTrac** This application (Figure 2.1) encourages the user to fill in details of their day with parameters such as: mood, exercise, and symptoms in Norwegian language. The application also shows a visual summary of how the user is performing when it comes to logging, exercise and symptoms. The application focuses on physical health and monitoring. The physical health functionality shows easy exercises the user can carry out in their home. To register symptoms, the user is presented clickable points on a body part and to register how they feel.

**MS Self** This application (Figure 2.1) has a clear focus on monitoring and mental health. The application presents motivational cards called “fact cards” that inform on coping strategies and



Figure 2.1: The three selected applications; A) SymTrac, B) MS Self, C) My MS Manager.

accepting living with MS. The application asks for detailed information regarding the user mood, mobility, symptoms, as well as activities and energy levels. The Main functionality is the journal, as described, generated reports for selected period of times and specific symptoms, and goal tasks the user wishes to fulfil. The application is only available in English language.

**My MS Manager** The main focus in this application (Figure 2.1) is on monitoring and mental health. There are three main categories in this app: medical settings, daily record, and resources and progress. In the medical setting users can add information of any treatment such as medication or acupuncture, their health conditions in general and their care team. In the daily record the user can add information on how their day has been, mood, symptoms and activity. Users can also add information about a specific symptom represented on a scale from 0 to 10 based on the question. The application is only available in English language.

## 2.6.2 Related selected applications

This section provides artifacts that were selected regarding the problems and main functions they offer. Both web-frameworks and mobile applications are presented.

**HapticMaster** This study shows an artifact, HapticMaster, that is an adaptive personalised training tool for persons with MS. The prototype automatically adjusts the level of difficulty during the exercise to minimize the therapist's involvement [17]. The advantage of this artifact is that it can be tailored to meet individual needs during the rehabilitation. The user testing showed that participants found the artefact challenging by offering diverse training which made the exercise more fun. Having an adaptive training model is an advantage as the symptoms affects each person differently. This artifact solves the specific class of problems by giving each individual personalised exercise. In the general class of problems, this artifact can be used in other contexts such as training for professionals in sports.

**Rules for defining short-term activity goals** Fatigue and pain are non-motoric symptoms of MS, and by setting short-term activity goals the authors explored the problem space, and found out that there is interest to help users define their "sweet spot" target for physical activity [18]. The participants needed to imply how many steps they would walk in one day, and then set that number of steps as a short-term activity goal. If the participants were suffering from symptoms, the goal was reduced with 500 steps or more, and if there was no symptom the new goal included 500 additional steps.

Results from the formative study showed that persons with MS would be interested in setting short-term activity goals, thus the tools should be adaptable on a daily basis. The tool would help users plan their energy with respect to symptoms, for example fatigue and pain. This tool can also be used in a general class of problems in other contexts such as weight loss programs.

**Memo-it: Don't write your diary, sense it** Authors of Memo-it made a prototype to help users let the diary sense activities performed by the user. Memo-it collects sensor data for different activities and aggregates it into digital memories with minimal intervention of the user [19]. This application has the main function to registrate activity automatically and is attractive for patient self-management that requires the minimal effort by the user. Automatic recording of activity would be of help since cognitive difficulties are one of the symptoms of MS.

**Telerehabilitation web application** A web-based application could be one artifact to provide guidance on physical activity. A telerehabilitation web application was developed to support face-to-face sessions at the medical centre for introducing home exercise during the week. Twenty users with MS and ten professionals have evaluated the application using System Usability Scale to evaluate the web [20]. Results from the study showed that patients found it useful to carry on with the rehabilitation at home, without the need to travel often to the facility centre. This could help persons with MS to save energy and empower them through the challenging periods.

**More Stamina** Giunti et al. [9] investigated how a gamified mHealth solution could improve the quality of life for persons with MS. The authors developed prototype of a mobile application to manage fatigue, one of the most common symptoms amongst persons with MS. The system was designed as an organizational tool to help users to manage their energy in their everyday life. The assessment of information needs involved 12 persons with MS and 12 healthcare professionals through a user-centred-design process. The prototype aims to use gamification to reward users. For example upon completion of specific tasks, leaderboards with the users' progress, achievements compared with their peers, challenges and quests to use and process the system and social features [9].

**Visualisation of health indicators** Szeto et al. [21] presents an integrated framework that includes data mining and statistical methods leading to the development of a system that visualises the health state for users. The system aims to teach users how to explore health indicator data and to summarize health information a quick overview. The authors included evaluation with nine study subjects suggesting adjustments.

## 2.7 Summary

The presentation of artifacts have introduced interesting functionalities; personalised adaptive exercise, short-term activity goals, a mobile diary that senses the input, and a telerehabilitation web application for self-management. All but one artifact have persons with MS as a target

group. The mobile diary had adults as a target group, but it can be used by persons with MS. These artifacts for self-management in comfort of the users' home.



# Chapter 3

## Medical theory

MS is a chronic demyelinating disease in the central nervous system, and there are three types of MS; relapsing-remitting, secondary progressive, and primary progressive MS. Environmental issues such as smoking, mononucleosis, low level of vitamin D together with genetic factors could trigger the disease. However, the origin of MS is unknown and the disease affects mostly people between the age of 20 to 40. In 2016, it was estimated that 11.000 people in Norway with the disease [5].

### 3.1 Autoimmune demyelinating disease

MS is a chronic autoimmune demyelinating inflammation disease which affects the nervous system. One reason is that the isolation around nerves, myelin, is removed by the body's own eating cells, called macrophages. Every part of the brain and spinal cord could be affected, as followed by different symptoms. The disease affects more women than men. The disease might not inheritable, however genetic factors along with different environmental factors could trigger the disease. For instance, if close relatives have the disease there is a higher risk of developing MS. Known environmental factors are smoking, infection of mononucleosis (Epstein-Barr virus), low level of vitamin D [5], as a recent study has indicated, lower level of physical activity could be one factor [22]. Currently there is no cure for the disease, but there is preventive medicine to slow down the progression of relapse-remitting form of MS. However, today there

is no medicine for the progressive part of the disease.

## 3.2 Types of MS

Relapsing-remitting MS contains relapsing attacks where the person has months with good periods, followed by months with bad periods. Persons with relapsing-remitting MS can take a medicine to suppress the disease development, but it could also take turn for worse and evolve in secondary progressive MS. It is not unusual to develop the secondary progressive form of the disease, which also bring worsening of the condition and more severe symptoms.

A person with primary-progressive disease might be experiencing an attack that will lead to gradual worsening of the condition. If a patient starts with the pattern described in secondary progressive MS, and not with relapsing remitting MS, the patient will most likely develop a progressive form of the disease. For which in 2018 there is no preventive medicine available.

## 3.3 Symptoms

Symptoms of MS can be numbness in different parts of the body, reduced vision and blurred vision, loss of energy called fatigue, and memory difficulties [5]. These symptoms are called invisible because a person can appear to be well, but in reality, the person is suffering from a disease with somewhat invisible symptoms. Symptoms can be categorised into non-motoric and motoric symptoms. Non-motoric symptoms are as follows: mood swings, change in appearance, numerical difficulties, memory difficulties, depression, fatigue, bladder and intestinal problems, pain, sleeping problems, sexual problems, speech difficulties, lung and respiratory problems, and visual difficulties. Motoric symptoms are follows: numbness, spasms, controlling body parts, walk and balance problems, arm and hand-problems.

## 3.4 Diagnosis of MS

MS diagnosis is established based on a collaborative evaluation of the patient record, and a clinical examination by a neurologist, findings from a magnetic resonance imaging (MRI), examination of the brain and spinal cord, findings from the spinal fluid, and in some cases examination of visual responses (VER) [23]. Guidelines for diagnosing MS include: activity of the disease spread out over several episodes, places in the brain and spinal cord with different symptoms, and if the likelihood of any other disease is excluded while MS symptoms are present [23].

Diagnosing MS usually takes longer time due to the number examinations and collaborative evaluations and not known genetic factors. Furthermore, at least one MS-attack must be documented with objectives as an outcome of a neurological examination, findings in VER, or typical changes confirmed by MRI-examination in an area characteristic for presence of MS. It is sometimes challenging to diagnose if a patient has MS, especially in cases of primary-progressive MS. Symptoms can then gradually appear over a period of at least 12 months without an MS attack, and without signs of disease improvement [23].

In general, a patient can be diagnosed with MS if it has been an increase of disease activity in combination with typical MS-changes usually confirmed by MRI-examinations, and examination of the spinal cord fluid.

## 3.5 The immune *self attacks*

During an MS attack, either new symptoms emerge or existing symptoms are increased. To classify an attack, the symptoms must be constant and last at least 24 hours [23].

If a person is suffering from an attack, new symptoms or increased symptoms appear. One of the reasons causing attacks is an inflammation the brain or spinal cord. This is a result of the central nervous system removing the myelin, causing nerve impulses to stop, or be slowed down [1]. Often, an attack can affect half of the body and can develop in few days. This affects motoric functions, for example problems in the right foot or left arm. However, when inflammation

gradually calms down, then the right foot could be better again if the body has produced new myelin around the nerve fiber. After an attack, symptoms can improve, but sometimes some of the symptoms persist, and is called residual symptom as an outcome of the attack, as the body cannot regenerate itself.

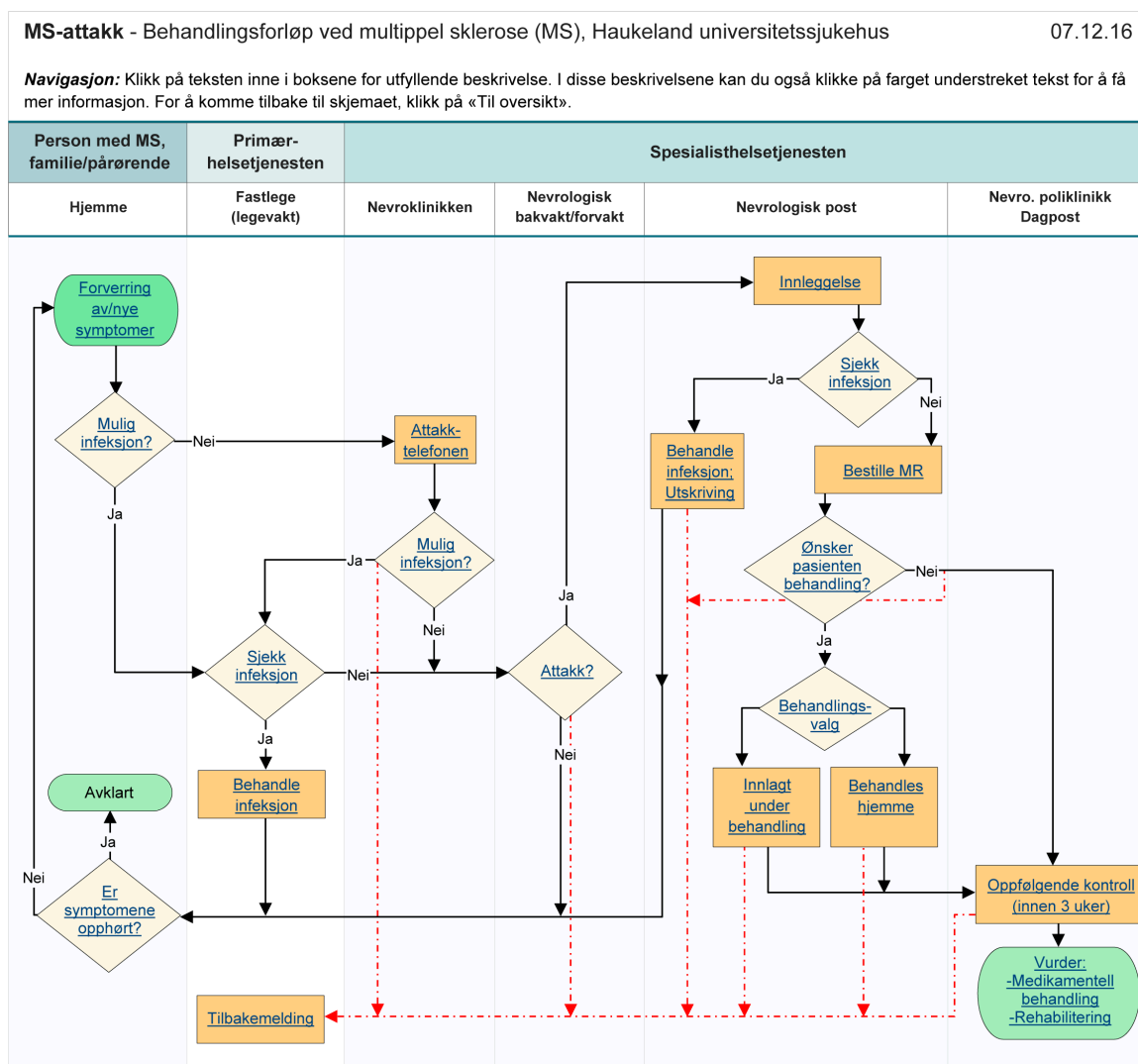


Figure 3.1: The course of treatment of an attack at Haukeland University Hospital [1].

### 3.6 Treatment of an attack at Haukeland University hospital

Haukeland University Hospital in Bergen has a competence centre for MS, and they have developed a course of attack treatment [1]. To treat an attack, three instances are involved: person with MS/family/next of kin (1), primary health care (2), and specialist health services (3). Each

instance has several check-points on how to first identify an attack, and how to treat it. The full description of the treatment plan is given in the Figure 3.1.

### 3.6.1 Person with MS/family/next of kin

(1) A person with MS has to be aware of any changes of symptoms if they aggravate or new symptoms occur. The course of treatment plan has a checklist with three questions to identify a possible attack for the affected person:

1. *Do I experience new symptoms or aggravation of symptoms that has lasted more than 24 hours?*
2. *Has it been a month since my last attack?*
3. *Am I free of fever or infections?*

The course of treatment plan states that if the person can answer yes to the questions above, then the person is advised call the MS attack telephone number that is directed to the hospital. If symptoms are improving, then the likelihood of attack is lower. However, if health personnel managing the MS attack telephone number does not initially classify the symptoms as an attack, and symptoms still aggravate, the patient is advised to call the MS attack telephone number again [1].

### 3.6.2 Primary health care

(2) If a person with MS has fever or infection after consulting the MS attack telephone number, it is advisable that the primary health care treats the possible infection. If there is no infection and symptoms are improving, then there is no attack.

In the event of an attack, and having established the presence of an infection, treatment of the infection must commence first before treating the attack. In case of no infection and worsening symptoms, the specialist health services need to be contacted for further treatment [1].

### 3.6.3 Specialist health services

(3) If a patient with MS has shown no signs of infection, and experiences worsening of symptoms, the specialist health services are contacted by the primary health care to determine if the patient is suffering from an attack. Once the infection is treated, the patient is hospitalised and further detailed examination is performed.

If there is no infection in the brain or spinal cord, treatment is offered to the patient. The patient can then choose between medical treatment, rehabilitation or no medical treatment. If the patient chooses treatment, this can be given at the hospital ward or ambulatory based on the recommendations from the hospital. After a hospitalisation, patients are followed up by the specialist health services to follow-up the effect of the given treatment. A new health check within three weeks is offered to patients who choose no treatment.

### 3.6.4 Medical treatment and rehabilitation

Results from the MRI scans can provide evidence on efficiency of the preventive treatment, and what the adverse effects are. If the patient is not prescribed a preventive medicine, then the specialist health care recommends the patient to start with the preventive medicine. The new medicine can be offered to reduce the occurrence of attacks.

Rehabilitation is offered to patients who has experienced symptoms as a result of the attack. Occasionally, the symptoms can persistent or permanent. The patient can apply at the specialised rehabilitation centres such as Hakadal [24] to learn more about self-management.

## 3.7 Patient self-management

In addition to classical instructions offered by MS specialised staff, patients and persons with MS could consider using applications to support their self-management in their everyday lives, something that is emerging as a new strategy [10].

# Chapter 4

## Methodology and methods

This chapter introduces the methodology used in the research which combines design science research principles, development methods, artifact development and evaluation.

### 4.1 Design Science Research

Design Science Research is a method that establishes and operationalizes research when the desired goal is an artifact or a recommendation [2]. Design Science Research is a method that is oriented to the solving of specific problems to obtain a satisfactory solution for the situation even if the solution is not optimal [2]. This means that the artifact produced is not meant to be a finished solution, but in this case, a prototype that can demonstrate a proof of concept. This could contribute to the science and environment and people the artifact is developed for.

The Figure 4.1 shows the model of the Design Science Research, and the three main concepts *rigor*, *relevance* and *design*. These are essential ingredients, as relevance brings concepts from the problem area, and rigor uses knowledge from science while the design process happens in between. Together, relevance and rigor could contribute problem solutions by an artifact or a theory in a creative and practical way.

Furthermore, the environment refers to the environment the problem is being observed in where

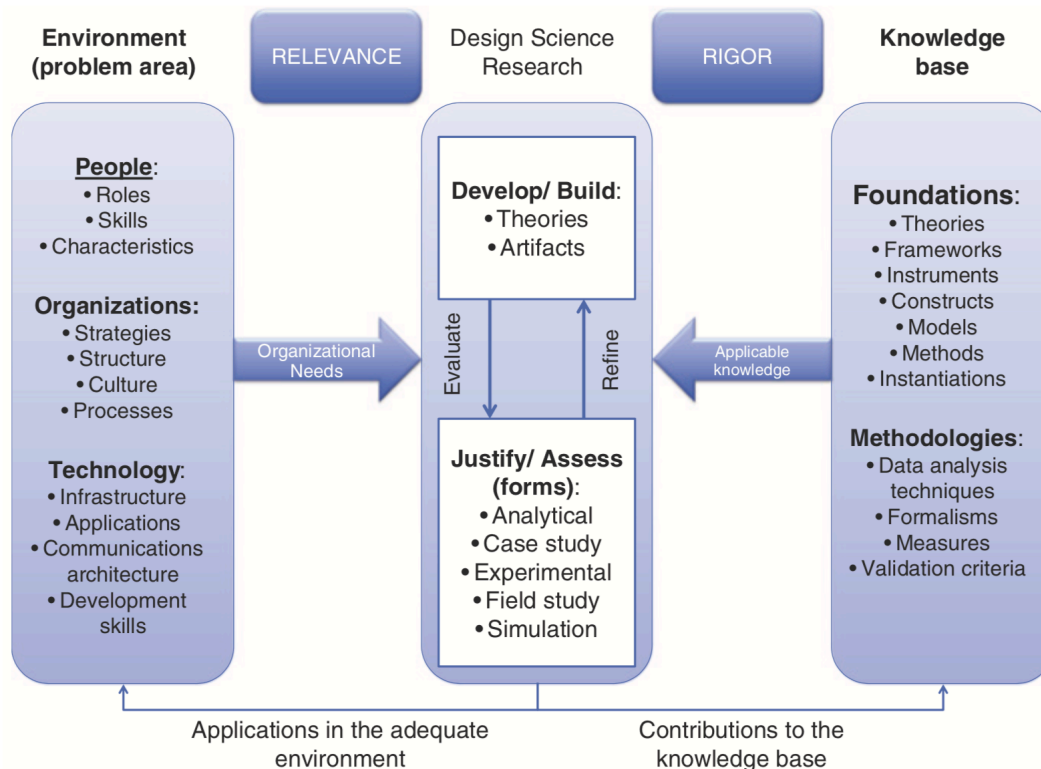


Figure 4.1: The Design Science Research model [2].

the phenomenon of interest to the researcher is obtained [2]. As shown to the left (Figure 4.1), this is where knowledge about people, organizations, and technology is explored to aid the development of an artifact or theory and strengthen the knowledge base. Understanding the problem area in the environment provides relevance to the Design Science Research method.

The knowledge base can be defined as the environment in which the researcher can determine which theories or artifacts were previously used or developed by researchers [2]. As shown to the right (Figure 4.1), this is where knowledge of foundations and methodologies are explored. The importance of knowing what theories, frameworks, models, techniques, and validation criteria there is, can determine the rigor the researcher brings to the design science research method. The knowledge base is composed of well-established foundations and methods that are recognized by the academic community [2]. If the researcher is not using scientific ground, then the contribution of artifacts or theories would not be beneficial for the knowledge base due to the lack of rigor.

Understanding the relevance of the environment and the rigor from the knowledge base makes



it more likely to successfully contribute both to the environment and to the body of knowledge base by contributing new knowledge resulting from the research. The development uses both relevance and rigor to solve a specific problem in a specific context. During the development, justifications such as simulations, field study, experimental research, case study and analytical reasoning is used to both evaluate the process of development, and to refine the artifact or theory, shown in the middle (Figure 4.1). As a result, the development process can contribute with new knowledge to the knowledge base and provide applications in the adequate environment.



Figure 4.2: Seven criterias for conducting the Design Science research [2].

The design science has introduced seven guidelines principles for sound research, as shown in The Figure 4.2.

### 4.1.1 Artifacts

An artifact is something that is manmade; an interface between the inner environment and the outer environment of a given system [2]. The artifact will be used to solve a class of problems, and there can exist several artifacts that can answer classes of problems. As an artifact is something that is manmade it can be a theory, a physical object or artificial. In this research project, the artifact is a self-management mobile application for persons with MS.

### 4.1.2 Class of Problems

There is no conceptual definition of class of problems or a suggestion for its construction. This discussion, however, seems to be central because classes of problems could provide an alternative that could be used instead of considering only solutions that are primarily occasional and specific [2].

Having this in mind, the artifact that is going to be developed can also be used by other target groups than in the field of MS. The application can be used by other persons with an inflammation disease or chronic disease. The class of problems in the environment can also be used to find related work in a specified area to identify classes of problems the artifact is addressing. Thus, there can be developed several artifacts concerning the class of problems with for example artifact A, artifact B, and artifact C [2].

## 4.2 Methods

This section introduces the methods and techniques used in the research project.

### 4.2.1 Semi-structured interviews

Semi-structured interviews combine features of structured and unstructured interviews and use both closed and open questions [3]. This is partly explorative and unstructured by design and enables the researcher to gain a better understanding of a topic. Main questions are for guidance and open answers are to inquire as much information as possible. The method was used in each design iteration to assess user needs of persons with MS and to elicit knowledge from medical experts.

### 4.2.2 Case study

A case study entails the detailed and intensive analysis of a single case [25]. A case study can consist of a single community, school, family, organization, event and a person. In this research, a case study was used to formalise experience of living with the disease and coping strategies. The study also recorded user preferences with regard to the existing applications. Additional cases could be easily built following this case structure.

