Designing a smartphone application supporting young people living with Rheumatoid Arthritis in consultations with Rheumatologists

- a participatory design study

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Number of characters with spaces: 293.267

Pages: 122,2

ABSTRACT

Objective This study researches how to develop a smartphone application that supports young people living with Rheumatoid Arthritis in consultations with their Rheumatologists. The design process is performed as a participatory design approach, by involving **Methods** young people with Rheumatoid Arthritis as part of the design team. The development process builds on an extensive research of the problem situation by conducting focus group interviews, contextual inquiry, a conceptualisation workshop, and cooperative evaluations. Two Rheumatologists have also been a part of the design process during semi-structured interviews, as well as through cooperative evaluations. This ensures that all stakeholder requirements have been located and met, even tertiary ones. Results Young people living with Rheumatoid Arthritis are challenged in almost every aspect of their everyday life because of their condition. Understanding their relation to their Rheumatologists reveals a potential for enhancing their position when attending consultations. Rheumatologists are rather protective of the sparse amount of time allocated for each consultation. Thus, designing an application for smartphones to support patients has to consider this requirement of the Rheumatologists in order to be successfully adapted by the young people living with Rheumatoid Arthritis. Conclusion The study concludes that developing a smartphone application to support young people living in consultations with Rheumatologists can enhance patient empowerment. Developing a successful application relies extensively on involving all stakeholders in the problem situation throughout the whole process. The data input in the application has to follow a linear path to ensure user engagement and data quality. The data has to present data that is visualised as simply and recognisably as possible to the Rheumatologist, in order to be adapted into the preexisting practice of consultations.

RESUMÈ

Formål Dette studie undersøger, hvordan en smartphoneapplikation, der støtter unge mennesker med leddegigt i deres konsultationer med reumatologer, kan udvikles. Metoder Studiet er udført som et participatorisk designstudie, med unge mennesker med leddegigt som deltagere i designteamet. Undersøgelsesdesignet bygger på følgende kvalitative undersøgelsesmetoder: Fokusgruppeinterview, kontekstuelle undersøgelser, etnografiske observationer, designworkshop og kollaborative evalueringer. Anden del af designteamet inkluderede to reumatologer. Undersøgelsesdesignet bestod i denne fase af semi-strukturerede interviews og kollaborative evalueringer. Tilsammen styrker dette brede undersøgelsesdesign muligheden for at afdække systemkrav fra alle involverede interessenter. Resultater Unge mennesker med leddegigt er påvirket af deres sygdom i næsten alle aspekter af deres liv. Undersøgelsen af relationen mellem unge mennesker med leddegigt og deres reumatologer viste, at der er et stort potentiale for at forbedre udbyttet af denne Reumatologer har meget kort tid til hver konsultation, og er derfor meget tilbageholdende med at inddrage for mange udefrakommende, tidskrævende faktorer. Derfor er det afgørende for udviklingen af en smartphoneapplikation, der skal bringes i spil i konsultationer, at den tager højde for lægernes tidsbegrænsning, ved at tilbyde informationer, der er overskuelige og genkendelige. Studiet konkluderer at en smartphoneapplikation udviklet til unge med **Konklusion** leddegigt kan styrke patient empowerment. For at udvikle en smartphoneapplikation, der kan støtte unge med leddegigt i deres konsultationer, er det afgørende at både de unge og reumatologerne bliver inddraget i udviklingsarbejdet, for at applikationen kan blive anerkendt af begge parter. For at smartphoneapplikationen kan præsentere kvalitetsdata, kræves det at indtastningsmulighederne foregår i et lineært forløb. Det lineære forløb øger også brugernes tilskyndelse til at bruge smartphone-applikationen. Data præsenteret på smartphoneapplikationen skal præsenteres simpelt og indeholde genkendelige værdier, før reumatologer vil tage den til sig i den allerede eksisterende praksis i konsultationen.

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1 INTRODUCTION

The prevalence of chronic disease is rising in all major developed countries (Newbould, Taylor, & Bury, 2006). The rising number of people dependent on health related services is also a significant tendency in Denmark, where one out in every three people live with a chronic disease. These people account for more than 70% of all health-related expenses in Denmark (Moth, 2008). As a direct consequence of the increasing number of people living with chronic disease, focus on correct treatment of people living with a chronic condition has become more prevalent (Danske Regioner, 2014), as expenses rise and as people demand higher quality treatment. In Denmark and in the European Union, the implications of these tendencies are addressed in a variety of ways (Danske Regioner, 2013; Enope, n.d.). Among these approaches, patient empowerment is addressed as a central concept, emphasising patients taking control of their own disease (Feste & Anderson, 1995), by becoming increasingly better educated about their disease (Danske Regioner, 2013; Enope, n.d.).