### 4.2.3 Likert scale

Likert scales are used for measuring opinions, attitudes, beliefs, and consequently they are widely used for evaluating user satisfaction with products [3]. The structure of a Likert scale is that the interviewee is presented assertions about a system with five answers (i.e. *strongly agree*, *agree*, *OK*, *disagree*, *strongly disagree*), and the interviewee responds by crossing one of the five answers. This method was used several times during this study starting with assessing patient preferences and during evaluation.

### 4.2.4 Measuring usability by user preference

Nielsen & Levy [26] present a meta-analysis of 1937 published comparisons between systems from 1994 in which usability has been measured for both subjective preferences and objective performance. They found out that one has a reasonably large chance of success if one chooses between interfaces based solely on users' opinions. The meta-analysis considers only user preference after the user have used the interface being evaluated [26].

In the first design iteration, three MS applications were selected with a case study and were assessed within the case study and were used as a part of the semi-structured interviews to evaluate the three existing MS applications using a Likert scale. Moreover, collecting data about the study subjects' user preference based on their opinion strengthened the assessment of information needs for design of a MS mobile application.

### 4.2.5 Conceptual design

Conceptual design is concerned with transforming requirements into a conceptual model [3]. Based on collected data from the first iteration, a conceptual model was developed to show the concept of suggested functionalities of prototype. The conceptual design was first captured using a low-fidelity prototype which displayed main functionalities, i.e. how the users would like the system to behave.

### 4.2.6 Design prototyping

A prototype is a manifestation of a design that allows stakeholders to interact with it and to explore its suitability [3]. There are two types of prototypes: low-fidelity and high-fidelity prototypes. A low-fidelity prototype captures basic functionalities and is a quick way to show the stakeholders solutions based on user needs. The low-fidelity prototype is cheap, cost effective and quick to develop. A high-fidelity prototype is more like the finished product, as it has implemented functionalities and is fully interactive. The high-fidelity prototype provides the look and feel and is good to explore details of functionalities. The intention is to provide a UX that is close to what the final product would offer.

Through four design iterations, the prototype evolved from a conceptual design to low- and eventually high-fidelity prototype.

### 4.2.7 Interaction design lifecycle

There are four basic activities for interaction design, see The Figure 4.3, and these include establishing requirements for the UX, designing alternatives to meet those requirements, prototyping alternative designs so that they can be communicated or assessed, and evaluating what is being built throughout the process and the user experience it offers [3].

Iterative design key in the interaction design lifecycle process, as it allows designs to be refined based on feedback from the users. Iteration is inevitable because designers never get the solu-

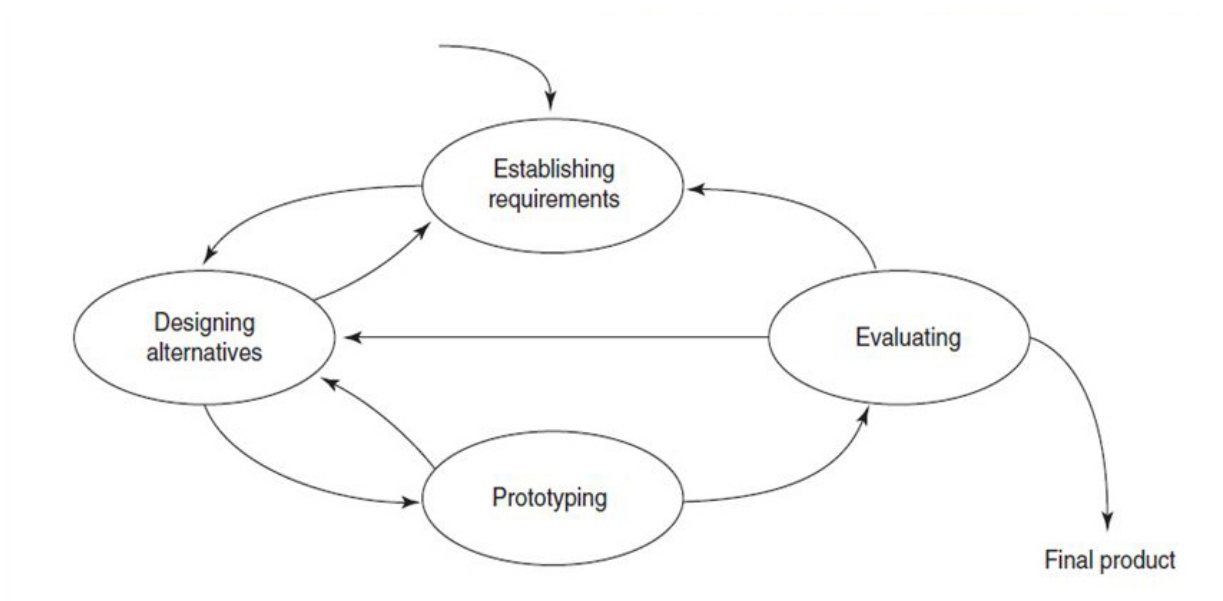


Figure 4.3: The interaction design lifecycle model [3].

tion right the first time [27]. This research project has undertaken four design iterations with persons with MS and medical experts to support the users by meeting their needs with iterative design.

#### 4.2.8 Usability goals

All user-centred-design has the ambition to be useful and user friendly and meet the needs of the users. Therefore, the development is informed by the following usability guidelines from Usability.gov [28]:

- Learn if participants are able to complete specified tasks successfully.
- Identify how long it takes to complete specified tasks.
- Find out how satisfied participants are with your Web site or other product.
- Identify changes required to improve user performance and satisfaction.
- Analyse the performance to see if it meets your usability objectives.

### 4.2.9 System Usability Scale (SUS)

SUS is a usability scale used to quickly measurement how people perceive the usability of computer systems on which they are working [4]. The questionnaire consists of ten questions where the five responses range from *strongly agree* to *strongly disagree* [29].

The questions consist of five positively worded questions and five negatively worded questions. The use of both positive and negative items leads to one level of complexity; the responses to the questions indicate strength of agreement or disagreement, so strongly disagreeing with a negative statement is equivalent to strongly agreeing with a positive one [4].

To measure the prototypes' overall usability, SUS was used several times in the last three design iterations. The evaluation of the system using SUS provided quick and efficient feedback on how the users experienced the system. However, SUS provides a general measure not giving any specific feedback [4].

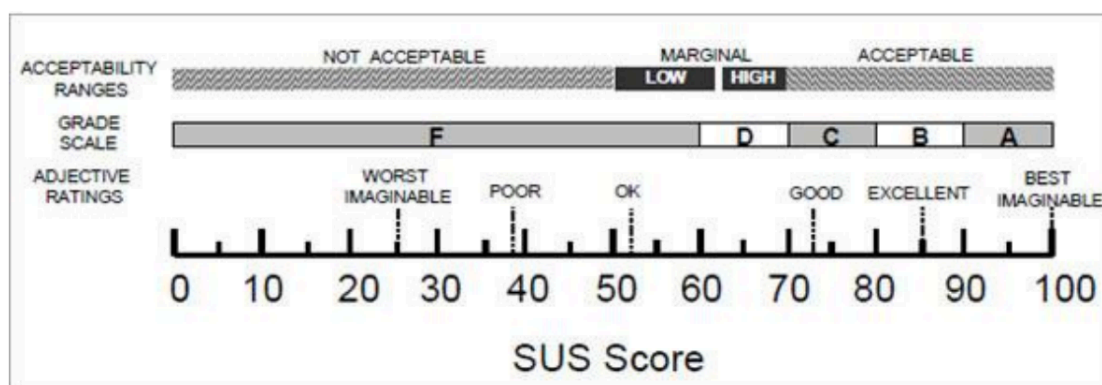


Figure 4.4: The SUS scores and how they can be interpreted [4].

The SUS score must not be confused to be percentages, as the SUS score is a percentile ranking. The Figure 4.3 displays the acceptability ranges of a score, with a SUS score between 65 to 100 referred to as an acceptable/good usability score [4].

### 4.2.10 Usability testing

The main goal of testing is to understand how users experience and interacts with the system. There are many aspects of the system that can be tested, one of them is interaction design which

is often done using Nielsen's heuristics[3]. The other important aspect of testing is to be able to experience the system by performing a specified set of tasks with different level of difficulty for which scores and times could be measured. That way the system is being tested for more than just appearance. However, both the interaction and system content are making user like and trust the system. Regarding the context and how it is presented to the user, an expert evaluation is appreciated for addressing aspects that are not just matter of design or implementation. For example, when presenting an application to persons with MS, lots of credibility will be gained by approval of medical staff that is specialised in treating MS.





# Chapter 5

## Establishing requirements

### 5.1 Design iteration one

User requirements were established through interviews and a case study with persons who live with MS. The goal was to understand how MS affects life, what are coping strategies and what are views on applications and IT tools. A detailed study was carried out as a case study and five additional interviews were conducted with two men and three women.

#### 5.1.1 Case study

A case study was conducted in May 2017 with a 43 years old female subject who is living with MS for 12 years and has developed her own coping strategies. The objective was to understand her preferences regarding the usage of MS applications and her attitude towards IT technology.

The interview guide used in the case study was also used with additional group of five persons living with MS to assess information needs. The intention was to gain more insight and have different perspectives on using IT tools for self-management.

The subject was asked about IT habits, everyday habits regarding exercise, how she was coping with symptoms living with the disease, what were her preferences regarding functionalities to

be included in an MS application and elements she would like to include in an MS application. Finally, she was presented three publicly available MS applications from the iOS app store using a mobile device and was asked to point out which functionalities would best to suit her needs. The search terms used to select the applications was Multiple Sclerosis and MS.

The study subject has chosen three applications as the most appropriate for her self-management [11]. Those were namely: SymTrac [30], MS Self [7] and My MS Manager [8] available via free download.

In general, the study subject said that the MS application should focus on positive aspects, such as how to live with the disease and how to cope with symptoms. Moreover, she pointed out the importance of treating users as not being sick, but as healthy persons living with MS. *”The disease does not define a person, a person is always more than the disease.”*

### 5.1.2 Selecting study subjects

Prior to the selection of study subjects, the study was approved by the Norwegian Centre for Research Data (NSD), see Appendix B. NSD goes through the objectives of the study, the informed consent form, the interview guide, and evaluates the study based on how sensitive data (i.e. name, phone number or address) is treated by the researchers.

The study subjects were recruited via a Facebook group called MS Venner. The group has over 4 400 members and is comprised of both persons directly affected by MS and close family members. The disease experience varied from short to long term. The age was in range of 28 and 60 years; there were two males and three females.

### 5.1.3 Information acquirement

Five study subjects were interviewed in a natural setting to collect initial requirements for a new mobile application. The semi-structured interview consisted of two parts; one part with questions, and the second part with evaluation of the publicly available MS applications selected in the case study.

The disease onset and disease type differed. Four study subjects reported that they had relapse-remitting MS, and one did not have a precise diagnosis. Regarding the disease onset, two study subjects reported that they received the diagnosis less than 3 years ago, two study subjects received it diagnosis some 13 years ago, and one subject received the diagnosis 33 years ago.

The first part of the qualitative interview aimed to collect information about the subjects' experience and habits. For example, how to plan a day if the symptoms are present, what coping strategies they had, and what IT habits they had.

The second part consisted of an evaluation of three MS applications selected in the case study (SymTrac [30], MS Self [7] and My MS Manager [8]). To evaluate the selected applications, the design by user preference [31] was used in combination with a Likert scale [32].

#### 5.1.4 Results from information acquirement

Results from the first part of the qualitative interview gave insights into the study group's use of technology to support, monitor, and record disease related events.

Three study subjects classified their IT habits as an average user. They said that an average user is a person who uses applications on their mobile device on a daily basis. Furthermore, two study subjects classified their IT habits as relatively experienced, and one as advanced due to the education and current profession.

Persons with MS experience symptoms differently, both due to the way of coping and the intensity of symptoms. The study group reported non-motoric symptoms as the most challenging. The group specifically mentioned fatigue, memory difficulties, and headache. One study subject reported motoric symptoms, especially spasms as a noticeable disease effect.

To manage motoric and non-motoric symptoms the study group reported everyday activities, outdoor activities and physical exercise. Additional coping activities included baking a bread, fishing and practical work around the house that were proven remedies for symptoms. Hiking outside was also mentioned. Two study subjects reported that even simple exercise was good enough to curb symptoms. In contrast, three other study subjects found such activities

beneficial, but too exhaustive.

The study group reported the need to have an application as means of communication with the environment, such as friends, family and colleagues. Moreover, the study group pointed out that there was also a need to communicate about social activities with other persons. Such activities could for example be sharing experience of the disease while hiking. Finally, the study group had no experience of using IT tools for self-management in their everyday life.

The study group was also asked about their preferences regarding functionalities they would like to include in an MS application. One study subject identified a list containing five most important activities to accomplish during one day. Three study subjects reported a function to track and register symptoms in a diary, and be presented a graphic summary of data entries for the most important feature. One mentioned the importance of being aware of changes in symptoms that could lead to an MS attack. However, one study subject said that the focus should not be on a diary *but getting through the day*. Furthermore, the study subject noted the importance of removing stress, not adding it. The reason for this was avoiding additional stress related to data input.

The second part of the qualitative interview consisted of an evaluation of three selected applications, shown in chapter two (Figure 2.1). Feedback from users showed that *SymTrac* was reported as the application which was the most straightforward and easiest to use. That was followed by *MS Self* and *My MS Manager*. Furthermore, all applications offered a diary module where the user could add symptoms, mood, activity and general notes. Four study subjects rated *MS Self* as having the best diary module.

During the interview debrief, one study subject said that exercise gave some effect with stabilisation of the disease. However, the subject found it boring, and quit exercising after five years. One concern shared by another subject was that having MS was shameful, because this was a chronic disease and the study subject felt that the disease was downplayed by doctors. One example was that the subject felt that Haukeland University Hospital did not focus on protentional of a healthy diet and vitamin D, which the subject thought would be helpful.

### 5.1.5 Discussion of the information acquirement

The study subject reported different IT skills and experiences. The three could be seen as average users, and two of them as experienced users that utilized mobile applications daily. Surprisingly, none reported using MS applications as a part of their daily routine. The selected applications are representative of a wider group, offering different IT-support to potential users. The SymTrac application seemed to appeal most to the group which might be also explained by the usage of Norwegian language. Results indicated a need for an application to support their daily routines. For example, providing of registration of symptoms and presenting them in a simple graph to support the self-management. However, this was not fully utilized by the group.

One study subject raised the question *Why should I use my time to write a diary on my mobile device?*. The subject argued that the focus should be on removing stress rather than adding it by writing a diary. However, this was surprising as the same subject was aware of monitoring the condition and appearance of new symptoms, which is important to treat and prevent a possible MS attack. The rest of the group was positive towards an IT solution for the same reason, i.e. to control the symptoms and prevent attacks. Therefore, in the case of MS attack, the hospital must be alerted, which could be done using an application. Our focus is to design an efficient and uncomplicated mobile application that will support such functions and others in accordance with information needs. The modular build of the application should allow users to use and prioritise functionalities they find most useful.

Developing a mobile diary to register symptoms was perceived as useful by the majority of the study group. For other reasons, the mobile diary can also be used in interaction with medical personnel. For instance, if the doctor asks, *How have you been since last visit?*, then the patient can show the mobile diary containing symptoms, graphs, and other relevant information.

The qualitative interviews were facilitated to reduce bias by dividing the interview in two parts. This way, the study subjects could not use the three presented applications as reference points, but rather gave them a chance to communicate their own needs.

### 5.1.6 User evaluation of MS applications

Following is the user evaluation of the selected MS applications. Users had opportunities to grade three selected applications by noting their likes and dislikes on the likert scale.

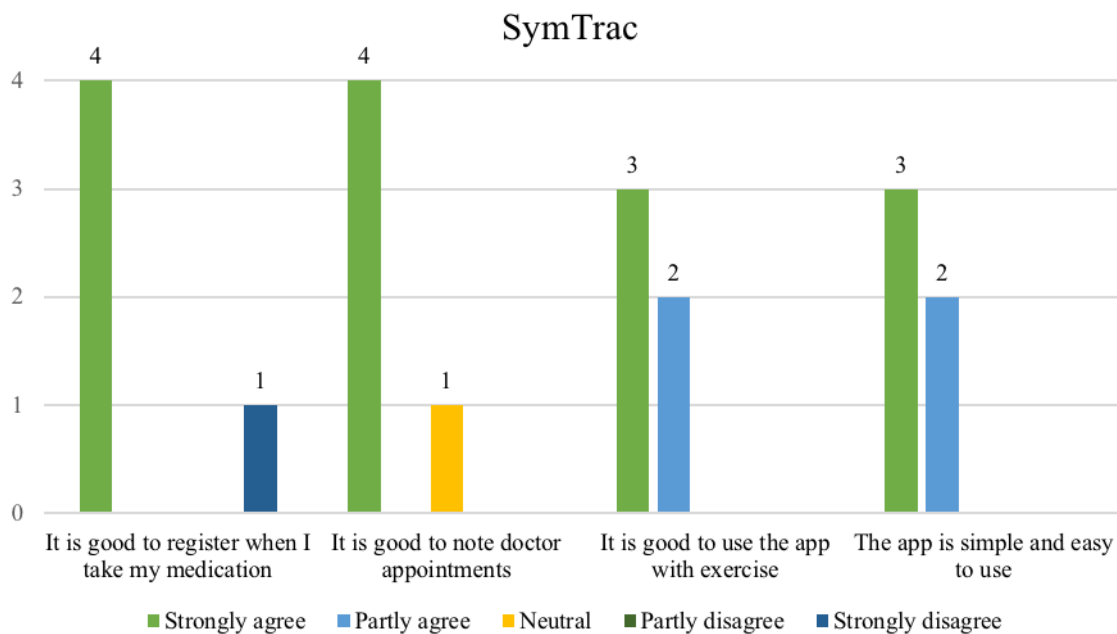


Figure 5.1: User evaluation of SymTrac.

The users have found the SymTrac (Figure 5.1) application features such as registration of medication and doctor appointments as useful, while they were less enthusiastic but positive about using it with exercise. Practically all found it simple and easy to use.

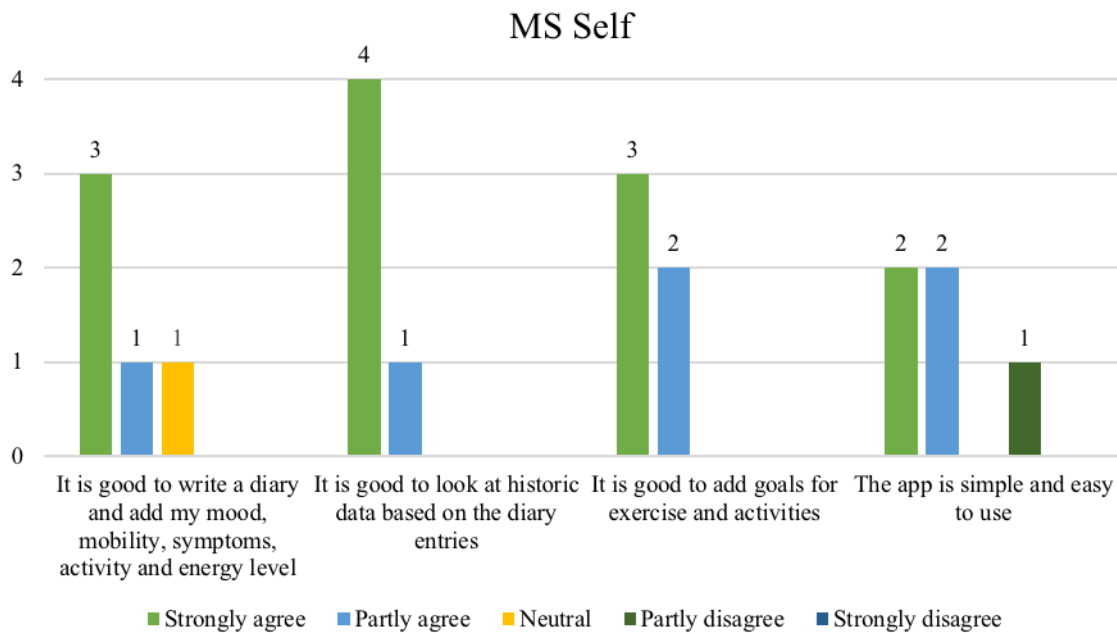


Figure 5.2: User evaluation of MS Self.

The users have appreciated MS Self (Figure 5.2) for keeping a diary by allowing the registration of mood, mobility, symptoms and activity levels. The same goes for the summarising of data based on the diary entries. They were also open-minded about defining goals for exercise and activities. They seemed to find the design relatively simple, but not optimal.

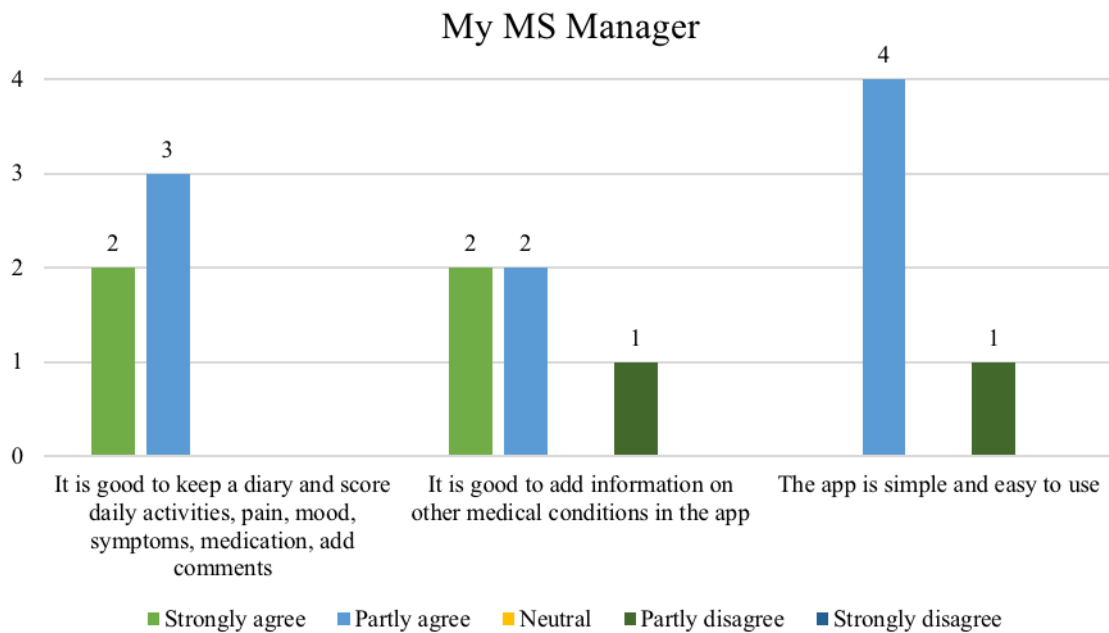


Figure 5.3: User evaluation of My MS Manager.

The users were somewhat more reserved with diary module of My MS Manager (Figure 5.3) that allowed features like activity, mood, symptoms registration, as well as medications and comments. They also realised that they could specify additional health concerns, but only two of them would consider using it. Lastly, the design was only partially judged as simple and straightforward.



# Chapter 6

## The application *msHelse*

This chapter provides overview of main functionalities in the application. The application contains four modules; *Diary module*, *Summary statistics module*, *Stress management module* and *to-do list*. This design has evolved through four design iterations. Details of development will be presented in the next chapter *Prototype development*.

### 6.1 Diary module

The *diary module* has a main task to register data about the user in three steps. The module inquires about current mood, symptoms and daily activities. The first step concerns mood and the user can choose among three answers; *good*, *average* and *lousy*. Each answer is represented in text and emoticons. The second step requires from users to enter data about their symptoms at their convenience. There are four selected symptoms some of which can be seen as taboo symptoms (i.e. urination and erection problems). Here, users can add other symptoms by choosing from a list of motoric and non-motoric symptoms. Each symptom is represented in a card containing detailed questions to the user about the symptom. Then, the user is free to click on a card and register information. Each symptom card contains detailed questions to identify what the actual problem is rather than the general situation. For example, if a user clicks on the symptom “urination”, then the card displays the following questions: *Did you feel that you needed to use the toilet but could not urinate?* or *Did you urinate yourself and did not feel the*

*need to use the toilet?*. The answering options are yes or no. The third step prompts the user to enter data about current activities or since the last registration. To do so, the user can click on a list of personalised activities represented in buttons. The user is also asked to report any possible MS attacks during a period of cycling by pressing yes or no button.



Figure 6.1: The time-frame of the *Summary statistics module*.

## 6.2 Summary statistics module

The *summary statistics* presents graphs calculated on the data collected through the *diary module*. There are three graphical presentations available, presented in The Figure 6.1; consultation, user overview and overview of registered activities.

The *consultation* (Figure 6.1) consists of an overview of data over a period of six months with graphs containing symptoms and mood. The symptom section presents two bar graphs; a summary and detailed overview of symptoms. The summary part reveals the number of registrations for each symptom. The detailed graphs then reveal detailed information about a symptom, such as the time of day the symptom occurred and the specific problem with that symptom.

The mood graph contains a monthly overview of the data displayed as a line graph. The points are average values of monthly recorded data as mood scores, which come in range from 0 = *lousy*, 5 = *average*, and up to 10 = *good*.

The *user overview* (Figure 6.1) summarises data over a one-month period in form of two graphs: symptoms and mood. The symptom section contains two bar graphs; a summary and detailed overview. The summary part reveals the number of registrations of a symptom. The detailed part reveals detailed information about a symptom. The mood graph contains a one-month assessment of the mood which is providing the count for each possible score and details entered

by the user.

The *dialogue* (Figure 6.1) contains data registered in the diary module to store information of activities carried out in a day or since last registration. The data entries can be filtered based on the preference of the user (i.e. show data entries from last month, last three months or last six months). This way, the application allows the user to look into the number of activities carried out in a period of time and compare it with the symptom development, and the mood.

### 6.3 Stress management module

The *stress management module* is implemented as a relieve from current stress and can be visited in any situation when the user feels for calming down from either stress or activity. A breathing exercise contains an image of a sunflower combined with sequenced instructions to help breathing. The user is instructed to breathe in when the sunflower increases and breathe out when the sunflower decreases. This exercise can be presented in several other ways such as low-pulse exercise or suggestion for a short walk to focus on the current moment.

### 6.4 To-do list

The *to-do list* is a help for economising the energy. The user can define reminders, priorities, daily or weekly goals. The prioritisation helps avoiding the feeling of being overwhelmed and suggests a hierarchy of tasks. By managing to accomplish most important tasks helps feeling less stressed if tasks of lower priority are left out for next time. Prioritising also leaves time to do something the user is looking forward to do. Moreover, the list could also have an upper limit of number of tasks that helps the user to understand ones' own limits and learn how to best live with MS. The upper limit of tasks can be decided by the user or in a patient – physician consultation.

## 6.5 *msHelse* as a self-management system

The application is a self-management system for persons with MS. The aim is to help user to monitor the disease development, learn personal limits and how to live MS and use application as a tool during patient – physician consultation.

The application is also a source of information which is both personal and about MS. The idea is to tailor and complement information to what can be found in online resources. For example, reading more about the disease types from the Norwegian neurological website, receiving news from the Norwegian MS association and research through *MS-Veileder* from the Norwegian MS competence centre at the Haukeland University Hospital.

The application notifies and reminds the users in order to bring a greater awareness of symptoms and possibilities to predict MS attacks. It is important for users to be aware of reoccurring symptoms, to interpret them and learn what causes them and adjust activities and lifestyle to prevent attacks. The application notifies users (i.e. every third day or once a week) to fill in the data into the diary, in order to gather valuable information that nobody else can assemble and appreciate as users themselves. The consultation between the patient and the physician benefits also from the collected data.

# Chapter 7

## Prototype development

This chapter describes prototype development through different phases, from low- to high-fidelity prototypes. It presents development tools, implementation, and involvement of users.

### 7.1 Development tools

#### 7.1.1 NativeScript

NativeScript is an open source framework to build cross-platform native iOS and Android applications [33]. The framework can be used to write applications in JavaScript, XML and CSS. This framework was chosen since it could develop solutions for both iOS and Android systems with the same source code.

#### 7.1.2 SourceTree

To control the development a source control tool called SourceTree was used. The software is a graphical source control often used in software teams to control the source code of a software [34]. The work was structured around the source code with a documented development and showing the timeline and the developers' comments. The advantage of source control is that

the software helps control the workflow and documentation while developing. For example, if there is a bug in the source code and the developer cannot identify or fix the bug, then the developer can use the timeline to retrieve an earlier version of the source code.

### 7.1.3 Trello

Tasks in this research project concerning prototype development used Trello to manage and prioritise tasks [35]. The tasks are represented as cards belonging to a list, and the list belongs to a board. Three lists are kept throughout the development; *to-do*, *doing* and *finished*. Trello is useful for structuring workflow, formalising requirements and makes the work process transparent.

### 7.1.4 SQLite database

SQL is a query language for relational database systems [36]. The database used in the mobile application is SQLite database that stores data locally on the mobile device. For the research project, the plug-in solution provided the SQLite database through the NativeScript environment. The database could be upgraded to be in other databases regarding the health care systems. The database was initially populated with random values to generate graphs in the *Summary statistics module* of the prototype, but in real use data will be collected through the *Diary module*.

### 7.1.5 Adobe XD

Adobe XD is a software for design and prototyping [37]. The software allows to build static layouts and display concepts for functionalities in a system. The usage of Adobe XD in the prototype process helped to make modifications to the design in the second design iteration. There are other software programs that can create design and prototypes with clickable navigation such as Balsamiq, Invision and Sketch that could be considered.

## 7.2 Development

The design iteration one contained following activities: assessing information needs of persons with MS, conducting a case study, developing a conceptual design of the prototype and first implementation of the prototype in NativeScript. The development will be presented chronologically starting with the low-fidelity prototype design.

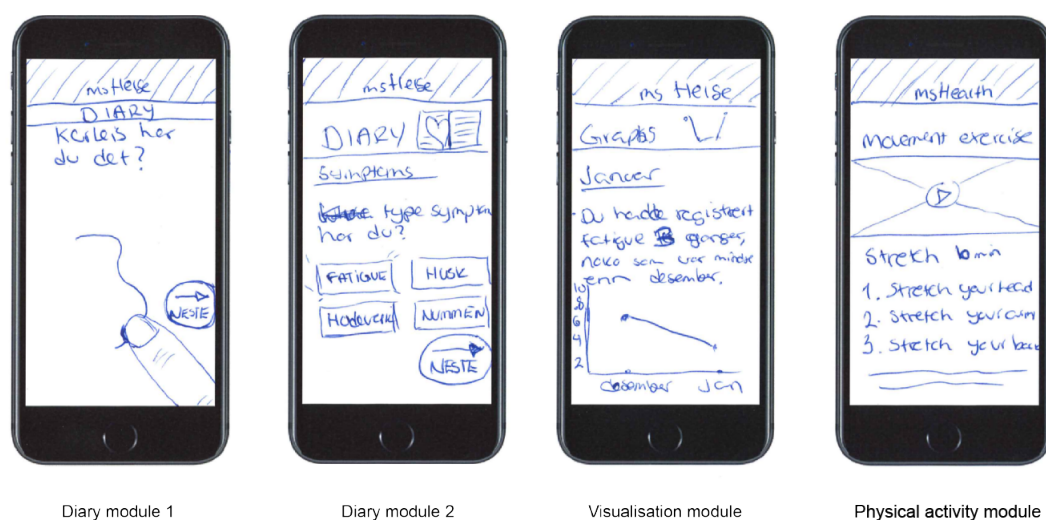


Figure 7.1: A selection of four wireframes of the low-fidelity prototype.

### 7.2.1 Developing conceptual design with pen and paper

Based on feedback from the study group, a conceptual design was developed using pen and paper, shown in The Figure 7.1. The *Diary module 1* (Figure 7.1) presents user a question, *How are you?* to assess the current mood and the user can simply swipe the screen to enter the data. The *Diary module 2* (Figure 7.1) presents the user a selection of non-motoric and motoric symptoms to register. The *Visualisation module* (Figure 7.1) presents data collected through the diary module in form of graphs. The period is displayed as well. The *Physical activity module* (Figure 7.1) guides the user to perform an exercise, for example, stretching exercises with a step-by-step guide.

## 7.2.2 Developing mixed-fidelity prototype in NativeScript

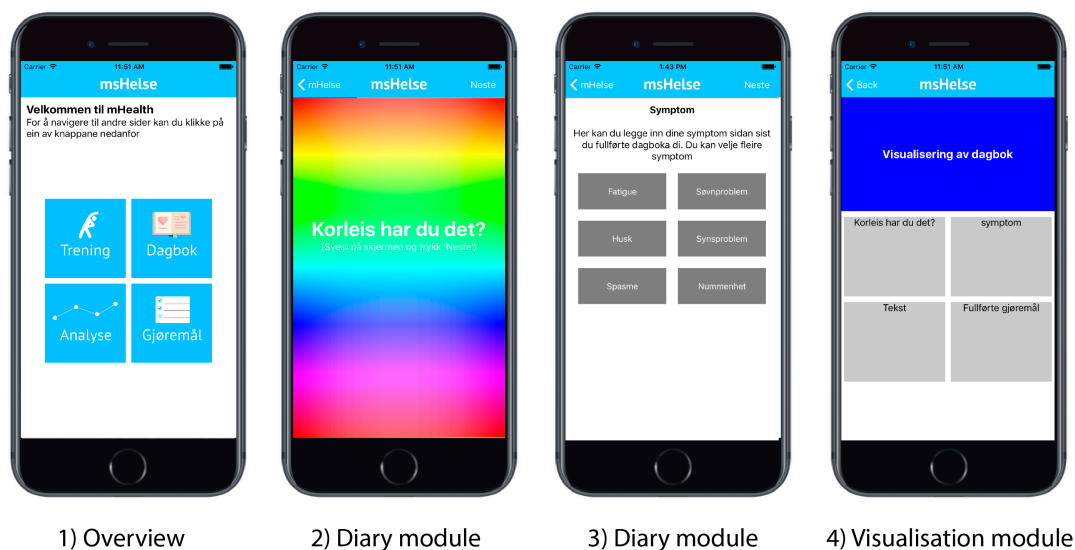


Figure 7.2: The mixed-fidelity prototype.

The Figure 7.2 shows the mixed-fidelity prototype of the application. The *Overview module* shows the main four functionalities in the prototype; *Physical activity*, *Mobile diary*, *Visualisation* and a *To-do list*.

The *Diary module 2* (Figure 7.2) presents the user a colourful screen to register data about the current mood by swiping the screen. The *Diary module 3* (Figure 7.2) presents the user a selection of symptoms. The *Visualisation module* (Figure 7.2) illustrates the fields that are not implemented, but are meant to contain the graphical representation of collected data. The level of detail is based on the information inquiry from users.

## 7.3 Design iteration two

The design iteration two has included results of semi-structured interviews with two medical experts at the Haukeland University Hospital in Bergen, Norway. They were invited to evaluate the first iteration prototype (Figure 7.2) and to give their professional feedback based on patient management and medical treatment. The feedback was implemented in a high-fidelity prototype using NativeScript.



### 7.3.1 Medical expert knowledge acquisition

Two medical experts were interviewed at the Haukeland University hospital: MS-specialist nurse Anne Britt Rundhovde Skår, M.Sc., and neurologist and consultant Lars Bø, PhD., both from the Norwegian competence centre of MS. The semi-structured interviews consisted of two parts; one with questions on which the experts could elaborate, and one with evaluation of the mixed-fidelity prototype using SUS questionnaire.

The MS-specialist nurse works mainly with newly diagnosed patients, and the neurologist and the centre leader works with clinical studies, and provides treatment information to both patients and medical staff.

The prototype (Figure 7.2) was shown on a computer simulating a mobile device on a Xcode simulator, and on a physical mobile device to give the experts a chance to navigate in the system.

### 7.3.2 Results from the medical expert knowledge acquisition

Feedback from medical staff was promising and detailed. They suggested how to modify the prototype to fully personalise it and encourage the user to plan activities and learn to live with the disease.

Both the experts reflected on exercise and stated that it could curb symptoms, but that depended on the severity of symptom and patient status. The neurologist believed that exercise was in general helpful, but during fatigue periods, it could be problematic to exercise since fatigue drains energy. The MS-specialist said that exercise could give an opportunity *to learn know the body*. For instance, if a patient is suffering from bladder dysfunction, the patient needs to know how to interpret body signals and understand when it is time to use the toilet. Furthermore, shifting focus from what to do if suffering from a symptom over to how to prevent it. If a patient has problems with sleep, then the MS-specialist would then try to map what might cause the sleeping problem. *Has the patient experienced a lot of stress, or does the person have many worries?*

When it comes to patients writing a diary with information about the disease, health personnel are generally interested in the patient's symptoms. MS-specialist nurse said that it would be interesting to know when the symptom occurred (i.e. morning or evening) provided in simple graphs. On the other side, is the focus on symptoms good? The neurologist said that data entries of symptoms must be represented in a good way to get a quick and effective overview. Additionally, does the patient use preventive medicine and should they also log this in the diary. The primary goal would be to answer the question: *How has the patient been since last consultation?*

If a patient is suffering from symptoms and how to plan their day, the MS-specialist nurse and neurologist said that it depends on what symptom the patient are having. The neurologist said that if a person has relapsing-remitting MS, he/she must be aware of an MS attack. If a person is suffering from an MS attack and live in Hordaland they must call the "attack-number". In general, MS-specialist nurse said that a person with MS should try to live as normal as possible and listen to the body when the disease is prominent.

When they were asked if they recommended applications to monitor the disease only MS-specialist nurse had recommended a patient to use SymTrac [30]. MS-specialist nurse said that she was curious on the effects of using such applications. However, she did like that SymTrac asked the user questions regarding sexual activity. The neurologist did not recommend any applications, but mentioned My MS Manager [38] as a starting point for building a new Norwegian MS application. The neurologist said that My MS Manager was created for Americans and for the American health system.

If they made a diary it should contain a diary with information about symptoms, visualisation and development of the disease since last consultation. MS-specialist nurse said that the application should support the patient, either before or during a consultation with a doctor. Furthermore, having reminders to take prescriptive medicine was important for the patient and health personnel. The neurologist said that the application should systematically go through the data before a patient-doctor consultation. He added that the application could be used to control the patients' medical journal to validate that the doctor has every detail of recent development of the disease.

In the second part of the interview, both provided feedback on the mixed-fidelity prototype (Figure 7.2). MS-specialist nurse said that the *Diary module 1* (Figure 7.2) should use three classification suggestions (*good, medium and poorly*) answering the question *How are you?*. The neurologist said that the *Diary module 2* (Figure 7.2) should also consider anxiety, depression and how this is connected MS related symptoms. Both stated that the *Diary module 3* (Figure 7.2) should provide grading of symptoms and whether the patient experienced a symptom in the morning or evening. Moreover, the neurologist said that the application should provide knowledge such as, information about the disease, insurance and help for the user.

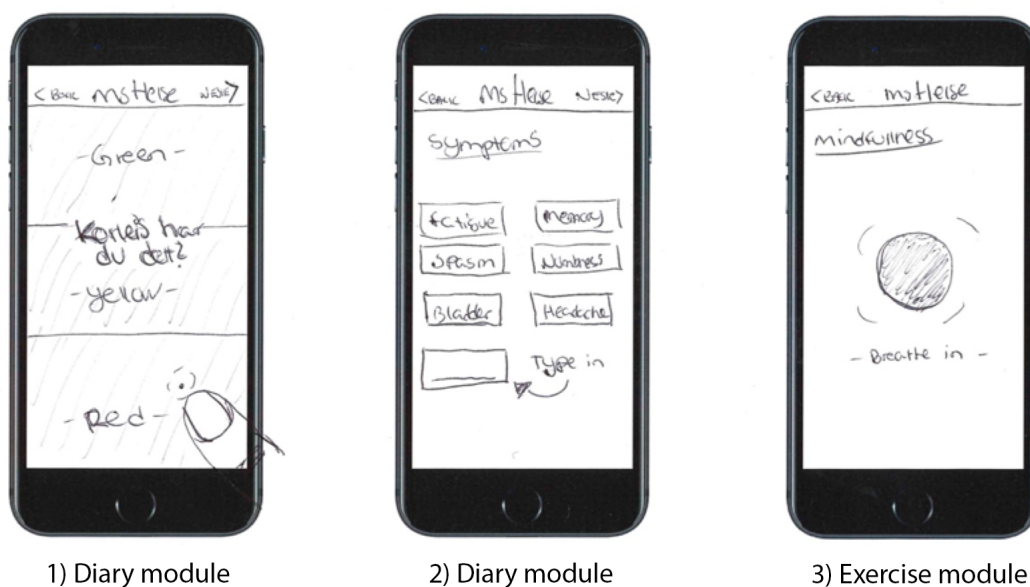


Figure 7.3: Three wireframes based on feedback from medical experts.

The Figure 7.3 represents three wireframes with design based on feedback from the medical experts. The wireframes were created during the interviews to illustrate the concepts as they were giving feedback on the mixed-fidelity prototype (Figure 7.2).

Both the medical experts were asked to evaluate the application's usability with SUS; MS-specialist nurse rated the application to have 82,5 points and the neurologist gave it 85 points.

### 7.3.3 Feedback from the medical experts

Figure 7.3 represents results from the first interview with two medical experts. The *Diary module 1* (Figure 7.3) suggests categorising the feedback from a user into three categories. The three categories are green, yellow and red. Green represents *good*, yellow represents *medium* and red representing *poorly* answering the question, *How are you?* By classifying the answers in three categories would increase the ability for users to understand and interpret the data presented in a graph. The *Diary module 2* (Figure 7.3) highlights the need for a user to select a symptom that is not listed by selecting a new symptom based on a list of other symptoms. The *Exercise module 3* (Figure 7.3) shows a dot that guides the user through a breathing exercise to lower the pulse. When the user inhales air, then the dot increases. When the user exhales air, then the dot decreases.

### 7.3.4 Discussion of the medical expert acquisition

Their feedback in design iteration two focused on changing the mind-set of the user, as well as on improvement on functionalities in the mixed-fidelity prototype (Figure 7.2). Surprisingly enough, they reported that they generally did not recommend MS specific applications to their patients. One reason could be the lack of such applications available in the Norwegian language, and that the existing ones do not fit into the Norwegian healthcare system. There is no guideline based on application data that is acting accordingly to the Norwegian care guidelines, and how to react in an event of a possible MS-attack. Hence, a national guideline regarding IT technology is needed to define and suggest actions to the user.

The neurologist said that data entries of symptoms must be represented in a good way to get a quick and effective overview, and that they should support a patient - physician consultation. Based on feedback from MS-specialist nurse, the *Diary module 1* (Figure 7.2) could classify answers into three categories. This could help users to register their mood in a quick and efficient way.

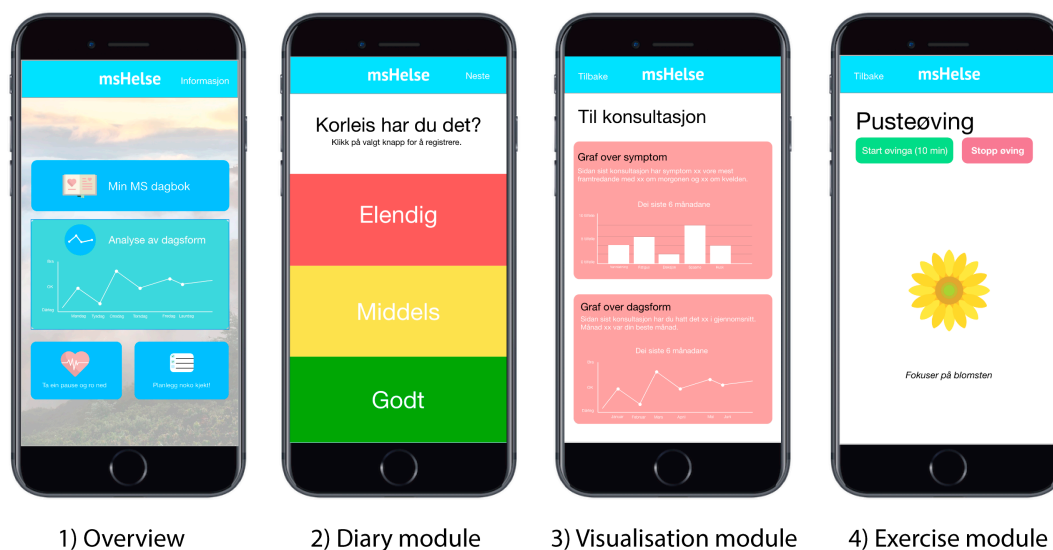


Figure 7.4: Mock-up in Adobe XD.