In Denmark, musculoskeletal disease is the most prevalent chronic disease, impacting more than 700,000 people. One chronic musculoskeletal condition severely impacting quality of life negatively is Rheumatoid Arthritis (RA), which in Denmark affects between 0.5-1% of the population (Gigtforeningen, 2011).

Alongside these rising expenses in the treatment of chronic disease in general, and RA specifically, technological solutions are being developed to support people with chronic disease. Accordingly, within the two major application (app) repositories, App Store and Google Play, there are 20,000 and 8,000 health related apps (Zapata, Fernández-Alemán, Idri, & Toval, 2015). With the pervasiveness of smartphones at a penetration ratio of 77% in Denmark (Danmarks Statistik, 2015), developing health care tools to smartphones is about to become mainstream.

Considering the challenges related to disease management when it comes to RA, and the capabilities of smartphones, they are considered adequate platforms for useful applications for people with RA. Living with RA implies a variety of factors impacting the overall quality of life (Sanderson, Morris, Calnan, Richards, & Hewlett, 2010). Hence, self-monitoring is a method used to structure the variables impacting the disease. Smartphones have an advantage regarding self-monitoring, due their pervasiveness as well as their capabilities of storing self-monitored data over long periods of time. Logging health-related data on digital devices is not a completely new phenomenon, though the emerging market of smartphones has completely taken over the technologies used for self-monitoring (Azevedo, de Sousa, Monteiro, & Lima, 2014). The usage of smartphones in the strategy to support people with chronic disease is emphasised in Denmark (Danske Regioner, 2013).

1.1 BACKGROUND AND NEED

The general background for this master's thesis relates to the increasing focus on health apps. As Denmark is known to be among the most digitalized countries (Bilbao-Osorio, Dutta, & Lanvin, 2014), staying persistent in the focus on developing technological application within the health care industry is important. Another important factor is the existence of Rheumabuddy (Daman P/S, 2015), an app specifically devoted to support young people living with RA in their disease management.

Collaboration between the patient organization for young people with Rheumatic Disease, FNUG, and the Health IT-company Daman is the empirical case in this master's thesis. This collaboration provides an opportunity to inquire into the comprehensiveness of smartphone apps as supporting tools in the consultation between young people living with RA and their Rheumatologists. The case is interesting, as it provides a target group, young people with RA, and a loosely declared outcome; to enhance the quality of life for the target group.

Inquiring how technology can play a role in disease management for people living with a chronic disease requires some ethical considerations. Therefore, the aim of developing a system able to support young people living with RA requires a research design reflecting the respectful approach to people with a chronic disease. Hence, carrying out a participatory design study (Spinuzzi, 2005) is considered adequate, both in terms of its methodological strength, but also because that approach relies on extensive user involvement. By emphasising user involvement throughout the design process, risks that the system is designed on behalf of the people with a chronic disease, rather than in collaboration with them, is addressed. Moreover, a review of literature regarding smartphone apps for people with RA has revealed a tendency that most systems being developed within that field are not relying on continuous user involvement throughout the design process (section 2).

1.2 SIGNIFICANCE

Because the amounts of people with chronic disease rise, the health care expenses grow accordingly. Alongside a fast paced growth in technological capabilities of smartphones, pursuing more sophisticated self-management tools for people with chronic disease will become a part of the solution. If this emerging market of smartphone self-management applications and the shift within the health care paradigm continues, people living with chronic disease will become more and more independent of the health care system. This master's thesis will inquiry how young people with RA can become their own caregivers by paying attention to their own condition (Sunyaev & Chornyi, 2012), yet demanding more involvement in the decisions made regarding their own treatment.

1.3 PROBLEM STATEMENT

How can smartphones support young people with Rheumatoid Arthritis, in consultation with Rheumatologists?

1.4 RESEARCH QUESTION

In order to solve the problem stated in the problem statement additional research questions have been formulated. They will be researched by various qualitative research methods. The research questions will be answered chronological following the structure of this master's thesis that consists of seven stages. Stage 1 and 7 are structured different because none of them are direct parts of the design process therefor none of them having a research question. They research questions of the remaining 5 stages are:

Stage 2:

What are the challenges of a consultation between young people living with RA and Rheumatologists?