### 7.3.5 Adjusting new functionalities in Adobe XD

The Figure 7.4 displays an upgrade of the conceptual model using Adobe XD to quickly design a blueprint version of the prototype. The prototype was updated with colours throughout the whole design in order to make the prototype more visually appealing to the users. The *Overview module 1* (Figure 7.4) is an overview of available functionalities in the prototype with a calming background image, rather than a white background. Moreover, the *Overview module 1* aimed to enhance the user experience by making the user want to interact with the prototype and its functionalities. The *Diary module 2* (Figure 7.4) displays the three answer categories, also in three colours, as suggested by the medical experts. The *Visualisation module 3* (Figure 7.4) displays an overview of all the data within a time-frame of six months, as a consultation normally occurs every six months. The data presented is an overview of patient entered values of symptoms and the mood represented in cards using bar and line-graphs. The *Exercise module 4* (Figure 7.4) displays a sunflower that will rotate and scale during the breathing exercise. The rotation and scaling of the sunflower would guide the user with visual information to control the breathing in addition to the instructive text below the sunflower.

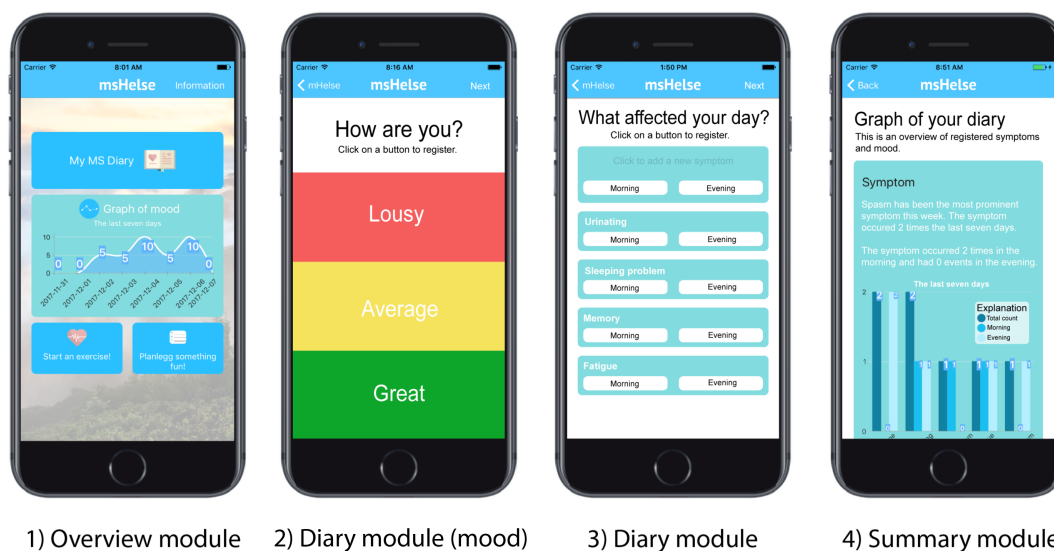


Figure 7.5: Implemented in NativeScript.

### 7.3.6 Implementing functionalities in NativeScript

The Figure 7.5 represents a selection of four screenshots of selected functionalities from the first high-fidelity prototype. New features included the fully implemented summaries of data in the *Overview module 1* and the *Summary module 4* (Figure 7.5) with graphical presentation of data. Since the SQLite database was initially empty, and could provide no data to generate graphs, the database was populated with random data to illustrate how the graphs could appear to the user. Furthermore, a short explanation was added to complement the graphs and highlight prominent symptoms and time of their occurrence.

The *Diary module 2 (mood)* (Figure 7.5) went through a design iteration from the colourful screen to the three categories that the user could chose to assess the mood in a straightforward way. Three answers with corresponding numeric values (*good* = 10, *average* = 5 and *lousy* = 0) help summarize the mood data numerically and enables a graphical presentation with line-graphs as shown in the *Overview module 1* (Figure 7.5). Still, the line-graph would benefit from displaying labels with the three answers (*good*, *average*, *lousy*) rather than using numbers only, it could help the user to quickly interpret the mood.

The *Diary module 3* (Figure 7.5) got a design update, as well. The prototype presents the user symptoms in cards as before, but it also displays more attributes such as the time of a symptom occurrence (i.e. morning or evening).

---

The *Summary module* (Figure 7.5) needed numerical values to represent the graphical information collected through the *mobile diary*. For example, when a user registers a symptom, the system registers the type of symptom together with the number of occurrences of the symptom in a period. The attributes representing the estimated time of the day the symptom occurred also handle numerical values the same way as the symptom occurrences. The data stored in the database is then stored as objects that is sent to the *Summary module* (7.5) and being graphically displayed to the user.





# Chapter 8

## Evaluation

This chapter presents two design iterations, third and fourth, emphasizing the role of user and expert evaluation as instrumental for design upgrades. The third design iteration presents the evaluation of the high-fidelity prototype conducted with persons with MS and medical experts. The fourth design iteration presents usability evaluation with ten IT experts and a demonstration of the high-fidelity prototype with eighteen IT students.

### 8.1 Design iteration three

The design iteration three consisted of the following activities: evaluation feedback from medical experts and persons with MS on the high-fidelity prototype, improvement of the prototype followed by implementing changes according to user preferences.

#### 8.1.1 Evaluating the prototype with medical experts

The second evaluation of the application with medical experts consisted of a semi structured interview with two parts. The first part was to show main functionalities of the high-fidelity prototype, presented in the Figure 8.1, which was followed by a SUS evaluation. Then, specific questions were asked on what could be improved regarding each functionality.

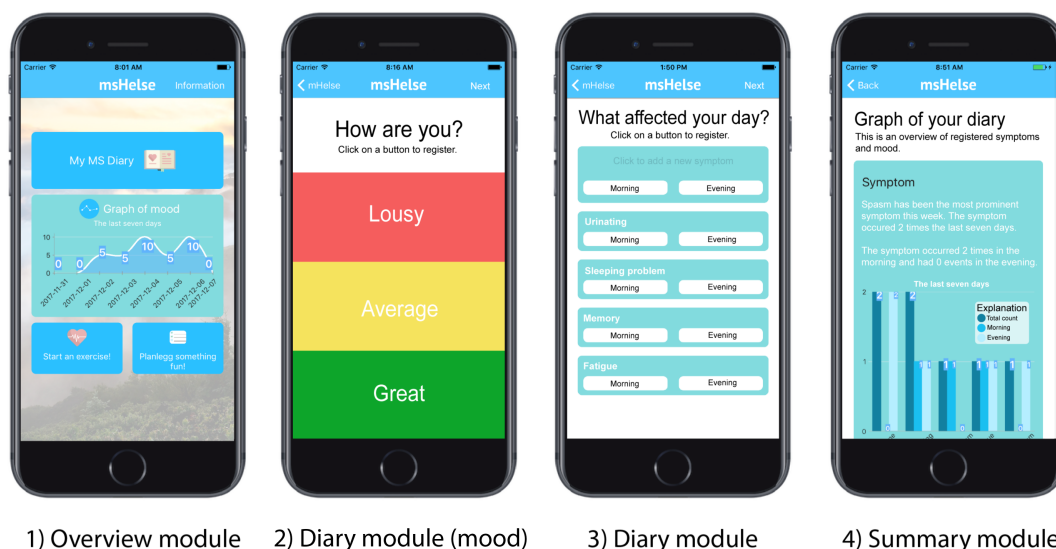


Figure 8.1: Four selected wireframes of the prototype used in the evaluation with persons with MS and medical experts.

The interview provided insights as how to adjust representation of patient entered data in the *Summary module 4* (Figure 8.1), and how a user could register data in the diary in a better way. Additionally, the feedback also focused on how the application could support in a patient - physician consultation.

### 8.1.2 Feedback from medical experts

The symptom registration in the *Diary module 1* (Figure 8.1) should prompt specific questions to the user with purpose to identify the severity of the symptom. For example, the MS-specialist nurse thought that the symptom urinating is a general symptom and does not highlight the severity of the problem. The system should ask following questions: *Did you feel that you needed to use the toilet, but when you came to the toilet you did not manage to urinate?* or *Did you urinate yourself and did not feel the need to use the toilet?*

The dialogue module in the mobile diary should rather ask *What fun activities did you do today?* or *What was positive about this day?*. This way the system could steer the focus to the positive side.

The *Summary module 4* (Figure 8.1) should be flexible enough to select and present variables

that are of interest for a patient or physician. For example, by allowing users to display a specific time-period would help select interesting data the user wants to see. Another example concerns medication, if the patient received new medicine at the last appointment, then the physician could at the next consultation look at the effect the medicine had on symptoms. The neurologist said that the symptom graph would benefit from displaying the data as a range, as he was more interested in the variation of symptoms rather than the symptoms' frequency. Furthermore, the MS-specialist nurse suggested to move additional information about the symptom to a layer below, for example, if the user tapped on one bar in the graph, it should display the symptoms' attributes (i.e. total count, occurrence at time of day and what specific problem the patient had with the symptom).

The *To-do list* should support prioritising tasks to the user and to add reminders of tasks. For example, if the user has five tasks to do one week, then the user should be able to prioritise the most important task in order to learn to plan a day if the disease is active. Additionally, the neurologist suggested separate lists with different focus, such as having one list of things the user would like to talk about with their physician at the next appointment.

The *Stress management module* should have the ability to register hikes in addition to the implemented stress-management module with the implemented breathing exercise. The MS-specialist nurse expected the breathing exercise would have a calming effect.

For this third design iteration, the SUS score from the MS-specialist nurse was 92.5 and from the neurologist it was 87.5.

### 8.1.3 Results of semi-structured interviews with the medical experts

The medical experts provided feedback mainly on the *Diary module* and the *Summary module* (Figure 8.1). The variation of symptoms was more important than displaying the frequency of each symptom. The neurologist found that displaying the variation of symptoms as more informative than displaying them in great detail. This is especially useful when a new medication is given to reduce or remove a symptom. Such insight would be of help to the user to better understand their own situation.

The presentation of symptoms as shown in the *Diary module 2* (Figure 8.1), includes the functionality to register when a symptom occurred. There is a variation of symptoms related to MS, but not all of them might be relevant for all persons. That is why the application is not listing a long list of symptoms, as the application has a functionality to enter the symptoms based on user needs and even preferences.

Overall, the medical experts suggested small changes to present information in a clinically more relevant way and they provided practical solutions to improve the functionalities. One example was to allow users to prioritise tasks in the *To-do list*, and to create additional lists with topics where with information the user would like to discuss with their physician. The other one was to have reminders of everyday tasks. Additionally, the *Exercise module* could be coordinated with a physiotherapist to recommend exercises to the user. This would help the users economise the personal energy and be rational about the priorities. The exercise should be adjusted to the current condition and determine the right level of activity, all of which is crucial for the user's well-being.

The evaluation of the system using SUS provided quick and efficient feedback on the third design iteration.

#### **8.1.4 Semi-structured interviews with persons with MS**

Four study subjects participated in the evaluation of the high-fidelity prototype (Figure 8.1). The study group was interviewed at the University of Bergen and at a café in Bergen. The first part consisted of a presentation of the third design prototype to the study group followed by questions, and the second part consisted of a SUS evaluation to capture the overall usability of the prototype.

#### **8.1.5 Feedback from the study group**

During the interview, the study subjects commented on functionalities as they were shown to them. All study subjects asked how often the mobile diary should be filled out. Two study

subjects suggested that the diary should support occasional registration, for instance when a user forgets to fill out the diary, or if the user prefers to register data when the disease is active. Moreover, the study group suggested that the diary should also send reminders to the user to register data within a reasonable timeframe (i.e. every night or every third day).

In the mood registration of the *Diary module 2* (Figure 8.1), one study subject said that the system could ask follow-up questions based on the data entries. For example, if a user clicked on *great*, then the system could ask why the reason for feeling great. Furthermore, the study subject suggested to re-arrange the order of the three buttons having *great* at the top, and *lousy* at the bottom, since the user would always want to be on top.

In the symptom registration in the *Diary module 3* (Figure 8.1), two study subjects said that they would expect to add specific time registration of when a symptom occurred. Providing the user with only two options, *morning* and *night*, was too narrow. Furthermore, one study subject suggested that each symptom could have a grading of severity or at what stage the selected symptom affected the user that day, or since last registration, using a scale from 0 to 10 (where 0 is nothing and 10 is much). One study subject believed that the four selected symptoms in the *Diary module 3* (Figure 8.1) represented *taboo* symptoms (i.e. urinating and erection problems).

In the dialogue module of the mobile diary, one study subject said that the diary should ask whether the user has experienced an MS attack. This would help keep track of the disease activity and have it presented in the *Summary module 4* (Figure 8.1). Additionally, one other study subject said that the dialogue module should rather provide buttons representing activities that the user can easily click on rather than making the user enter the activities. An example of such buttons could be, *I worked today, I visited a friend, I relaxed, I made a good dinner*. Furthermore, the study subject thought that the activities should be tailored to the individual user.

The study group provided feedback on the *Summary module 4* (Figure 8.1) to be fine-tuned to be simple and filter information. One study subject suggested that the bar representing total count of each symptom could be removed, as it was too much information at one time. One study subject said that it should be possible to flag an interesting time period of data points,

(having the data represented in term of days). Two study subjects said that it would be interesting to combine graphs with data from the dialogue module from the mobile diary with information containing MS attacks, data from the exercise module and whether the user was taking prescriptive medicine. Both the evaluators said that by combining graphs with different data (i.e. a graph containing symptom bars, line graph of MS attacks and an overview of exercise), one could possibly derive interesting information from such combined graphs.

The presentation of data of the *Summary module 4* (Figure 8.1), and over the period of one week, could also be improved. One study subject suggested that the data could be represented in a calendar, where a day in the calendar could be selected and graphs from that day would appear to the user. Furthermore, the same study subject said that the time period of one week was too narrow and the graphs would show more interesting data by expanding the time period from one week to at least one month. That way the study subject could see the bigger picture of the disease development.

The *Stress management module* was positively perceived by the study group. One study subject said that it should be possible to register a hike with for instance distance walked or time used in a hiking session. One study subject would like to receive detailed data via the phone with steps walked, stairs walked and the distance in kilometres made during one day. One study subject said that the breathing exercise should be adjusted to the individual user by measuring time to breathe in and out.

In general, the study group would like the prototype to be more proactive by providing reminders and notifications to the user. One study subject said that the prototype should remind the user to fill out the diary within a reasonable timeframe by user preference (i.e. every day or every third day). One study subject said that the *To-do list* should support reminders of tasks. The two other study subjects said that they would like to receive notifications with information about a symptom or how to best live with the disease. For example, if a user has one or more prominent symptoms, then the prototype should provide more information about the prominent symptoms and link to resources provided by medical staff online.

Furthermore, the study group said that they enjoyed the overall visual elements and design of the prototype. One study subject said the large buttons in the prototype was satisfying.

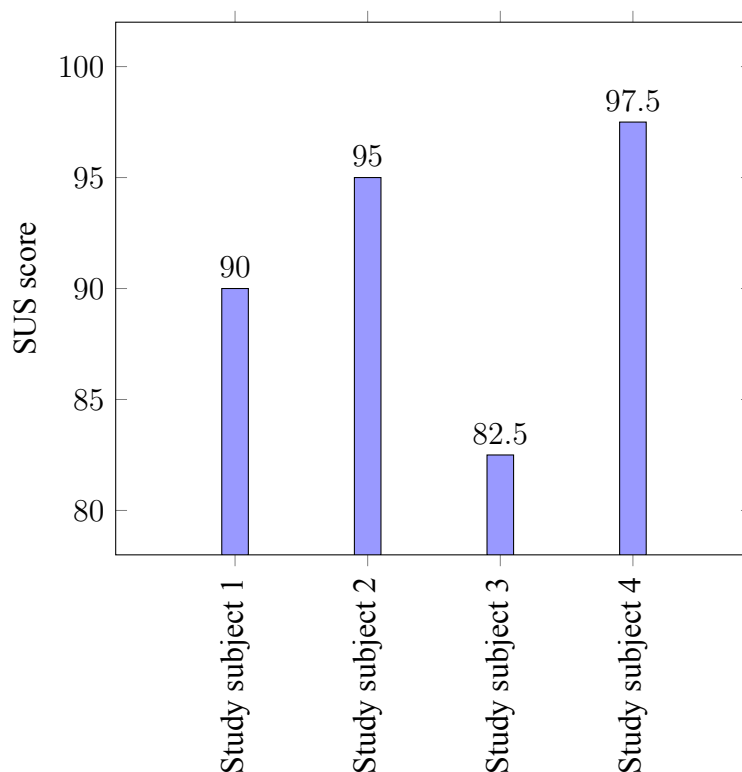


Figure 8.2: The SUS Scores from the evaluation of the prototype with four persons with MS.

### 8.1.6 Results of the evaluation with persons with MS

Feedback from the study group was positive. The *Mobile diary* and the *Summary module* received most feedback and was perceived as the two most useful components in the application (Figure 8.1).

Automation, personalisation and registration was in general highlighted throughout the study group's feedback. For example, when a user registers activities then the application should anticipate what the user is likely to do. The automation could be implemented by adding a one-time registration of information about activity, typical symptoms, and types of exercises the user favors. This registration could benefit the user by providing such personalised information and buttons to minimize effort at each registration in the *Mobile diary*. The application requires the user to register data to generate content, so ideally this would be done according to the user preference. This in turn would positively affect the quality of collected data and the quality of the graphs in the *Summary module*.

The intention of the research has been to put the use in the centre by paying attention to the user's input and feedback on the design features right from the beginning. The high SUS scores obtained in the design iteration one showed that the application was designed to the users' liking, as it can be seen in the Figure 8.2. However, the study subject 3 resulted in the lowest SUS score 82.5, and the study subject provided the most feedback with suggestions to combine the graphs in the *Summary statistics*. The average SUS score from the study group was 91, which is a high SUS score.

### 8.1.7 Feedback from persons with MS and the medical experts

Based on the feedback from the medical experts and persons with MS is illustrated in the Figure 8.3.

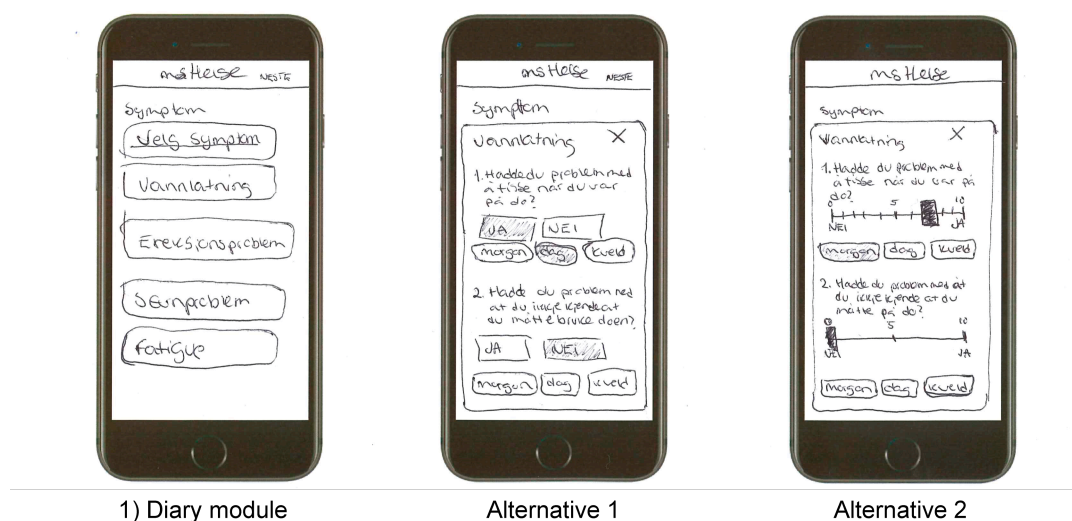


Figure 8.3: Suggested functionality of the symptom registration in the diary module.

The symptom registration process was discussed among both the groups so that symptom registration would address the specific challenges rather than the general situation. *Diary module 1* (Figure 8.3) represents the list of symptoms in form of four selected symptom cards and one card dedicated to selecting a symptom from a list. Each card representing a symptom is expandable by the touch of the card. For example, when a user clicks on the symptom card urination, then the card would expand with questions about the specific problem regarding that symptom. There were two suggestions on how to present the specific questions proposed from



the study group with MS; *Alternative 1* (Figure 8.3) provides the user questions the user can answer by clicking a button yes or no, *Alternative 2* (Figure 8.3) provides the user questions the user can answer with a scale to register the grade of severity of the symptom and buttons to register the time the symptom occurred. Eventually, the *Alternative 1* (Figure 8.3) was chosen as it could provide sufficient data requiring minimal effort to finish the registration of symptoms. However, the *Alternative 2* (Figure 8.3) would collect more detailed data from the user, but the focus was on the minimal effort demanded from the user to enter data for which the choice of using buttons would expedite the registration process.

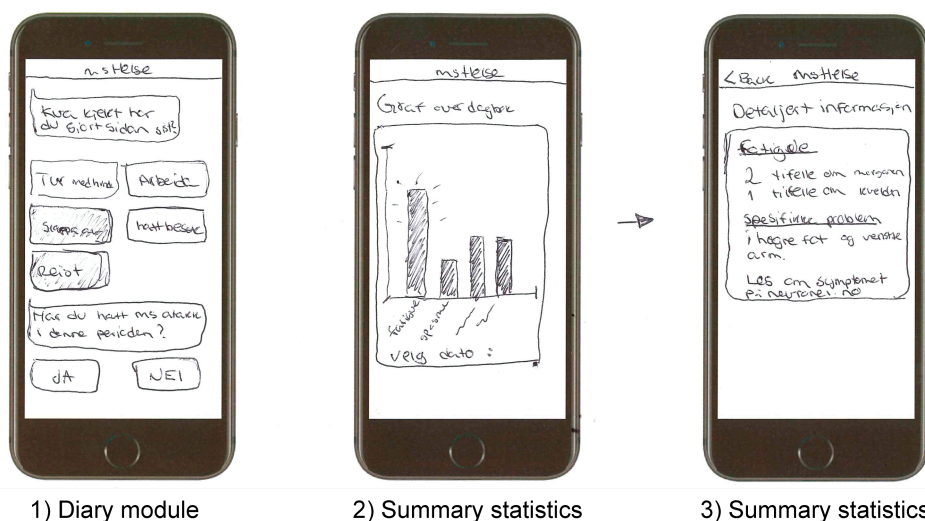


Figure 8.4: Feedback from persons with MS on automation and the *Summary statistics*

The Figure 8.4 represents additional feedback on design features from both the study groups comprised of person with MS. The *Diary module 1* shows the dialogue registration in the mobile diary. The way the user can register data about activities since last registration, or on that day, was to type in activities with a keyboard. The study group has also suggested that it should be easier to select activities when they are represented as buttons arranged to list activities the user has most likely carried out. In addition, the prototype asks the user in the dialogue a possible MS attack since last registration.

There was also feedback on how the *Summary statistics* presented the data in bar graphs. It was suggested that the bar graphs containing the symptom occurrence could be removed or moved to a layer below. For example, when a user clicks on a bar in the symptom graph, *Summary statistics 2* (Figure 8.4), then the system should reveal a detailed overview of the selected symptom to the user, as shown in the *Summary statistics 3* (Figure 8.4).

## 8.2 Design iteration four

The design iteration four included usability evaluation with ten IT experts and a demonstration to seventeen students. The goal was to identify how the usability was perceived.

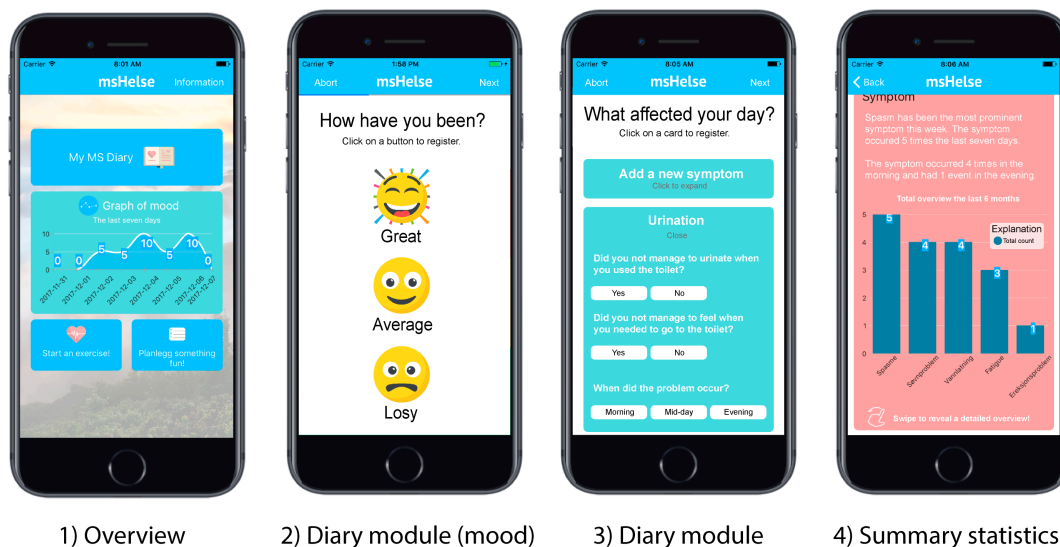


Figure 8.5: Three screenshots from the latest version of the high-fidelity prototype.

### 8.2.1 Usability evaluation with IT experts

To measure the usability of the high-fidelity prototype, a usability test with ten study subjects was conducted. The usability testing consisted of two parts: one with six tasks, and one with SUS questionnaire. The tasks were as follows: register data in the *Diary module*, locate the overview graphs and detailed graphs in the *Summary module*, add a new task in the *To-do list*, start the breathing exercise in the *Stress management module* and locate information sources about MS. There were six males and four females subjects within the age range of 22 - 30.

### 8.2.2 Usability testing results

The task that were carried out without problems were the registration of tasks in the *To-do list*, start the breathing exercise in the *Stress management module* and locate information sources about MS. Two errors occurred for all study subjects; finding the detailed overview of symptom occurrence in the *Summary statistics 3* shown in The Figure 8.5 and expanding the card of each symptom in the *Diary module 2* (Figure 8.5).

When the study group was asked to locate the detailed graph of symptoms, many found it difficult. One task that was hard to finish was to find the detailed overview of symptoms in the

*Summary statistics 3* (Figure 8.5). In order to locate the detailed graph, the users were required to swipe to the left to reveal the detailed overview. The study group said that the system should always provide feedback to the user at all times on available actions, as they did not see the instructive text at the bottom with information to locate the graph: “*Swipe to reveal the detailed overview!*”. Three study subjects suggested to move the instruction text above the graph and increase the font-size to highlight available actions.

During the task of the symptom registration into the *Diary module 2* (Figure 8.5) all study subjects found it hard to expand each card representing a symptom to enter data. Five study subjects said that the whole card representing each symptom should be clickable, and not just appear as the title.

When the study subject was asked to add a new task in the *To-do list*, one study subject suggested that the system should have a plus icon (+) to add a new task in addition to the “*add task*” button in the header. Furthermore, three study subjects said it should be possible to add a new task by pressing on the list in addition to the add task button in the header. One study subject highlighted that it could be clearer what the “*plan something fun*” represents such as in the *Overview module 1* (Figure 8.5), and it could be clearer calling the functionality for example ‘tasks’. That way the user would know what the button represents at once, as it requires information to know that the “*plan something fun*” represents a to-do list.

When the study subjects were asked to navigate to the *Stress management module* and start the breathing exercise, two study subjects said that the breathing exercise should have a start button to start the exercise. Instead of pressing the flower to start the breathing session it should be possible to press the *start* button.

In general, the study group provided feedback on navigation, grouping of functionalities in the *Overview module 1* (Figure 8.5) and examples on how to improve the system. One study subject said that the navigation back to the *Overview module 1* (Figure 8.5) should make the screen slide to the right and not to the left. This was because of the hierarchal structure in the built-in navigation in iOS systems; if a user is navigating back then the screen should slide to the right to go a level back, if a user is navigating forward then the screen should slide to the left. Furthermore, one study subject thought that the clickable buttons in the *Overview module*

*I* (Figure 8.5) should be moved closer to the thumb, as it could be easier to navigate between the functionalities. Three study subjects said that they would like a user guide explaining basic functionalities for first time users, as they did not feel entirely confident using the system. Finally, three other study subjects said that information formulated as instruction should be different from information formulated as explanatory information. They reported that by differentiating instructive information from explanatory information would benefit the overall user experience, as the instructive information would guide the user and give information on available actions.

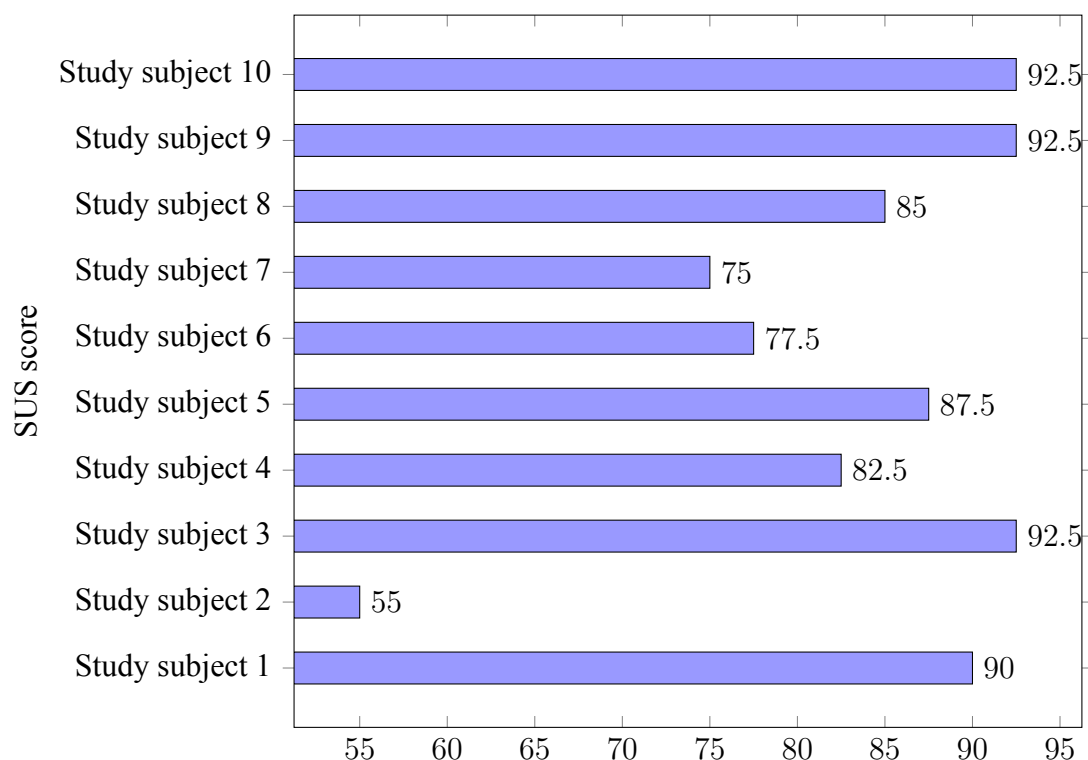


Figure 8.6: The SUS scores from the usability evaluation with ten IT experts.

The SUS scores from the IT experts presented in the Figure 8.6 was in average 83, which is acceptable score according to the SUS scale [4]. However, study subject 2 gave a SUS score of 55 which is below the acceptance rate of 67 [4]. Furthermore, the feedback from the study subject during the debriefing session was that the study subject thought that the system was hard to use and was uncertain about using the system. The study subject also said that the learning process was steep, as it was perceived that it would take a lot before one could use the system

### 8.2.3 Recording time spent on a task

The study group were asked to carry out tasks by navigating to a specific functionality or a destination within the prototype. The study group was presented following tasks: *registration of data in the mobile diary, locating the graph of overview of symptoms and mood, locating the detailed overview of symptoms, adding a new task in the To-do list, locating the web resources containing information about the disease and finally locate the breathing exercise and start the*

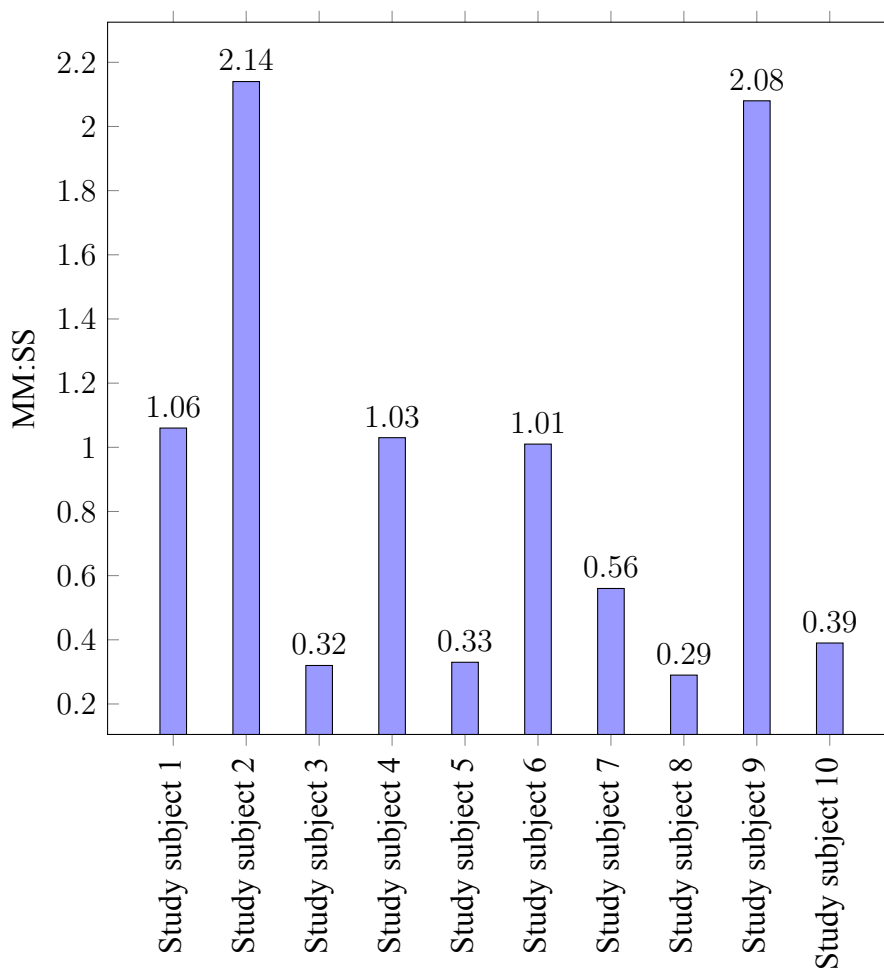


Figure 8.7: The average time spent on filling out the diary was 01:04 minutes.

*exercise*. The time was captured on how each study subject performed on each task.

Results from the tasks show that the time to fill out the diary and locating the detailed graph overview of symptoms varied within the study group. The Figure 8.7 represents the time used by each study subject to fill out the *mobile diary*, and The Figure 8.8 represents the time used by each study subject to locate the detailed graph with overview of symptoms.

The average time to finish a registration of the *mobile diary* was 1 minute and 4 seconds (Figure 8.7). However, study subject 2 used 2 minutes and 8 seconds, and study subject 9 used 2 minutes and 14 seconds to complete the registration process. The general feedback during the debriefing session with the IT experts included the symptom registration process as the cards were not entirely responsive to the touch of the user, and this could have caused the registration process of the *mobile diary* to take up to 2 minutes to complete. The two time outliers suggested that the

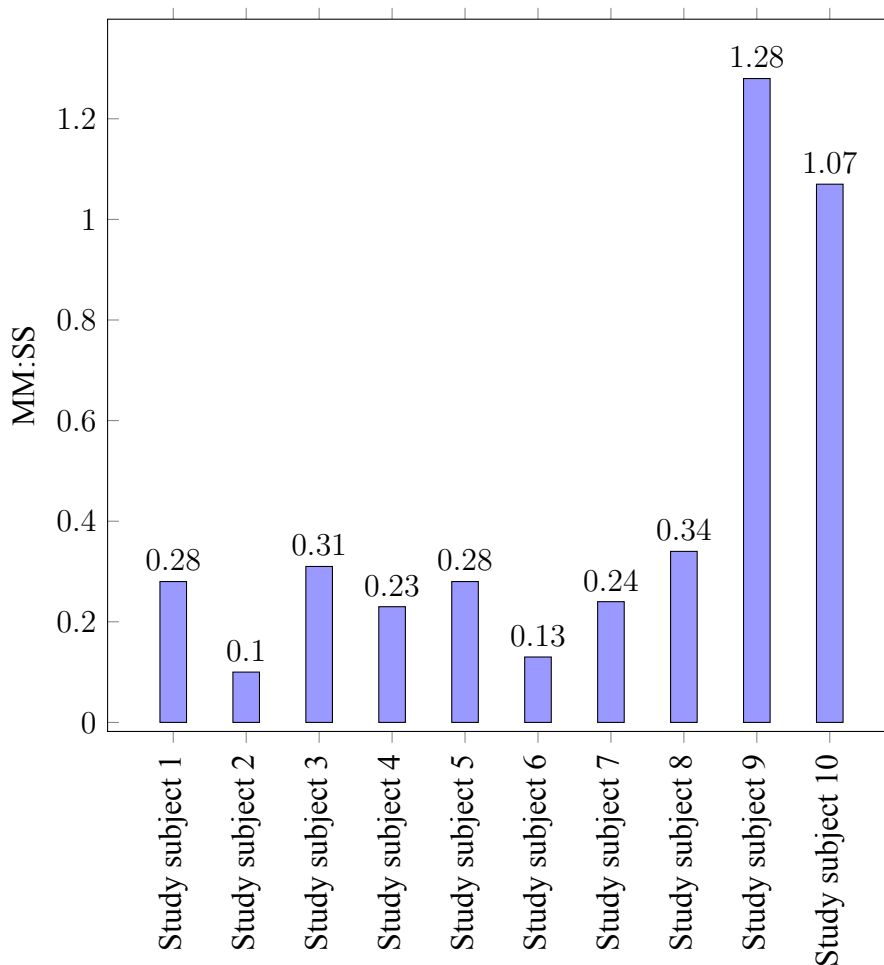


Figure 8.8: The average time spent on locating the detailed graph overview of symptoms was 00:36 seconds.

diary module must be further adjusted to support effective communication of what is needed from the user, and simplify the registration process in addition to keeping the level of detail.

When the IT experts were asked to locate the detailed graph of symptoms, the results suggest that it was not an easy task to complete due to the location of the detailed graph (Figure 8.8). However, there were two outliers in the task: study subject 9 used 1 minute and 28 seconds, and study subject 10 used 1 minute and 7 seconds. The task to locate the detailed graph was perceived as one of the cumbersome tasks to complete, as all study subject used in average 36 seconds to complete the task. One interesting note is that the study subject 9 also used longer time to complete the registration process of the mobile diary, similar to the task to locating the detailed graph. The SUS score from study subject 9 was 92,5, which showed that the study subject enjoyed the prototype.



### 8.2.4 Application demonstration with usability evaluation

A demonstration was conducted during spring 2018 with seventeen master students of Information Science studying at the University to Bergen. Fourteen students had a background in information science, two students had a background in new media and one in cognitive science. There were fourteen males and three females in the age range from 22 to 30.

The demonstration presented all functionalities of the application which was shown on a big canvas using a projector. After the demonstration, all students were asked to give feedback on the design and fill out a SUS questionnaire resulting in the scores presented in the Figure 8.9.

In general, there were suggestions on how to improve the design and specify functionalities in the prototype. Some suggested that there should be a guide for first time users, as the application needed additional information to explain functionalities (i.e. what the numeric values in the mood graph referred to). Navigating back to the main screen was also highlighted as an improvement, which was the case even with the screen slides to the left and not to the right.

Security was also mentioned among the students as necessary feature since symptoms and activities is sensitive information. Moreover, some suggested that there should be more contrast using white font colour on the blue background. One student noted that he was not good using scheduling and diary applications that required users to enter data actively.

Automation and personalisation was also mentioned, where the application could adjust suggested exercise in the *Stress management module* and provide a list of symptoms that the user has in the *diary module* when registering symptoms. Furthermore, the use of notifications should to include tips to the user from the doctor on how to manage symptoms, as well as and reminders to take prescriptive medicine.

The application design was generally appreciated by the group. Some reported that the system was easy to use and they could understand how the functionalities worked. They also thought that the combination of colours in the prototype was enjoyable.

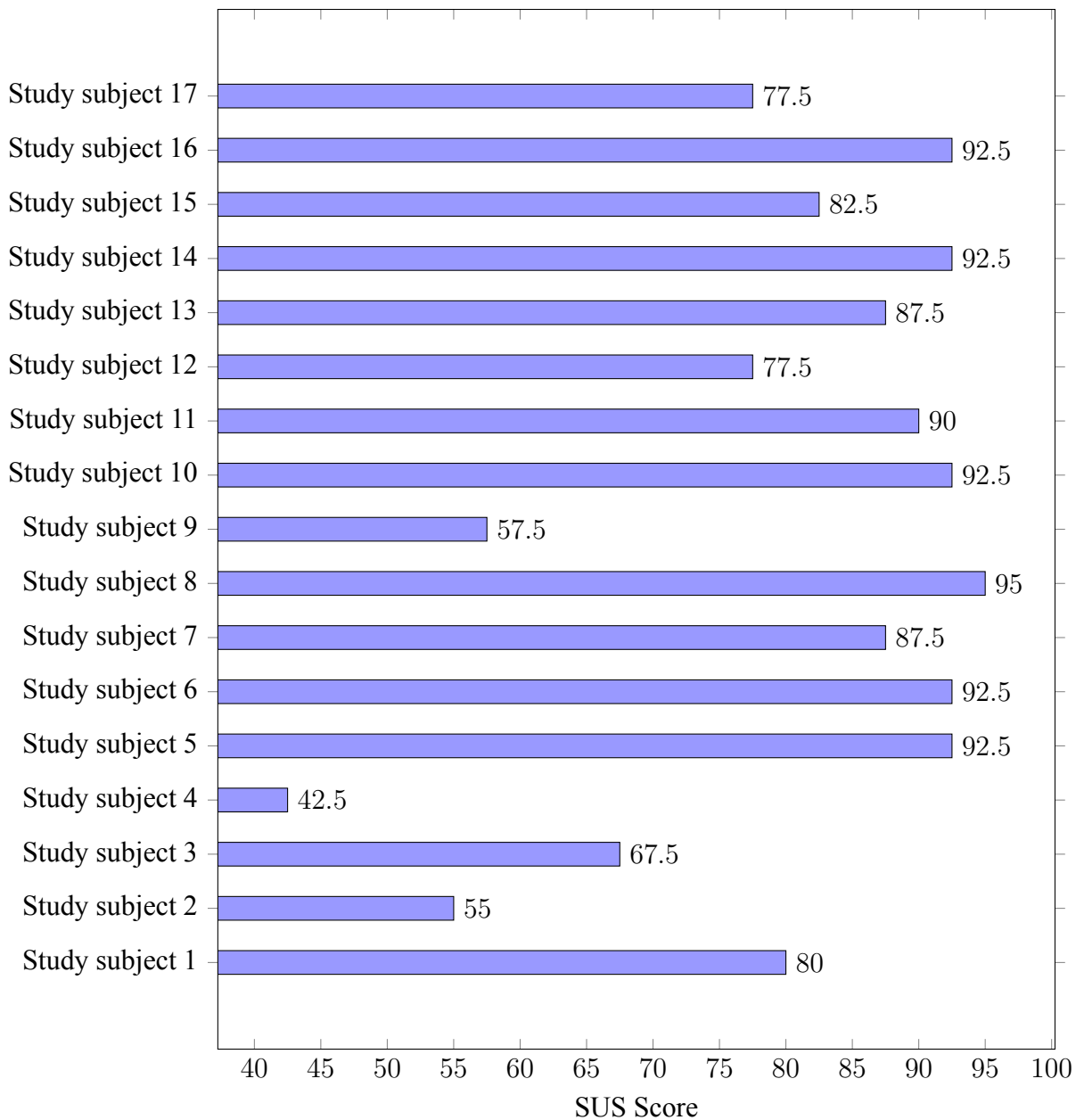


Figure 8.9: SUS Score from the demonstration with IT master students.

---

The feedback from the demonstration of the prototype to seventeen IT students provided also SUS scores that can be seen in the Figure 8.9. The average SUS score was 80 similar which is close to the overall average SUS score of 83. However, there were three study subjects with SUS scores below the SUS score of 67, that is considered as good or acceptance score [4]. Study subject 2 resulted gave the score of 55, study subject 4 of 42.5, and study subject 9 the score 57.5.