Stage 3:

Which aspects of the consultation does the system need to support?

Stage 4:

How can a smartphone app, from the perspective of the users, most comprehensively support a consultation?

Stage 5:

How do the participants of the design team perceive the prototype?

Stage 6:

How can the prototype improve the consultations from the perspective of the Rheumatologists?

1.5 CASE DESCRIPTION

The following is a description of the case this master's thesis is based on.

1.5.1 DAMAN

This master's thesis has been made in cooperation with Daman. It is a digital agency specialised supporting pharmaceutical businesses. They deliver everything from consultancy, to design and implementation of full digital media strategy. Daman is a full-house agency in the sense that they employ programmers, user experience experts and project managers. The size of the team varies from 6-12 people depending on the current workload. (Daman, 2015)

Daman has provided access to the participants through the patient organisation FNUG to Rheumatologists at Glostrup Hospital, shared insights about their development of the app RheumaBuddy, and they have provided full access to their office facilities.

1.5.2 FNUG

FNUG is a patients organisation devoted to people aged 12-35 years living with arthritis (FNUG, n.d.). FNUG has existed since 1983 and it is a national patients organisation in Denmark. FNUG consists besides its members of 35 volunteers, 9 of them are members of the board. Their mission is to gather young people with Arthritis with the purpose of discussing common challenges, raise awareness of the condition, and to host events for pure enjoyment (FNUG, n.d.).

Recruiting participants for the design team of this master's thesis via FNUG was made for several reasons. Firstly, FNUG has asked Daman to develop the app, RheumaBuddy. This made it natural for the research of this master's thesis to build on that relation. This of course made it necessary to make some considerations as to how this might affect the design process.

1.5.3 RHEUMABUDDY

This section will provide an overview of the already existing app Rheumabuddy and how this master's thesis relates to this.

RheumaBuddy is an app that provides young people with RA with a self-monitoring tool to help them monitor and assess disease activity. It has been made as a product for FNUG that needed a tool for helping their members get a more detailed understanding of their life with RA (Daman P/S, 2015). This has resulted in RheumaBuddy that has been made in cooperation with members of FNUG. The app is a digital diary with features that derives directly from the young people's input. As such, the system has no direct intended use elsewhere but to support the young people in their understanding of their condition.

The design focus of this master's thesis differs from RheumaBuddy. It focus as mentioned on self-monitoring that support the young people in getting insights about their condition. The focus of this master's thesis however, is to conduct research into how the young people can be supported by a similar tool when attending consultations. This aspect has not been covered by the work of RheumaBuddy.

The work of the design process of RheumaBuddy consisted of several workshops with the purpose of getting insights about how everyday life is affected by RA for young people.

The work of this Master's Thesis are chosen to build on the elements from RheumaBuddy due that the documentation of the development and the process itself has been considered to be thorough. The fact that the app has been developed on the basis of findings from several workshops it is considered to be valuable in relation to the design approach and the beliefs of this master's thesis.

However, it has been considered necessary to begin the research of this master's thesis explorative by pursuing insights on how life of young people is affected by RA. It could be argued that the work done by Daman supported by claims from the research literature could be considered a starting in conducting the design process. Nevertheless due to the participatory design approach of this master's thesis, which will be elaborated in the framework, it has been considered important to include young people living with RA in the initial phase of researching how RA affects everyday life. This was done to give the researchers a more solid basis of knowledge but also to include the participant so that they feel certain that the design process is centered around their participation.

This means that some of the visual design had been reused in the prototype made in this master's thesis. Certain aspects such as the pain map and the possibility of monitoring pain, stiffness, fatigue and mood has been reused as the participant in this master's thesis qualified these parameters to be essential for them to monitor. This will be elaborated and reflected on in section 6.2.1.

1.5.4 RHEUMATOID ARTHRITIS

Living with RA is a severe condition impacting all aspects of life, both physically and psychologically. In addition to that, being young with chronic arthritis has proved complicated, as new ways of relating to health care professionals create tension. In the following a diverse array of papers will discuss relevant ways to enhance this complicated relation to Rheumatologists.