# Chapter 9

## Discussion

This chapter discusses the methods and the four design iterations through which the application was developed. It answers the research questions and reflect on Design Science as the research framework.

### 9.1 Semi-structured interviews

All interviews with persons with MS and medical experts were conducted as semi-structured interviews to allow freedom to the study group and experts to use pre-defined questions as starting points and provide input they wanted. The method has provided useful qualitative data that helped assess information needs of persons with MS which was complemented by information and suggestions from medical experts.

The responses were based on the study subjects' own experience of living with the disease. However, asking open ended questions has not help establishing relationships in data that would be possible if a structured from such questionnaires and close-ended (as pre-defined answers and to check a box) questions were used. For example, the results could have indicated that the IT habits were bound to the age of the study subject. Furthermore, since the main objective with these interviews was to assess information needs, the semi-structured interviews with open-ended questions allowed to collect various kinds of data. In fact, in the first part of research

the interviewees were asked about their coping strategies and IT habits. Conducting the semi-structured interviews was time-consuming, as it required individual interviews with each study subject at different times and locations, but it was beneficial and highly relevant for the design solutions.

## 9.2 Applying for ethical approval

Prior to the data collection, the study was approved by the Norwegian Centre for Research Data (NSD) see The Appendix B. The application included interview guide, informed consent form, and evaluation methods such as SUS or a Likert scale.

## 9.3 Recruiting study subjects

This research is not clinical, but it needs to be credible from the clinical point of view as well as it must be relevant for the users and therefore it was critical to involve in it real persons who had experience with MS. The selection of study subjects was challenging with limited resources and lack of direct access to persons who participate in the research. To identify the right channel of communication, I contacted the Norwegian MS Association both nationally and locally in Bergen, and the Norwegian competence centre of MS at Haukeland University hospital. After initial communication with one person in each organisation, the leader of the Norwegian MS Association suggested join a Facebook group called *MS Venner*, and ask the members to participate the study. In order to gain a membership in the group, I needed to be a dependent or a close friend of a person with MS. If the person with MS was a member of the group, then an application text should be submitted to the group administrator and the administrator would then ask the person with MS whether to approve the application. One more restraining factor was that all potential study subject had to be located in Bergen, or close to it, and be willing to meet at a place that felt natural for the study subject (i.e. at a café, at home or in a meeting room at UiB).

The recruiting process started with a pre-study in which user preferences regarding already

available applications were tested. The study subjects were engaged in the evaluation throughout the evaluation in design iterations and of the high-fidelity prototype which put some demands on the study subjects since the work got more challenges with more features implemented and tasks to test. Some members of the Facebook group did like the post, but few persons were willing to participate. The reason could be that the timing of the post was perhaps competing with other priorities the members had, but the attitude was positive and the initiative got many *likes*. It would have been beneficial to have even a larger study group, though, to assess information needs in the design iteration one, and secure even more robust user evaluation in the design iteration three. However, the sample size of persons with MS included in the development was nine which was certainly very satisfying and rewarding since all the participants gave their feedback on various aspects of IT development and provided their personal insights.

In 2016, I contacted the Norwegian Competence Centre, the Norwegian MS Association and the rehabilitation centre specialised to MS via e-mail to gain new contacts with medical staff. In addition, each organisation was asked whether they needed IT technology and if they felt that could improve the situation for persons living with MS. They were also asked about other challenges met, but could not manage to facilitate IT solutions in their own. All contacted responded to my e-mail; the physiotherapist working at the Competence Centre at Haukeland suggested that I would meet the group of healthcare professionals to exchange information on their work at Haukeland, and how I could contribute with my knowledge and background. The meeting gave me an opportunity to get attention of chief consultant and neurologist Dr. Lars Bø and MS specialist nurse Anne Britt Rundhovde Skår. Both were willing to participate in the two design iterations and evaluate two versions of the prototype which was most beneficial for the research and patients since they also advised on what to include in the application such as how to look on symptoms.

#### **9.4 Likert scale to measure usability by user preference**

The Likert scale is a simple and easily understandable tool that was useful to assess information needs of persons with MS that helped identify most preferable functionalities in already available applications in addition to the user feedback. For example, the majority of the study

group said that the application with English language was better than the two others, the second one in the Norwegian language and the third in the English language.

A limitation of the selection process of the three MS applications used to test user preference was that it originates in iOS Apple Store for iOS devices and not Google Play used by Android systems. The inclusion of both app stores could benefit the diversity of MS applications and might affect the outcome. However, the results seem not to be affected from having too few options to consider, the study group had plenty of different alternatives to choose from. Presenting too many applications with all their functionalities could be overwhelming and counterproductive.

## 9.5 SUS

The SUS usability scale is another well-established tool that was used in interviews with persons with MS, medical experts, as well as in the usability evaluation with IT experts and in the demonstration with IT students. The SUS scale provided quantitative data based on the perceived usability of the prototype which was helpful to put into perspective views on usability by the different evaluation groups. However, the usage of SUS with IT experts and with students was somewhat confusing as they are not intended user groups. One of the IT students wondered how to really assess the first question in the SUS questionnaire:

1. *I think that I would like to use this system frequently.*

Lewis and Sauro [39] present a way to leave the first question out of the SUS to make it easier to evaluate for the study subjects. They propose to adjust the item scores to compensate for the dropped item. This was not done with the results in this research project, but could have been considered to make it easier for non-users to evaluate a system. and provide.

Some study subjects asked what they should answer or should not answer at all. During the evaluation, the study subjects were instructed to answer in the middle if they were uncertain of the assertion following the SUS guidelines [4]. The results from the evaluation showed a



variation of the total SUS scores. The average SUS score from the study group was 83 and showed that there is still place for improvement regarding navigation that should be logical to the users. Similarly, the results from the demonstration with students showed that the average SUS score was 80.

## 9.6 Prototyping

Using low- and high-fidelity was useful to visualise functionalities. The usage of high-fidelity prototypes provided an excellent use experience since they felt like already implemented in the application that could be testing using a mobile phone. This generated useful feedback during interviews with persons with MS and medical staff since no time was wasted on explaining what could be tested in a natural way. However, the feeling of a complete device might distract users from giving more detailed and critical feedback. Functionalities might seem definite and leaving impression that there is not much else to do. To assure the dialogue during each interviews the information was given that any suggestion, adjustment and opinion was important and will be considered in the next design iteration.

On the other side, using a mixed-fidelity prototype could give an impression that the application is still a work in progress. For example, looking at such prototype, the neurologist thought that the evaluation of the prototype was incomplete before all functionalities were implemented. However, he was reassured that it was important to receive feedback on the prototype in all phases in order to continue the development towards the third design iteration.

## 9.7 Usability evaluation

The usability evaluation proved to be important because it highlighted challenges in functionalities. The evaluation consisted of seven tasks that each study subject should carry out, in order to provide feedback. This exercise was instrumental for further development. Not only that it helped identify weaknesses, it gave also an opportunity to observe the study subjects' body language and how they navigated in the system. Whenever the study subject had problems to

finish a task, they seemed to struggle, which was also a sign to offer help. The problem was then discussed as a part of the debriefing session.

There were two tasks that were highlighted as important in discussion. The registration process in the *Diary module*, and the location of the detailed graph in the *Summary module*. The average time the study group used on the registration of the *Diary module* was 1 minute and 3 seconds. Two study subjects spent more time than that, which was an indication of difficulty. The debriefing showed that they felt they needed a guide that would help them to use the application properly. A proper learning session was not conducted since it was assumed that the application was straightforward and easy to use. Knowing too much would actually make the evaluation results biased since it would be hard to un-learn the way to operate through functionalities. We assumed that it would be more natural to simulate a situation in which a user downloads an application and learns by experience how to utilize it.

The average time the study group used to locate the detailed graph in the *Summary module* was 36 seconds. However, in two cases, this time was substantially longer, 1 minute 28 seconds and the second outlier used 1 minute and 7 seconds. This has illustrated that the detailed graph was not optimal and intuitive for all to find. This was regardless of the instruction that suggested how to navigate to the graph. Perhaps the choice of colour made it hard to read the information. That came clearly from the study group was that suggested for instructions to be differentiated by font, colour or location.

Having more IT expert evaluators than persons with MS was natural for this case, although a few more study subjects with MS would be beneficial to include in the usability evaluation. There could be more older and younger men and women with different attitudes towards IT and expectations, which could return more details and critical opinions on the design. This is not easy to secure in a smaller project. On the positive side, the project has results that can inform design larger studies to be carried out in the future.

## 9.8 The self-assessment process

The *msHelse* application allows several ways for data entries into the *Diary module*. During the registration process, the user is asked how they have been since last registration. The *mobile diary* does not require the user to register data every day since it is more acceptable to use the application when users feel for it. However, this could have a negative reflection on the data if there is no registration of symptoms, the mood and activities. Consequently, the disease picture will not be complete, and there will be no sufficient data to run the *Summary statistics* on. However, during the patient – physician consultation, a lack of a registration activity could be discussed with the physician. It might be that the person felt poorly, experienced fatigue and did not use the application, or the person was very engaged in life, doing well and living as normal as possible. In such cases, notifying the users to fill out the diary is an important feature that could prevent lack of data and misleading results from the *Summary statistics*. Nevertheless, the system does not need to be annoying and notify too often. The module is designed to support registration in the situation when, for example, symptoms occur, or when the user decides to register symptoms in retrospect (i.e. for one day or one period).

## 9.9 Shared decision making

In 2017, there was a status report of implementation of patient involvement in the Norwegian health care [10]. The research showed a need for studying a long-term effects of involving patients in the decision-making process that concerned the choice of medication and treatment. The developed system is called Samvalg or DECIDE treatment as it was translated in English [10]. However, no training was given to medical staff as how to communicate and engage a patient in the decision making process [10]. That also means that DECIDE treatment has reminded a pilot study with a few reported cases. There is an ambition to use here developed *msHelse* application to contribute to the shared decision making during a patient – physician consultation. Both persons with MS and medical staff believed there was a potential to use the data from the application to make decisions regarding treatment and assessing the patient situation.

In light of the status report, the Norwegian directorate for e-health was established in 2016 with the responsibility to improve the national standard and how to better utilize IT technology in the Norwegian health care system [40]. The standardisation of the use of IT technology would contribute to the future integration of IT tools and patient data records, where the *msHelse* application would be one good example of the decision support. Thus, there is clearly a need for testing such applications with patients to show the clinical potential.

## 9.10 Generalising the prototype

The *msHelse* application developed using Design Science research framework is a specific application for persons with MS. The positive outcome of the design process was specialised application to which both users and medical staff contributed a lot. However, the application could be generalised for persons living with chronic inflammatory diseases. This would be done to tailor the domain requirements in terms of data and by adjusting functionalities. Many chronic inflammatory diseases request a patient follow-up and patient self-management which *msHelse* offers now to persons with MS.

There are two reasons for building a new MS application. Feedback from the study group with MS suggested that the existing MS application was not in the Norwegian language or they were not aware of any such applications. Furthermore, the medical experts pointed out that the existing MS applications were not compatible with the Norwegian health care system, and therefore they did not recommend existing MS applications to their patients.

## 9.11 Certification of a mobile application

There are thousands of mobile applications available, all made to strengthen the health care sector. Certification of mobile applications was discussed in an editorial letter [41], on how to make the certification of mobile applications to advance the health care using IT technology. That requires review and evaluation of existing mHealth applications before selecting a few appropriate applications. As the authors point out:

*Apps come in many forms and can be broadly characterized as designed for patients or health care practitioners. Just as it would be unrealistic to expect patients to have the medial literacy to evaluate the many of their medical devices or pharmaceuticals, it is unrealistic to ask them to evaluate all apps.* ([41], p 1156.)

The challenge with the certification of mobile applications is that there are too many applications to evaluate and it would require knowledge and standards on how to certify such applications in practise. In the development of the MS application in this research project the challenge was more practical since it had to involve persons with MS, medical experts to compensate for a lack of a proper forum that would certify the application. This was not a necessarily a weakness since all the involved participants were willing to give their time and feedback regarding the design features and clinical expertise. This can be considered as a substantial merit since there is no other application that has passed this kind of test in Norway. Long term, a solution to the challenge of certification could be solved by appointing an appropriate committee or a board within the health care facility. Furthermore, there is a need for competent personnel to handle the development, maintenance and security of the mobile applications. In big systems like Helse-Vest, there is a potential already to take this task on.

## 9.12 The Design Science Research

Throughout this research project, the Design Science research framework was used following its main principles: *design as artifact, problem relevance, design evaluation, research contribution, research rigor, design as a research process* and *communication of the research*.

The design as artifact means that the research must provide viable artifacts in the form of a construct, model, method or instantiation [2]. This research has produced a mobile application as the main artifact.

The problem relevance means that the purpose should be to develop solutions to solve important and relevant problems for organisations [2]. This was satisfied by developing an artifact capable of improving quality of life through self-management. Patients, physician and health-care systems are receivers of results from this research.

The design evaluation means that the utility, quality and efficacy of the artifact must be rigorously demonstrated via well-executed evaluation methods [2]. The evaluation methods were both qualitative and quantitative, they included both user groups, clinical professionals, and they provided scores which made the evaluation results comparable to the results published in the literature.

The research contribution means that the research conducted by the design science research method must provide clear and verifiable contributions in the specific areas of the developed artifacts and present clear grounding on the foundations of design and/or design methodologies [2]. The artifact developed in this research project has contributed to the field of medical informatics and in the field of MS. The foundations of the artifact is built on the need from persons with MS and for the medical experts working with MS. The artifact can be a basis for further research in clinical trials with persons with MS.

The research rigor means that the research should be based on an application of rigorous methods in both the construction and the evaluation of artifacts [2]. The development has gone through low, mixed and high-fidelity prototypes that was evaluated with the study groups. Furthermore, the development has involved several methods to build the artifact through four design iterations.

Design as a research process means that the search for an effective artifact requires the use of means that are available to achieve the desired purposes, while satisfying the laws governing the environment in which the problem is being studied [2]. This research project started out as an empirical observation that suggested that persons with MS could benefit from using IT technology. The research process went through several design evaluations and improvements.

Communication of the research means that the research conducted by Design Science research must be presented to both an audience that is more technology-oriented and one that is more management-oriented [2]. The research project has provided results presented in three scientific papers, all accepted for publication. The first published paper is “Assessing Information Needs for a Personal Multiple Sclerosis Application” [11], the second published paper “Multiple Sclerosis Application Design with Medical Expert Evaluation” [42], and the third published paper “User Evaluation of a Multiple Sclerosis Self-management Mobile Application” [43], see

Appendix A for all publications.

### 9.13 Research questions

The four research questions have involved how to design a self-management application for persons with MS, how to detect and alert the user about changes in the disease development, how the application can support in a patient – physician consultation, and how can the application can help users to control symptoms and extract useful information from the collected data.

*RQ1: How can a mobile application be designed to help persons with MS support to self-manage the disease?*

A total of nine persons with MS was involved in a user-centred-design to answer this question. Their expectation was formalised as user requirements that were to register symptoms, mood, managing daily activities, social activities and physical exercise [11]. That was implemented as four modules; *Mobile diary*, *Summary statistics module*, *Stress-management module* and a *To-do list*. The design research included five persons with MS, additional four persons with MS evaluated the design process and provided generous feedback [42]. Self-management functionalities are result of already practised strategies that were here implemented as the *msHelse* application.

*RQ2: How can a mobile application detect disease related changes of symptoms and alert the user for developing an MS attack?*

All user entered data can displayed in the *Summary statistics module*. Understanding patterns in data and disease dynamics would be a basis for understanding the disease development, especially through changes of symptoms. That gives a possibility to identify patterns that are characteristic of an MS attack. Unique to the mobile application is a possibility to alert about this change and make the person aware of risk of MS attack. However, the particular potential of the *msHelse* application needs to be tested in a clinical trial.

*RQ3: How can a mobile application be designed to facilitate a patient – physician consultation?*

Medical experts were included in two design iterations to acquire information on how they used IT technology in current practices. During a patient – physician consultation the doctor might ask how the patient has been since last visit, and for some patients suffering from memory difficulties it might be a hard answer to give. The collected data from the *msHelse* application would provide detailed and accurate information collected over the period of time and presented by graphs containing symptoms, mood and activities. Throughout all design iterations, the *msHelse* application was developed to facilitate a patient – physician consultation

*RQ4: How can a mobile application support persons with MS to control symptoms and extract useful information from the collected data?*

Data collected through the *mobile diary* can be used to inform the user about prominent symptoms together with detailed information on how the symptom occurs and how to treat it. That way, the user can track their disease dynamics and learn the personal limits and live as normally as possible. Furthermore, information sources such as *MS Veileder* from the Norwegian MS competence centre, and *Nevronel* from the Norwegian health informatics are examples of providing highly relevant general information about MS. However, the application *msHelse* has the ability to be particular and close to the user through its functionalities.



# Chapter 10

## Conclusions

### 10.1 Conclusions

This Design Science research framework was used to develop a self-management mobile application for persons with MS. The development has included four design iterations in a user-centred-design process including nine persons with MS, two medical experts at the Haukeland University Hospital and ten IT experts in the usability evaluation. The *msHelse* application had finally four modules; *Diary module*, *Summary statistics module*, *Stress management module* and a *To-do list*.

The first design iteration acquired information from five persons with MS using semi-structured interviews and design by user preference [26]. The results showed that IT technology was not used for self-management. The qualitative analysis of interviews resulted in a low-fidelity prototype with four main functionalities: *Mobile diary*, *Visualisation module*, *Physical activity module* and a *To-do list* [11].

The second design iteration elicited medical knowledge in semi-structured interviews with one neurologist and one MS specialist nurse. The results showed that there was a need to fully utilize the potential of IT tools in patient – physician consultations. Furthermore, the medical experts provided their feedback on the mixed-fidelity prototype and suggested adjustments of the *Mobile diary* and *Summary statistics* [42].

The third design iteration consisted of evaluation of the high-fidelity prototype including four persons with MS and the medical experts. The results showed that the persons with MS would like the *Mobile diary* to be more personalised and automated with regards to the data registration, and they suggested to combine graphs in the *Summary module* to gain new insights into the disease development [43]. The evaluation with the medical experts resulted in improving the *Mobile diary* to ask specific questions about symptoms and how to best summarise general and detailed information in the *Summary module* [42].

The fourth design iteration included usability evaluations with ten IT experts and a demonstration with seventeen master students. The evaluation results suggested to include a user guide for new users, differentiation of instructive and explanatory information presented to the user, and minor improvements with the navigation in the application.

This research project has shown that there is a need to employ the full potential of IT technology in the Norwegian patient routine care to support the patient self-management. The *msHelse* application can enable the users to understand their own patterns and disease dynamics. Furthermore, the medical experts provided their knowledge and expertise in taking part of the development of the mobile application. They believed that the *msHelse* application would be a tool to enhance the patient – physician consultation relying on patient entered data.

The collected data could be basis for further data mining and building of a personalised decision support. The decision support would aid the user in following the disease development and notifying changes or new occurrences of symptoms, all in order to prevent an MS attack. The data mining would look at the big pool of data to identify patterns in the disease that could help predict MS attacks and contribute to new knowledge.

## 10.2 Future work

The future work concerns technical implementations, integration into the Norwegian health care system and conducting a clinical trial with the *msHelse* application to assess clinical outcomes.

Particular improvements of the *msHelse* application regard implementing enhancements in the *Summary statistics module* to enable filtering of data according to dates and combining graphs such as symptoms, prescriptive medicine and exercise. Furthermore, the *Stress management module* could include sensors from mobile devices to measure steps and distance for one day. To enhance the user experience, a user guide must be implemented for new users. Lastly, there is a need to design solutions for decision support starting with the consultation.

Future steps include integration of *msHelse* with the Norwegian healthcare system to combine unique patient entered data with the rest of the patient record. And a proper clinical trial should be carried out with a greater number of study subjects to understand the clinical value.



# **Appendix A**

## **Related publications**

# Assessing Information Needs for a Personal Multiple Sclerosis Application

Aleksander Nygård TONHEIM<sup>a,1</sup> and Ankica BABIC<sup>a,b</sup>

<sup>a</sup>*Department of Information Science and Media Studies, University of Bergen, Norway*

<sup>b</sup>*Department of Biomedical Engineering, Linköping University, Sweden*

**Abstract.** This paper presents a prototype of a mobile application for patient self-management within the field of Multiple Sclerosis (MS). Five study subjects provided information needs by suggesting functionalities and evaluating three existing MS applications. Prominent functionalities were to collect data about symptoms, physical activities, mood and goals in a form of a mobile diary. Collected data would be visually presented in a graph to support self-management and motivation. A low-fidelity prototype relies in first hand on four selected modules, two *Diary modules*, one *Visualisation module* and a *Physical activity module*. A high-fidelity prototype is being implemented and will be further evaluated by the experts.

**Keywords.** Application, Multiple Sclerosis, Information needs, Low-fidelity prototype, mHealth, Digital and Connected Health

## 1. Introduction

MS is a chronic inflammation in the central nervous system, and there are three types: relapsing-remitting, secondary progressive, and primary progressive MS [1]. Patient management of the disease has greatly improved symptoms. The quality of life could additionally be improved by patient self-management, and in later years with employing IT technology.

IT technology provides several possibilities to support patients with rehabilitation, such as telerehabilitation through a web application [2]. The technology was also used to improve by helping users set rules for defining short-term activity goals [3]. Furthermore, a visualisation framework was developed to monitor health indicators to facilitate users in understanding and exploring personal health data [4].

The main motivation to make an MS application is to meet user specific needs for persons living in Norway. We will contribute with a platform to collect data about the disease based on user input via a mobile diary. The application will use the collected data to suggest how the user should plan their day based on their personal historic data. Our goal is to provide self-management through functionalities, such as reporting symptoms, physical activity, as well as their mindset and mood.

The paper focuses on assessing information needs as a part of designing a prototype of a personal MS application.

---

<sup>1</sup> Corresponding Author: Aleksander Nygård Tonheim, e-mail: [aleksander.tonheim@gmail.com](mailto:aleksander.tonheim@gmail.com)



Figure 1. Publically available MS applications: A) *SymTrac*, B) *MS Self*, C) *My MS Manager*.

## 2. Method

Five study subjects were interviewed in a natural setting to collect initial requirements for a new mobile application. The semi-structured interview consisted of two parts; one part with questions, and the second part with evaluation of the publically available MS applications (Figure 1). These are *SymTrac*, *MS Self* and *My MS Manager*, all available through the iOS app store via free download.