RA is an autoimmune disease. The disease is most common for women and the onset of the disease peaks when people are about 50 years old (Alamanos & Drosos, 2005). Although RA is a physical condition, studies have found that psychological implications are commonly related to RA, as it affects almost every aspect of everyday life (Kristiansen, Primdahl, Antoft, & Hørslev-Petersen, 2012; Lempp, Scott, & Kingsley, 2006; Sanderson et al., 2010). Among the psychological implications of living with RA is the concept of regaining control over life. People diagnosed with RA change their self-perception, as normal everyday tasks become unrealistic to carry out. These adaptations are among the most prevalent factors impacting people living with RA (Sinclair & Blackburn, 2008). Another important factor related to RA, and specifically RA related to young people, is the difficult transition from paediatric care to adult health care. Young people are not significantly more exposed to risks of psychological implications of chronic arthritis than other groups of people living with chronic arthritis (LeBovidge, Lavigne, Donenberg, & Miller, 2003). However, the complicated transition from adolescent to adult living with chronic arthritis is still found to be a unique condition for young people with chronic arthritis (Ansell & Chamberlain, 1998).

2 FRAMEWORK

The framework for this master's thesis has to be described in a detailed manner, due to the unconventional way it is structured. Thus, this sections aims to provide a basis for understanding the framework, in order to be able to follow the argumentation throughout the master's thesis. First of all, rather than following the traditional format of *introduction, method, theory, analysis,* and *conclusion*, we have chosen to elaborate on the scientific point of, followed by an unfolding of the design approach, *participatory design*, which is key to the entire design process. Finally, Soft Systems Methodology (Dix, 2003a), an approach for structuring a design process will be elaborated on and used actively as the main reference point in the written outcome of this master's thesis.

2.1 THEORY OF SCIENCE

It is important to be cautious about how the implicated actors of this master's thesis are affected by the interventions carried out throughout the process. Because the master's thesis relies on a basic concept of intervention, implying change, a precise definition of what is understood by change, how the change has been executed and a definition of how the actors are understood is necessary.

A social constructivist approach similar to that of Berger and Luckmann (1966) has been applied. They elaborate on the concept of knowledge, based on everyday life. However, the argumentation is still adequate for this master's thesis. Their understanding of knowledge emphasises the concept that people must acknowledge the importance of something for it to be true: "Everyday life presents itself as a reality interpreted by men and subjectively meaningful to them as a coherent world." (Berger & Luckmann, 1966, p. 33) Within this quote lies an acknowledgement that reality, and thus knowledge, is what can be considered important or meaningful to people. The consequence of this ontology in this master's thesis is that, in order for knowledge generated in collaboration with users to be considered real, the users themselves must acknowledge the knowledge as real. By emphasizing this point in a systems design methodology, users need to be a part of the entire developmental process. Otherwise, the process would require the designers to create user needs on behalf of the users. The research methodologies applied are consequences of this choice. Participatory design (Spinuzzi, 2005) is founded on the belief that practices and ideas are not just negotiated, in fact they are created on the basis of human interaction. Thus, having potential users of a system become a part of almost every process of the systems development is crucial in order to determine whether it applies to the most important user needs. System requirements are not just seen from the perspective of the designer, but more importantly from that of the users.

The social constructivist approach has been a determining factor when choosing semi-structured interviews, focus group interviews and co-creation workshops as key methods for the qualitative data collection. These methods were found suitable due to their strong reliance on the human interaction; the interactions themselves will become the data source.

From a social constructivist perspective another important notion is that user needs might not even exist prior to a design process. They might arise during the process of designing, as more knowledge is gathered about the design situation. Hence, the importance to strive for data mostly derived from the same users is pursued, because emphasis is on the idea that user needs and particular use case scenarios arise during the design process. This does not mean that the users do not possess a need for change, however, they just cannot possess requirements in relation to the asyet non-existing system.

2.1.1 UNDERSTANDING THE PARTICIPANTS

As mentioned in the beginning of this section, a thorough presentation of the people involved is important. Not only due to the social constructivist approach, but also due the specific target group: Young people living with RA. Emphasising the people involved as whole persons and not as RA patients nor chronically ill people is of critical priority. RA is chronic and pervasive, thus being an integrated part of the lives of people living with RA. They cannot neglect their conditions (Lempp et al., 2006). Their well-being is constantly being renegotiated and changed based on their interaction with the world around them (Sanderson et al., 2010). Living with RA is not solely impacting physical factors like pain, stiffness, and fatigue. Psychological factors tend to have an impact as well. This master's thesis therefore finds it important to mention the people involved not as RA patients, nor chronically ill people, but rather as young people living with RA, leaving space for defining what it is actually like to live with RA from the perspective of the young people. Emphasis must be on the most important parts of what it is like living with RA even though it might not even be the disease itself.

2.1.2 ROLE OF THE DESIGNER

As an academic designer it must be acknowledged that being an intervening researcher and designer simultaneously implies impacting the field of research. This master's thesis aims to conduct research by doing participatory design following the main ideas of Argyris and Schön (1978) who developed the concept of action research. Their main point is that the validation of research involving interventions in the field, is done partially through continuous reflection upon the role as a researcher, and in this case as a designer. A main consequence of taking this kind of approach to research is to remain focused on how the findings from the research methodologies has been biased by the researcher's participation in the process of data creation. Acquiring objective, non-biased data is not considered feasible or comprehensive since expunging the subjective bias imposed by the researcher is impossible from a social constructivist point of view. Remaining reflective, however, will provide an opportunity to understand which factors that have impacted the design situation.

2.1.3 UNDERSTANDING OF TECHNOLOGY

As mentioned earlier, the relation between designer, design and user is complex. In this master's thesis the technology being developed is understood as an *instrument*. For a system to become an instrument it implies some sort of interaction. Otherwise it is understood as a completely inactive object; an *artefact* as Rabardel and Bourmaud (2003) outline. Distinguishing between artefact and instrument serve as the main reference to the overall social constructivist epistemology, which relies on the concept that objects and subjects, in order to exist, have to be manipulated or at least paid attention to. The same applies to the system being developed. It is has no value without the contributions from the users.

On top if this understanding of objects as either artefacts or instruments, another distinction is made based on the work of Ewenstein and Whyte (2009). They understand objects as either, *boundary, epistemic, or technical* instruments, ranging from abstract to concrete instruments. *Boundary* instruments can be understood as nothing more than concepts. In this master's thesis, the system is a boundary object when the design process is initiated, and the system consists of nothing more than ideas. As the system is transformed into more concrete abstractions it is transformed into an epistemic object, i.e. when the users are encouraged to draw the desired system. These drawings, as well as the prototype developed on the basis of the drawings, act as epistemic instruments, as these representations of the system can convey knowledge by letting the users manipulate the concepts. The final stage of an instrument is the *technical* instrument, which in this case would have been a fully functional app. Technical objects hold the properties that they

are functional, yet less likely to convey knowledge about the design process, as users might interpret the system as finished and as something that cannot be manipulated (Ewenstein & Whyte, 2009).

The focus will mainly be on boundary and epistemic objects, because this is a design process which emphasizes objects that have a high degree of manipulability. The ideas of Ewenstein and Whyte are applied in the prototyping of the system, due to the fact that they can act as tools for understanding certain properties of the prototype. (2009).

When combined, these two ways of understanding objects create a framework for understanding how technologies and, from now on, *boundary-, epistemic- or technical instruments*, are understood. Both conceptualizations of objects share an emphasis on the ideas, that objects can be manipulated by humans and vice versa. Hence, participatory design is applied as a viable method for designing in an academic manner, due to this approach, which emphasizes negotiation, not only between humans, but also between humans and non-humans.

A more thorough description of the implications of conducting participatory design is provided in the next section, where the particular concept will be unfolded in a more context-specific manner, looking into how the approach applies to the different parts of this master's thesis.

2.2 PARTICIPATORY DESIGN

As a consequence of the social constructivist epistemology, participatory design was chosen to support the approach due to its high level of dependency on the interaction between designer and user.

The participatory design approach is influenced by Spinuzzi (2005). The data that provides the basis for developing a system is generated in fluctuations ranging from input generated almost solely by the users to an analysis of the data carried out without user involvement at all (Spinuzzi, 2005).

When working with participatory design, a central assumption is that non-designers, such as the users, do have something to contribute to the design process. Spinuzzi puts it this way: "*It attempts to examine the tacit, invisible aspects of human activity; assumes that these aspects can be productively and ethically examined through design partnerships with participants, partnerships in which researcher-designers and participants cooperatively design artifacts* [...]" (Spinuzzi, 2005, p. 2) Although the users are supposed to contribute to and participate in the design, the process of the researcher in doing not only design but also academic research, makes it necessary to prolong a specific distinction between analysis and work being done in collaboration with the participants (Spinuzzi, 2005). These distinctions, which are effectuated in the oscillation between certain methods adequate for each type of activity, will be elaborated in the following section presenting the structure of the of this master's thesis.