The study subjects was selected through a Facebook group dedicated to MS during summer of 2017, and were interviewed at the University of Bergen, Norway. The group consisted of both persons with the disease and close family members. The range of the disease onset was from short to long term experience living with MS. The age was in range of 28 and 60 years; there were two males and three females.

The disease onset and disease type differed. The group had different experiences living with the disease, disease variation and use of IT technology.

The first part of the qualitative interview aimed to collect information about the subjects' experience and habits. For example, how to plan a day if the symptoms are present, what coping strategies they had and what IT habits they had.

The second part consisted of an evaluation of three selected applications for persons with MS. We conducted a case study with a person who had 12 years experience living with the disease. The purpose was to evaluate the three applications (Figure 1) which could be used as most representative of their type, and for which a qualitative interview could be carried out. These were selected due to the diversity of functionalities. To evaluate them, a Likert Scale [5] was used for the evaluation. There was enough of functionality variation to give the sense of what these applications offer.

## 3. Results

Results from the first part of the qualitative interview gave insights into the study group's use of technology to support, monitor and log disease-related events.

Three study subjects classified their IT habits as an average user. They said that an average user is a person who uses applications on their mobile device on a daily basis. Furthermore, two study subjects classified their IT habits as relatively experienced, and as advanced due to their education and current profession.

Persons with MS experience symptoms differently, both due to the way of coping and the intensity of symptoms. The study group reported non-motoric symptoms as most challenging symptoms. The group specifically mentioned fatigue, memory difficulties, and headache. One study subject reported motoric symptoms, especially spasms as a noticeable disease effect.

To manage motoric and non-motoric symptoms the study group reported everyday activities, outdoor activities and physical exercise. Additional coping activities included baking a bread, fishing and practical work around the house that were proven remedies for symptoms. Hiking outside was also mentioned. Two study subjects reported that even simple exercise was good enough to curb symptoms. In contrast, three other study subjects found such activities as too exhausting and could not experience them as beneficial.

The study group reported the need to have an application as means of communication with the environment, such as friends, family and colleagues. Moreover, the study group pointed out that there was also a need to communicate about social activities with other persons with the disease. Such activities could be sharing experience of the disease while hiking. Finally, the study group has not relied on IT based self-management in their everyday life.

The study group was also asked to identify the uppermost functionalities to include generally in an MS application. One study subject identified a list containing five most important activities to accomplish during one day. Three study subjects reported a function to track and register symptoms in the diary, and be presented a simple graph based on data entries as the most important feature. One mentioned the importance of being aware of changes in symptoms that could lead to a possible MS attack. However, one study subject said that the focus should not be on a diary, but *getting through the day*. Furthermore, the study subject noted the importance of removing stress, not adding it. Consequently, the subject would avoid additional stress related to data input.

The second part of the qualitative interview consisted of an evaluation of three selected applications, shown in the Figure 1. Feedback from users showed that *SymTrac* was reported as the application which was the most straightforward and easiest to use. That was followed by *MS Self* and *My MS Manager*. Furthermore, all applications offered a diary module where the user could add symptoms, mood, activity and general notes. Four study subjects rated *MS Self* as having the best diary module.

Based on user feedback, an initial low-fidelity prototype was developed. Figure 2 represents a selection of four wireframes of the low-fidelity prototype.

### 3.1. Low-fidelity prototype

The initial low-fidelity prototype had four modules. *Diary module 1* and *Diary module 2* in the Figure 2 represent an effortless registration process. *Diary module 1* prompts the user with *How are you feeling?* and records user input from gestures in form of a swipe on a colourful screen. *Diary module 2* shows a selection of motoric and non-motoric symptoms. Data stored from the diary module is then visualised in the *Visualisation module* presenting a simple graph to the user. Lastly, the *Physical activity module* is based on simple instructions to suggest exercise to the user.





Figure 2. A low-fidelity prototype based on feedback from the study group.

#### 4. Discussion

The study subject reported different IT skills and experiences. The three could be seen as average users, and two of them as experienced users that utilized mobile applications daily. Surprisingly, none reported using MS applications as a part of their daily routine. The selected applications are representative of a wider group, offering different IT-support to potential users. The *SymTrac* application seemed to appeal most to the group which might be also explained by the usage of Norwegian language. Results indicated a need for an application to support their daily routines. For example, providing of registration of symptoms and presenting them in a simple graph to support the self-management. However, this was not fully utilized by the group.

One study subject raised the question *Why should I use my time to write a diary on my mobile device?*. The subject argued that the focus should be on removing stress rather than adding it by writing a diary. However, this was surprising as the same subject was aware of monitoring the condition and appearance of new symptoms, which is important to treat and prevent a possible MS attack. The rest of the group was positive towards an IT solution for the same reason, i.e. to control the symptoms and prevent attacks. Therefore, in the case of MS attack, the hospital must be alerted, which could be done using an application. Our focus is to design an efficient and uncomplicated mobile application that will support such functions and others in accordance with information needs. The modular build of the application should allow users to use and prioritise functionalities they find most useful.

Developing a mobile diary to register symptoms was perceived as useful by the majority of the study group. For other reasons, the mobile diary can also be used in interaction with medical personnel. For instance, if the doctor asks, *How have you been since last visit?*, then the patient can show the mobile diary containing symptoms, graphs, and other relevant information.

The initial low-fidelity prototype (Figure 2) has been used as a basis in the process of developing a high-fidelity prototype, which will be an interactive version allowing users to experience basic functionalities. The interactive version is helpful to identify

important issues, such as time to finish a task, user experience with functionalities as they will be running for real.

We facilitated the qualitative interviews to reduce bias by dividing the interview in two parts. This way we wanted to prevent the study subjects to use the three presented applications as reference points, but we rather gave them a chance to communicate their own needs.

## 5. Conclusions

Results from qualitative interviews led to the low-fidelity prototype of a self-management application for persons with MS. Two *Diary modules*, one *Visualisation module*, and *Physical activity module* (Figure 2) seem to address most of the information needs. A high-fidelity prototype is being developed to enable a full user experience. The future development will include implementation of the application and a comprehensive evaluation with clinical and IT experts.

## Acknowledgements

The authors would like to thank the study group for their willingness to share information and to contribute to the study.

## References

- [1] Bø L. Generelt om MS. Norsk MS veileder. [Available from: <https://helse-bergen.no/norsk-ms-veileder>] Last access: 01.17.2018.
- [2] G. Eguiluz, B. Garcia-Zapirain, Telerehabilitation Web Application for Health Care Professionals and Adults With Multiple Sclerosis, *Proceedings of the 8th International Conference on Pervasive Computing Technologies for Healthcare* (2014), 286-289.
- [3] J. Lee, et al, Helping Users Set Rules for Defining Short-Term Activity Goals, *Proceedings of CHI Conference Extended Abstracts on Human Factors in Computing Systems* (2016), 2178-2184.
- [4] J. Szeto, et al., Visualization of Health Indicators: Utilizing Data Mining Techniques and Statistical Analysis for Effective Comparison of User Profiles, *Network Modeling Analysis in Health Informatics and Bioinformatics* **3**(1) (2014), 3-63.
- [5] M.C Kaptein, et al., Powerful and Consistent Analysis of Likert-type Ratingscales, *Proceedings of the 28th international conference on Human factors in computing systems* (2010), 2391-2394.

# Multiple Sclerosis Application Design with Medical Expert Evaluation

Aleksander Nygård Tonheim<sup>1,2</sup>[0000-0003-2882-2922] and Ankica Babic<sup>1,2</sup>[0000-0002-7532-6828]

<sup>1</sup> Department of Information Science and Media Studies, University of Bergen, Norway.

<sup>2</sup> Department of Biomedical Engineering, Linköping University, Sweden. [lncs@springer.com](mailto:lncs@springer.com)

**Abstract.** This paper presents a high-fidelity prototype of a mobile application for patient self-management within the field of Multiple Sclerosis (MS). **Method.** Development included mixed and high-fidelity prototypes which were based on the information needs inquired from the potential user groups and their reflection on publicly available applications. The aim was to design an application to suit Norwegian user groups. It is evident from the results that the application has four selected modules: *Diary module*, *Physical activity module*, *Summary module*, and a *To-do list*. Two medical experts were interviewed at two different times at the Haukeland University hospital in Bergen, Norway, to evaluate two design iterations. The semi-structured interview consisted of two parts; one with questions on which the experts could elaborate, and one with evaluation of the prototype *msHealth* using System Usability Scale (SUS). **Results.** The results have suggested that healthcare personnel would be interested in patient data from a mobile diary, and how a patient should plan a day if suffering from symptoms. These are the two most prominent functionalities. **Conclusions.** Feedback from medical staff using SUS was promising. Several suggestions were given, as how to personalise the prototype to encourage the user to plan desired activities and learn how to live with the disease. All these new functionalities are being implemented to reduce stress, and include the prototype application as a decision support during a patient - physician consultation.

**Keywords:** Application design, Multiple Sclerosis, mobile diary, expert evaluation, disease management

## 1 Introduction

MS is a chronic condition and affects the central nervous system [1]. The condition needs management through monitoring of symptoms, organising daily activities, exercise, taking daily medication and when pain and when symptoms are present. The treatment is symptomatic, and all affected by it are organising their lives according to their symptoms [2]. IT technology has been employed to deliver solutions in terms of monitoring symptoms, planning activities and

general well-being. This is especially helpful during longer periods where no additional treatment is included, as it gives insight into the disease dynamics. It is important to sufferers to understand what leads them to attacks, how to prevent them and how to keep up with the healthy routines [3]. The prototype consists of four modules: *Diary module*, *Physical activity module*, *Summary module* and a *To-do list*. The main components are the *Diary module* and the *Summary module*. The user can register mood, symptoms and activities in the *Diary module*. Data registered via the *Diary module* is then represented in graphs in the *Summary module*. Data collected by users can have an important role during a patient - physician consultation as a part of the disease monitoring [4]. The prototype aims to be a tool for persons with MS to follow the disease development and provide knowledge about the disease to the users. Lastly, we will explore at how IT technology can support the disease treatment and consultations.

## 2 Method

Two medical experts at Haukeland University Hospital Bergen Norway, were interviewed following two design iterations. The medical experts were MS-specialist nurse Anne Britt Skår, and neurologist chief consultant Lars Bø at the Norwegian competence centre of MS. They were selected and visited during autumn 2017 and early winter 2018 as the representatives at Haukeland when four semi-structured interviews were conducted in natural settings at the Hospital.

The first design iteration consisted of two semi-structured interviews with two parts; one with questions on which the experts could elaborate, and one with evaluation of the mixed-fidelity prototype, as presented in The Figure 1. The evaluation of the prototype entitled *msHealth* was assessed using SUS [5], which provided quick and efficient feedback on the applications' perceived usability. However, SUS does not give feedback on specific functionalities in a system alone. The mixed-fidelity prototype was shown on a computer simulating a mobile device via a Xcode simulator, as well as on a mobile device. The experts were able to explore the prototype during the interview.

After the second design iteration, two more semi-structured interviews with two parts were conducted. The first part was to show main functionalities of the high-fidelity prototype, presented in the Figure 2 which was followed by a SUS evaluation. Then, specific questions were asked regarding each functionality.

## 3 Results

Feedback from medical staff was promising in both design iterations. The first design iteration provided feedback on how to modify the prototype (Figure 1) to personalise it by encouraging the user to plan desired activities and learn to live with the disease. The second design iteration suggested adjustments of data collected in the *Summary module* (Figure 2), and how to speed up the diary registration process. The feedback also focused on how the application could support in a patient - physician consultation.

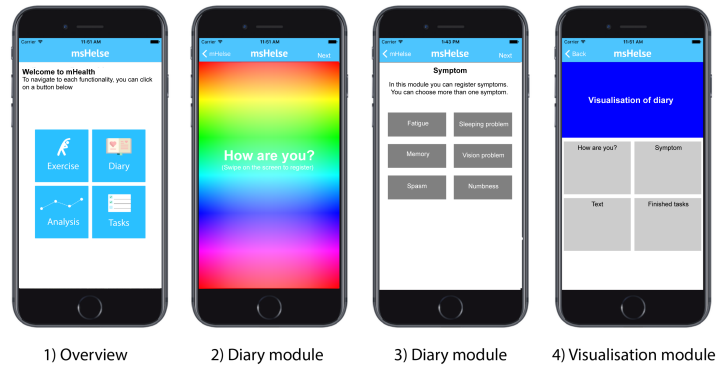


Fig. 1. Four wireframes of the mixed-fidelity prototype used in the first design iteration.

### 3.1 First design iteration

Both experts found exercise to be generally favorable, but needs to be adjusted to symptoms. However, it could be problematic to exercise when suffering from fatigue since fatigue drains energy. The MS-specialist nurse said that exercise could also be a learning process of understanding one’s own limits. Furthermore, it was important to shift the focus from managing symptoms to preventing them. Another issue is to address poor sleep, i.e. if a person sleeps poorly it is important to identify the underlying causes.

Among all the data captured by the diary, the health personnel are generally interested in the patient’s symptoms and the time they occurred (i.e. morning, mid-day, night) provided in graphs. The question has been discussed whether the focus on symptoms could be beneficial for users. The neurologist advised to register symptoms in a straightforward and effective way. He would also appreciate information on preventive medicine, medication reminders, and questions of interest prior to the consultation. That in turn helps answering the question; *how has the patient been since the last consultation?*

The experts found it important that persons are living as normally as possible, but pay attention to the symptoms. In case of relapsing-remitting MS, persons must be aware of the risk of developing a possible MS-attack.

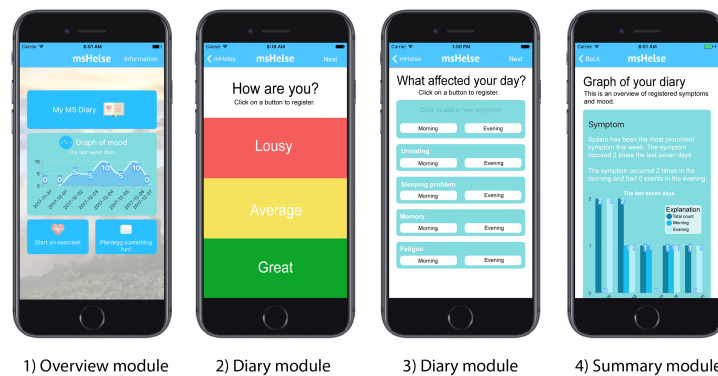
When asked if they would recommended applications to monitor the disease, only MS-specialist nurse recalled advising one patient to use SymTrac [6]. She was open minded about the effects of using such applications in managing the disease, but she had reservations about inquiring about sexual activity. In contrast, the neurologist did not recommend any applications. However, he mentioned My MS Manager [7] as a starting point for building a new Norwegian MS application.

The experts wishes were to create a mobile application containing a diary module with information about symptoms, visualisation and development of the disease since last the consultation. The MS-specialist nurse said that the

application should support the patient, either before or during a patient - physician consultation. The neurologist would expect the data to be systematically summarized prior to the consultation. He would validate such information with patients' medical journals.

In the second part of the interview, both the experts provided feedback on the prototype (Figure 1). The MS-specialist nurse said that the *Diary module 2* could use three classifications (good, medium and poorly) answering the question *how are you?* The neurologist said that the *Diary module 2* could also consider anxiety, depression and how this is affecting symptoms. Both said that the *Diary module 3* should provide grading of symptoms, i.e. if a patient is experiencing symptoms in the morning, mid-day or evening. Moreover, the neurologist suggested to provide additional information about the disease, insurance and about living with MS.

The MS-specialist nurse rated the SUS score to be 82,5 and the neurologist gave 85 in SUS score.



**Fig. 2.** A selection of four wireframes from the high-fidelity prototype.

### 3.2 Second design iteration

In the second design iteration, the medical experts provided feedback on all functionalities, specifically the *Diary module* and *Summary module* (Figure 2).

The symptom registration in the *Diary module 1* (Figure 2) should prompt specific questions to the user to identify the severity of the symptom. The MS-specialist nurse suggested that the symptom urinating is a general symptom and does not highlight what the actual problem is. The system should be specific and ask; *Did you feel that you needed to use the toilet, but when you came to the toilet you did not manage to urinate?* or *Did you urinate yourself and did not feel the need to use the toilet?* The neurologist also mentioned the need for the system asking specific questions to the user in addition to adding the specific time the

symptom occurred. The information about the symptom with specific questions and time could support the patient during a patient - physician consultation.

The *Summary module* (Figure 2) should be flexible enough to select and present variables that are of interest for a patient or physician. For example, by allowing users to display a specific time-period would help select interesting data the user wants to see. Another example concerns medication, if the patient received new medicine at the last appointment, then the physician could at the next consultation look at the effect the medicine had on symptoms. The neurologist said that the *Summary module* would benefit from displaying the data as a range of data, since he was more interested in the variation of symptoms rather than the total count of each symptom. Furthermore, the MS-specialist nurse suggested to move additional information about the symptom to a layer below, for example, if the user tapped on one bar in the graph, it should display the symptoms' attributes i.e. total count, occurrence at time of day and what specific problem the patient had with the symptom.

The *To-do list* should support prioritising tasks for the user and to add reminders. For example, if the user has five tasks to do one week, then the user should be able to prioritise the most important task in order to learn to plan a day if the disease is active. Additionally, the neurologist suggested separate topics lists with different focus, such as having one list of topics the user would like to talk about with their physician at the next appointment.

The *Exercise module* should have the ability to register hikes in addition to the implemented stress-management module with the breathing exercise. The MS-specialist nurse expected the breathing exercise would have a calming effect.

For this design iteration, the MS-specialist nurse SUS score was 92,5 and the neurologist SUS score was 87,5.

## 4 Discussion

Both the experts were selected as the representatives of the medical specialists as highly relevant for this study. They provided consistent comments and suggestions in both design iterations to secure a detailed and relevant feedback.

Their feedback in design iteration one focused on changing the mind-set of the user, as well as on improvement on functionalities in the mixed-fidelity prototype (Figure 1). Surprisingly enough, they reported that they generally did not recommend MS specific applications to their patients. One reason could be the lack of such applications available in the Norwegian language, and that the existing ones do not fit into the Norwegian healthcare system. There is no guideline based on application data that is acting accordingly to the Norwegian care guidelines, and how to react in an event of a possible MS-attack. Hence, a national guideline regarding IT technology is needed to define and suggest actions to the user.

The first mixed-fidelity version of the prototype did not include graphs representing data stored through the *Diary module* (Figure 1). The neurologist said that data entries of symptoms must be represented in a good way to get a

quick and effective overview, and that they should support a patient - physician consultation. Based on feedback from MS-specialist nurse, the *Diary module 1* (Figure 1) could classify answers into three categories. This could help users to register their mood in a quick and efficient way.

In the design iteration two, the medical experts provided feedback mainly on the *Diary module* and the *Summary module* (Figure 2). One suggested improvement concerned prompting a specific question regarding general symptoms, which could lead to describing the specific problem, rather than the general situation. By adding more specific attributes would provide another layer of information that will document the development of the disease. Graphically, this would be implemented in the *Summary module* (Figure 2) in which a bar could be double-clicked to reveal detailed information. Such insight would be of help to the user to better understand their own situation.

The variation of symptoms was more important than displaying the count of each symptom. The neurologist found that displaying the variation of symptoms as more informative than displaying them in great detail. This is especially useful when a new medication is given to reduce or remove a symptom.

The presentation of symptoms, shown in the *Diary module 2* (Figure 2) includes the functionality to register when a symptom occurred. There is a variation of symptoms related to MS, but not all of them might be relevant for all persons. That is why the application is not listing a long list of symptoms, so we included a functionality to enter the symptoms based on user preferences.

Overall, the medical experts suggested small changes to present information in a better way and provided solutions to make the implemented functionalities even better. One example was to allow users to prioritise tasks in the *To-do list*, and to create additional lists with topics where one could contain information the user would like to discuss with their physician. The other one was to have reminders of everyday tasks. Additionally, the *Exercise module* could be coordinated with a physiotherapist to recommend exercises to the user. This would help the users to economise the personal energy and be rational about the priorities. The exercise should not be too demanding on the body, and the right level of activity is crucial to determine the well-being of the users.

The evaluation of the system using SUS provided quick and efficient feedback on how the applications' usability was perceived. We also used a semi-structured interview to collect feedback on specific functionalities. The high SUS scores achieved in these evaluations reflect a satisfaction that the medical experts felt towards the designed outlines, which is encouraging. User input was assessed in a separate study [8]. However, the potential users would have the possibility to add their own preferences. This way, both groups could influence the design of the prototype.

## 5 Conclusions

All these new functionalities are being implemented to reduce stress and include the prototype application as a decision support during a patient - physician



consultation. This is something that is not currently being practiced in Norway, so the future research will attempt to address the potential of the application in the patient routine care. The development will continue through one more design evaluation, taking into account the feedback from this study. Finally, intended users will have one more opportunity to evaluate the application prototype.

## 6 Acknowledgements

The authors are thankful for neurologist Lars Bø, MD, Ph.D., and MS specialist nurse Anne Britt Rundhovde Skår, M.Sc., for sharing their expertise.

## 7 Compliance with Ethical Standards

The authors declare that they have no conflict of interest. The study has been approved by the Norwegian data protection official (NSD). All participants signed an informed consent form.

## References

1. Ljøstad, U., Mygland, Å., (2016). Diagnostikk av MS og Behandling av MS. Retrieved January 17, 2018, <http://nevro.legehandboka.no/handboken/sykdommer/demyeliniserende-sykdommer/>
2. Trumbic, B. et al., (2017). Is the Choosing Wisely ® campaign model applicable to the management of multiple sclerosis in France? Retrieved January 30, 2018, <http://www.ncbi.nlm.nih.gov/pubmed/29128151>
3. Tacchino, A. et al., (2015). A New App for At-Home Cognitive Training: Description and Pilot Testing on Patients with Multiple Sclerosis. JMIR mHealth and uHealth. Retrieved May 28, 2017, <http://www.ncbi.nlm.nih.gov/pubmed/26323749>
4. Engelhard, M.M. et al., (2017). Remotely engaged: Lessons from remote monitoring in multiple sclerosis. International Journal of Medical Informatics. Retrieved January 31, 2018, <http://www.ncbi.nlm.nih.gov/pubmed/28241935>
5. Brooke, J. (2013). SUS: A Retrospective, 8(2), 29-40. Retrieved December 2, 2017, <http://www.usabilityprofessionals.org>
6. Novartis UK, (2015). SymTrac MS. Retrieved January 30, 2018, <http://www.symtrac.com/ms/>
7. Multiple Sclerosis Association of America, (2017). Retrieved January 30, 2018, <http://mynsaa.org/msaa-community/mobile/>
8. Tonheim, A., Babic, A., (2018). Assessing Information Needs for a Personal Multiple Sclerosis Application. MIE, Medical Informatics Europe. Gothenburg, Sweden. 24-26 April 2018 Accepted for publication.

# User Evaluation of a Multiple Sclerosis Self-management Mobile Application

Aleksander Nygård TONHEIM<sup>a,b,1</sup> and Ankica BABIC<sup>a,b</sup>

<sup>a</sup>*Department of Information Science and Media Studies, University of Bergen, Norway*

<sup>b</sup>*Department of Biomedical Engineering, Linköping University, Sweden*

**Abstract.** This paper presents user evaluation of a high-fidelity prototype of a mobile application for patient self-management within the field of Multiple Sclerosis (MS). The application named *msHelse* consists of four modules: *Diary module*, *Summary module*, *Stress management module*, and a *Todo-list*. Four study subjects were interviewed in semi-structured interviews with questions regarding the functionalities and the user experience after using the application, as well as using System Usability Scale (SUS). User feedback resulted in functionality adjustments of the high-fidelity prototype, especially in data representation of the *Summary module* and the way the *Diary module* would assess user entered data. Thus, the *msHelse* application has been refined to tune into the needs of Norwegian users.

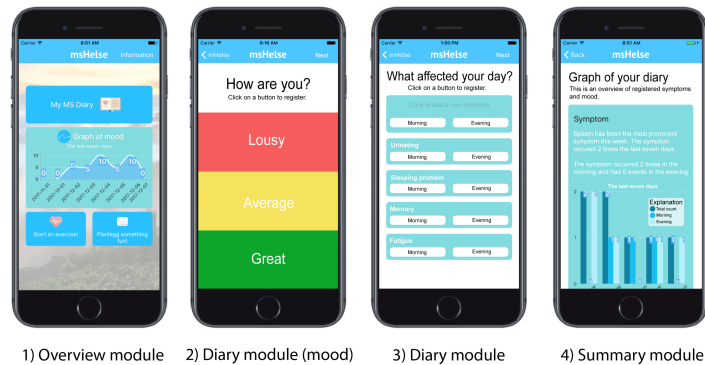
**Keywords.** Evaluation, Application, Multiple Sclerosis, Self-management

## 1. Introduction

Multiple Sclerosis (MS) is a chronic inflammatory disease of the central nervous system [1], and affects the body differently varying from person to person. The use of Information technology (IT) and mobile applications for self-management could support the users to economize their energy by planning and organize tasks in their everyday life [2]. However, there are reservations to use such tools in Norway. We found out that the medical experts at the Norwegian Competence Centre for MS at Haukeland University Hospital did not recommend MS applications to their patients due to the lack of the compatibility with the Norwegian healthcare system with national treatment plans [4]. Furthermore, a method for certification of mHealth applications in health care is needed [3]. To meet specific needs of Norwegian users, we have developed an application prototype entitled *msHelse* that consists of four modules: a *Mobile diary*, *Summary statistics module*, *Stress management module* and a *Todo-list*. Data gathered through the *Mobile diary* is represented in bar and line graphs in the *Summary statistics module*. This paper focuses on user evaluation of a high-fidelity prototype presented in The Figure 1. The development was based on assessment of information needs [5] and took several design iterations that resulted in the prototype of a personal MS application to support the user's self-management.

---

<sup>1</sup>Corresponding Author: Aleksander Nygård Tonheim; E-mail: aleksander.tonheim@gmail.com.



**Figure 1.** A selection of four wireframes from the high-fidelity prototype.

## 2. Methods

Four study subjects participated in the evaluation of the high-fidelity prototype (Figure 1). The study group was recruited through a Facebook group called *MS-venner* comprised of persons with MS or those who are dependents. The study subjects were interviewed individually at the University of Bergen and at a coffee shop in Bergen, Norway. There were three females and one male subject with age range of 27 to 50. The first part consisted of a presentation of the prototype where the users could navigate on their own (Figure 1) after which followed a SUS evaluation to capture the overall usability of the prototype. SUS was chosen as a standardized usability scale, which is simple, uses a ten-item scale to capture a subjective assessment of usability [6]. The second part consisted of a semi-structured interview with questions regarding the improvements of the prototype. Further, the study subjects were asked how they would use such application to self-manage the disease in their everyday lives. The responses was recorded using low-fidelity prototypes, see The Figure 2 for details, and using field-notes during the interviews. The content analysis was applied on the interview material using open-coding.

## 3. Results

The study subjects commented on functionalities as they were shown. Two study subjects suggested that the diary should support occasional registration if a user forget to fill out the diary, or if the user prefers to register data when the disease is active. The study group reported that the diary should provide notifications by reminding the user to fill out the diary within a reasonable timeframe (i.e. every night or every third day).

In the symptom registration in the *Diary module 3* (Figure 1), two study subjects said that they would expect specific time registration of when a symptom occurred, as the two available options were too narrow. Furthermore, one study subject suggested that each symptom could have a grading of severity or at what stage a symptom affected the user that day on a scale from 0 to 10 (where 0 is normal and 10 is severe).

In the dialogue module in the *Mobile diary*, one study subject said that the diary should ask if the user has experienced an MS attack to keep track of the disease activity and have it presented in the *Summary module 4* (Figure 1). Additionally, one other study subject said that the dialogue module should provide buttons representing activities that

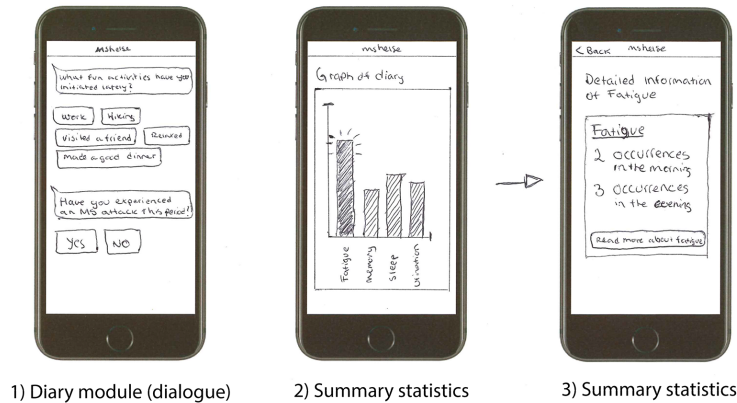
the user can easily click on rather than requiring the user type in activities. An example of such buttons could be: *Worked*, *Visited a friend*, *Relaxed* or *Made a good dinner*. Furthermore, the study subject said that the activities should be personalized.

The study group recommended that the *Summary module 4* (Figure 1) should be simplified, support filtering of data and expand the time period of data. One study subject suggested that the bar representing total count of a symptom occurrences could be removed, as it was too much information at one time. One study subject believed that it should be possible to flag an interesting time period of data points. Two study subjects thought that it would be interesting to combine graphs with data from the dialogue module in the *Mobile diary* containing MS attacks, data from the *Stress management module* and if a user is using prescriptive medicine. Both the subjects assumed that by combining graphs with different data the user could derive interesting information from such combined graphs. Moreover, one study subject suggested that the data could be represented in a calendar where one day would represent graphs that would appear automatically to the user. Furthermore, the study subject found that the time period of one week could be too narrow and the graphs would benefit by expanding the time period from one week to at least one month in order to see the bigger picture of the disease development.

The *Stress management module* was perceived positively by the study group. One study subject said that it should be possible to register a hike with, for instance, the distance walked or time used in a hiking session. One study subject would like to receive data via the phone's built in sensors (i.e. steps, stairs, and distance). One study subject would expect to adjust the time used to breathe in and out in the breathing exercise. In general, the study group would like the prototype to be more proactive by providing reminders and notifications to the user. One study subject said that the application should remind the user to fill out the diary within a reasonable time-frame according to the user preference. One study subject said that the *To-do list* should support reminders of tasks. The two other study subjects said that they would like to receive notifications with information about a symptom, and how to treat it, or information about the disease. For example, if a user has one or more prominent symptoms, then the prototype should provide more information about those prominent symptoms and link the user to information sources about MS provided by health officials. Finally, the study group claimed that they enjoyed the overall visual elements and design of the prototype. The SUS scores were as follows: subject one: 90, subject two: 95, subject three: 82,5 and subject 97,5.

#### **4. Discussion**

Feedback from the study group was positive. The *Mobile diary* and the *Summary module* received most detailed feedback and were perceived as the two most useful components in the application. Consequently, the high-fidelity prototype was updated to a new version. Automation, personalization and registration was in general highlighted through the study groups' feedback (Figure 2). For example, when a user should register activities, the application should then know what activities the user is likely to do. The automation could be implemented by adding a one-time registration of information about activity, types of typical symptoms, and types of exercises the user favors. This registration could benefit the user by providing such personalized information and buttons to support the minimal effort the user has to put in through each registration in the *Mobile diary*. The



**Figure 2.** Three low-fidelity wireframes with improvement suggestions resulting from the user evaluation.

application requires from the user to register data in order to generate content and supports registration of data based on the user preference. However, the quality of collected data could affect the quality of the graphs in the *Summary module*. The high SUS scores showed that the application was appealing to the group. However, the limitations of this study might be a small subject sample size, even though this study is a part of a larger research project [5][4].

## 5. Conclusions

Results from the user evaluation suggested improvements to the Diary and Summary module and consequently the *msHelse* functionalities were refined. The future development will include usability evaluation with IT experts to be carried within one more design iteration. The clinical value of the *msHelse* has to be assessed in a clinical trial.

## Acknowledgements

The authors are thankful to the study group for sharing their user experience in this study.

## References

- [1] Wesnes, K. et al., (2017). Physical activity is associated with a decreased multiple sclerosis risk: The EnvIMS study. *Multiple Sclerosis Journal*, p.135245851769408.
- [2] Giunti, G., Mylonopoulou, V. & Romero, O., (2018). More Stamina, a Gamified mHealth Solution for Persons with Multiple Sclerosis: Research Through Design. *JMIR mHealth and uHealth*, 6(3), p.e51.
- [3] Chan, S.R. & Misra, S., 2014. Certification of Mobile Apps for Health Care. *JAMA*, 312(11), p.1155.
- [4] Tonheim, A., Babic, A., (2018). Multiple Sclerosis Application Design with Medical Expert Evaluation. IUPESM, World Congress on Medical Physics and Biomedical Engineering. Prague, Czech Republic. 3-8 June 2018 Accepted for publication.
- [5] Tonheim, A.N. & Babic, A., 2018. Assessing Information Needs for a Personal Multiple Sclerosis Application. *Studies in health technology and informatics*, 247, pp.486–490.
- [6] Brooke, J. (2013). SUS: A Retrospective, 8(2), 29-40. Retrieved December 2, 2017, <http://www.usabilityprofessionals.org>



# **Appendix B**

**NSD**



Ankica Babic  
Fosswinckelsgate 6  
5007 BERGEN

Vår dato: 05.01.2018

Vår ref: 57298 / 3 / PEG

Deres dato:

Deres ref:

## Vurdering fra NSD Personvernombudet for forskning § 31

Personvernombudet for forskning viser til meldeskjema mottatt 20.11.2017 for prosjektet:

57298	<i>Assessing Personal Health Data in a Mobile Diary using Applied Machine Learning to Restrain Symptoms</i>
Behandlingsansvarlig	<i>Universitetet i Bergen, ved institusjonens øverste leder</i>
Daglig ansvarlig	<i>Ankica Babic</i>
Student	<i>Aleksander Nygård Tonheim</i>

### Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er meldepliktig og at personopplysningene som blir samlet inn i dette prosjektet er regulert av personopplysningsloven § 31. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

### Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

Vi forutsetter at du ikke innhenter sensitive personopplysninger.

### Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke [endringer](#) du må melde, samt endringskjema.

### Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i [Meldingsarkivet](#).

### Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt

*Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.*



Ved prosjektslutt 01.06.2018 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

Marianne Høgetveit Myhren

Pernille Ekornrud Grøndal

Kontaktperson: Pernille Ekornrud Grøndal tlf: 55 58 36 41 / [pernille.grondal@nsd.no](mailto:pernille.grondal@nsd.no)

Vedlegg: Prosjektvurdering

Kopi: Aleksander Nygård Tonheim, [aleksander.tonheim@uib.no](mailto:aleksander.tonheim@uib.no)



# Bibliography

- [1] Anne Britt Skår, Lars Bø, Randi Haugstad, Tori Smedal, and Jan Harald Aarseth. MS-attakk, behandlingsforløp, 2017. URL [https://helse-bergen.no/seksjon/MS\\_{\\_}veileder/Documents/Kapittel2SymptomervedMS{%}2Cogbehandlingsforl{\TU\o}p/2.1MS-attakk.pdf](https://helse-bergen.no/seksjon/MS_{_}veileder/Documents/Kapittel2SymptomervedMS{%}2Cogbehandlingsforl{\TU\o}p/2.1MS-attakk.pdf).
- [2] Aline Dresch, Daniel Pacheco Lacerda, and José Antônio Valle Antunes Jr. *Design Science Research: A Method for Science and Technology Advancement*. Springer International Publishing, 2016. ISBN 3319356097.
- [3] Helen Sharp, Yvonne Rogers, and Jenny Preece. *Interaction Design: Beyond Human-Computer Interaction*. John Wiley & Sons, 3rd edition edition, 2011.
- [4] John Brooke. SUS: A Retrospective, 2013. URL <http://uxpajournal.org/sus-a-retrospective/>.
- [5] Lars Bø. Generelt om MS, 2016. URL [https://helse-bergen.no/seksjon/MS\\_veileder/Documents/Kapittel%201%20om%20MS/1.1%20Generelt%20om%20MS.pdf](https://helse-bergen.no/seksjon/MS_veileder/Documents/Kapittel%201%20om%20MS/1.1%20Generelt%20om%20MS.pdf).
- [6] MS-forbundet. MS-forbundet, 2017. URL <http://www.ms.no/fakta-om-ms/faktaboks-om-ms>.
- [7] Acorda Therapeutics. MS self™ app, 2015. URL <http://www.moveoverms.org/multiple-sclerosis-app-ms-self>.
- [8] Multiple Sclerosis Association of America. My MS Manager™, 2017. URL <http://mysaa.org/msaa-community/mobile/>.

- [9] Guido Giunti, Vasiliki Mylonopoulou, and Octavio Rivera Romero. More Stamina, a Gamified mHealth Solution for Persons with Multiple Sclerosis: Research Through Design. *JMIR mHealth and uHealth*, 6, 2018. URL <http://www.ncbi.nlm.nih.gov/pubmed/29500159>.
- [10] Jürgen Kasper, Anne Regine Lager, Markus Rumpfeld, Simone Kienlin, Kristine Hoel Smestad, Tone Bråthen, Holly Ankell, Tore Knutsen, Rune Kløvtveit, Pål Gulbrandsen, Per Olav Vandvik, Anja Fog Heen, Signe Flottorp, Geir Tollåli, and Øystein Eiring. Status report from Norway: Implementation of patient involvement in Norwegian health care. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 123-124:75–80, 2017. URL <http://www.ncbi.nlm.nih.gov/pubmed/28546052>.
- [11] Aleksander Nygård Tonheim and Ankica Babic. Assessing Information Needs for a Personal Multiple Sclerosis Application. *Studies in health technology and informatics*, 247: 486–490, 2018. URL <http://www.ncbi.nlm.nih.gov/pubmed/29678008>.
- [12] J C Wyatt and Y Liu. Basic concepts in medical informatics. *J Epidemiol Community Health*, 56:808–812, 2002. URL <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1732047/pdf/v056p00808.pdf>.
- [13] I. Scott. MacKenzie. *Human-computer interaction*. Elsevier Science, 2012.
- [14] Jacob Nielsen and Don Norman. The Definition of User Experience (UX), 2017. URL <https://www.nngroup.com/articles/definition-user-experience/>.
- [15] Ben Shneiderman, Catherine Plaisant, and Bradford W. Hesse. Improving Healthcare with Interactive Visualization. *Computer*, 46:58–66, 2013. URL <http://ieeexplore.ieee.org/document/6415893/>.
- [16] Bradford W Hesse, Derek Hansen, Thomas Finholt, Sean Munson, Wendy Kellogg, and John C Thomas. Social Participation in Health 2.0. *Computer*, 43:45–52, 2010. URL <http://ieeexplore.ieee.org/document/5632036/>.
- [17] Johanna Renny Octavia, Karin Coninx, and Peter Feys. As I am not you. In *Proceedings of the 24th Australian Computer-Human Interaction Conference on - OzCHI '12*, pages 424–432. ACM Press, 2012. URL <http://dl.acm.org/citation.cfm?doid=2414536.2414603>.

- [18] Jisoo Lee, Eric B. Hekler, Emil Chiauzzi, Auriell Towner, and Marcy Fitz-Randolph. Helping Users Set Rules for Defining Short-Term Activity Goals. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems - CHI EA '16*, pages 2178–2184. ACM Press, 2016. URL <http://dl.acm.org/citation.cfm?doid=2851581.2892488>.
- [19] Karl Aberer, Jean-Eudes Ranvier, Matteo Vasirani, Zhixian Yan, Michele Catasta, Georgios Christodoulou, Ivan Gavrilovic, Filip Hrisafov, Mathieu Monney, Abdessalam Ouazaki, Boris Perovic, and Horia Radu. Memo-it. In *Proceedings of the 2014 ACM International Joint Conference on Pervasive and Ubiquitous Computing Adjunct Publication - UbiComp '14 Adjunct*, pages 203–206. ACM Press, 2014. URL <http://dl.acm.org/citation.cfm?doid=2638728.2638753>.
- [20] Gonzalo Eguiluz and Begonya Garcia-Zapirain. Telerehabilitation Web Application for Health Care Professionals And Adults With Multiple Sclerosis. In *Proceedings of the 8th International Conference on Pervasive Computing Technologies for Healthcare*, pages 286–289. ICST, 2014. URL <http://eudl.eu/doi/10.4108/icst.pervasivehealth.2014.255309>.
- [21] Jessica Szeto, Anthony Lycett, Xuan Yi, Salim Afra, Abdullah Sarhan, Konstantinos F. Xilogiannopoulos, Panagiotis Karampelas, and Reda Alhadj. Visualization of health indicators: utilizing data mining techniques and statistical analysis for effective comparison of user profiles. *Network Modeling Analysis in Health Informatics and Bioinformatics*, 3:63, 2014. URL <http://link.springer.com/10.1007/s13721-014-0063-0>.
- [22] Kristin Wesnes, Kjell-Morten Myhr, Trond Riise, Marianna Cortese, Maura Pugliatti, Inger Boström, Anne-Marie Landtblom, Christina Wolfson, and Kjetil Bjørnevik. Physical activity is associated with a decreased multiple sclerosis risk: The EnvIMS study. *Multiple Sclerosis Journal*, 2017. URL <http://journals.sagepub.com/doi/10.1177/1352458517694088>.
- [23] Lars Bø. Hvordan blir diagnosen stilt?, 2016. URL <http://nevro.legehandboka.no/handboken/sykdommer/demyeliniserende-sykdommer/ms/>.
- [24] MS-Senteret Hakadal. MS-Senteret Hakadal, 2018. URL <http://www.mssenteret.no/>.

- [25] Alan. Bryman. *Social research methods*. Oxford University Press, 5th edition edition, 2016. ISBN 9780199689453.
- [26] Jakob Nielsen and Jonathan Levy. Measuring usability: preference vs. performance. *Communications of the ACM*, 37:66–75, 1994. URL <http://portal.acm.org/citation.cfm?doid=175276.175282>.
- [27] John D. Gould and Clayton Lewis. Designing for usability: key principles and what designers think. *Communications of the ACM*, 1985. URL <http://portal.acm.org/citation.cfm?doid=3166.3170>.
- [28] Assistant Secretary for Public Affairs. Usability Testing, 2013. URL <https://www.usability.gov/how-to-and-tools/methods/usability-testing.html>.
- [29] Assistant Secretary for Public Affairs. System Usability Scale (SUS), 2013. URL <https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html>.
- [30] Novartis UK. SymTrac MS, 2015. URL <http://www.symtrac.com/ms/>.
- [31] Jakob Nielsen and Jakob. Enhancing the explanatory power of usability heuristics. In *Proceedings of the SIGCHI conference on Human factors in computing systems celebrating interdependence - CHI '94*, pages 152–158. ACM Press, 1994. URL <http://portal.acm.org/citation.cfm?doid=191666.191729>.
- [32] Maurits Clemens Kaptein, Clifford Nass, and Panos Markopoulos. Powerful and consistent analysis of likert-type ratingscales. In *Proceedings of the 28th international conference on Human factors in computing systems - CHI '10*. ACM Press, 2010. URL <http://portal.acm.org/citation.cfm?doid=1753326.1753686>.
- [33] NativeScript. About NativeScript, 2017. URL <https://www.nativescript.org/about>.
- [34] Sourcetreeapp.com. Sourcetree, 2018. URL <https://www.sourcetreeapp.com/>.
- [35] Trello.com. Trello, 2018. URL <https://trello.com/>.
- [36] Sqlite.com. About SQLite, 2018. URL <https://www.sqlite.org/about.html>.

- [37] Adobe.com. Adobe XD CC, 2018. URL <https://www.adobe.com/products/xd.html>.
- [38] PointofCare. Multiple Sclerosis, 2017. URL <http://ms.atpointofcare.com/pocweb/book/index.html>.
- [39] Lewis James. and Jeff Sauro. Can I leave This One Out? The Effect of Dropping an Item From the SUS. *Journal of Usability Studies*, 13:38–46, 2018. URL <https://dl.acm.org/citation.cfm?id=3173073>.
- [40] Direktoratet for e-helse. Direktoratet for e-helse, 2018. URL <https://ehelse.no/om-oss/om-direktoratet-for-e-helse>.
- [41] Steven R. Chan and Satish Misra. Certification of Mobile Apps for Health Care. *JAMA*, 312, 2014. URL <http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.2014.9002>.
- [42] Aleksander Nygård Tonheim and Ankica Babic. Multiple Sclerosis Application Design with Medical Expert Evaluation. *World Congress on Medical Physics and Biomedical Engineering*, Accepted for publication, 2018.
- [43] Aleksander Nygård Tonheim and Ankica Babic. User Evaluation of a Multiple Sclerosis Self-management Mobile Application. *Informatics, Management and Technology in Healthcare*, Accepted for publication, 2018.