2.3 SOFT SYSTEMS METHODOLOGY

As described above, emphasis is on building a comprehensive understanding of the interaction between the system and the humans. Soft Systems Methodology (Dix, 2003a) has been chosen as the overall framework, as it provides the necessary duality between user involvement and data analysis. It aligns well with the overall concept of knowledge, as it emphasises an iterative way of thinking. It is imperative in an iterative design approach to constantly remain open to unforeseen input. This is not only adequate from a design perspective; it also provides an option to maintain a high level of reflection, which is appropriate in a qualitative design study with a social constructivist approach. The concept of assessment throughout the process is similar to the idea imposed by Argyris and Schön (1978), who prescribe the importance of reflecting upon, not only the field of research, but also oneself as a researcher. These ideas are maintained in SSM.

2.3.1 SOFT SYSTEMS METHODOLOGY EXPLAINED

The framework consists of seven steps, which will be elaborated below. The elaboration of each step will act both as a description of the purpose of each step, as well as a reading guide describing what to expect from the content. The model is divided into two sections. The section above the dashed line, *real world*, refers to research focused on activities carried out in the actual design situation. On the other hand, *systems thinking about world*, refers to activities related to designing a system that can be adopted in the design situation.

The figure below is a visualisation of the structural framework (Dix, 2003a)(Figure 1).



Figure 1 - Soft Systems Methodology

Stage 1: Definition of problem situation - unstructured is aimed at providing sufficient background knowledge in order to ensure that the design and the inquired topics during this thesis have not already been inquired extensively. The stage consists of two parts. The first part looks into how systems with functionalities similar to Rheumabuddy have been executed prior to this design process. The second part is a literature review, devoted to finding relevant papers about related topics. One minor change to the original Soft Systems Methodology is that the first stage will be carried out as its own iterative loop, rather than as an unstructured process. The literature review will instead be based on a specific, iterative way of conducting literature reviews, developed by Combs, Bustamante, & Onwuegbuzie (2010).

Stage 2: Detailed description of problem situation serves as the first encounter with the young people living with RA. They are from now on named *participants* in cases when referred to in relation to participatory design. The term patients will only be used when referring to the attendees in the observations carried out in stage two. The detailed description is aimed at providing a multifaceted understanding of a consultation between young peoples living with RA and Rheumatologists. This is pursued by conducting a focus group interview with the participants, contextually inquiring six consultations, and by interviewing two Rheumatologists. This data will be analysed, pointing out tendencies in order to provide a detailed description. (Dix, 2003a). This analysis will be carried out as an explorative coding of the entire data set gathered from the focus group interviews, the interviews and the contextual inquiry.

Stage 3: Generate root definitions for the system is the only part of the master's thesis that does not contain any data generation. Instead, this stage will be an elaborate analysis of the data from stage 2. The qualitative data will be analysed from the scope of systems thinking by determining requirements of the various stakeholders. The process reveals challenges in relation to the consultations, providing insights into how different features provided by smartphones can support the challenges.

This is followed by a stakeholder analysis leading to a set of root definitions (Dix, 2003a), which is a generic set of definitions that must strive to support as many of the requirements of the stakeholders found during the analysis of the data as possible. These root definitions and the stakeholders discovered during the analysis will provide a basis for a rich picture. This will contain insights into the motives and requirements of each of the stakeholders presented. The rich picture is used as a visual representation of the problem situation. It will be presented below in the Stakeholders section (2.3.3).

Step 4: Conceptual Models will be carried out as a part of the participatory design, meaning that participants will be involved in a workshop. The purpose of this workshop is to bring the

participants into the design process, in a way, which lets them contribute with concrete design proposals. The workshop will generate insights into the participants' views on the system being developed, as well as validate the insights from the earlier stages. The combination of insights and validation of prior insights works as the basis for developing conceptual models that can be processed into a prototype. It will be designed on the basis of a set of UML diagrams (Whitten & Bentley, 2007). These are elaborations of the functionalities required for the system to work. The diagrams will act as technical documentation of the system, paving the way for the visual representation of the system.

Stage 5: Compare stage 2 and 4. This stage is carried out as a user testing of the prototype. User testing is applied in order to once again compare the insights from earlier stages with the user requirements provided through the on-going interventions with the participants. Stage 5 and stage 6 bring in the iterative way of thinking by testing the system on the users, providing knowledge about what must be adjusted for the system to work properly.

Stage 6: Determine desirable and feasible changes will be the second iteration in the testing of the prototype. The testing will be carried out on the Rheumatologists visited during the contextual inquiry, since they play a key role in the assessment of the functionality of the system.

Stage 7: Identify actions required for changes will bring in all knowledge obtained throughout the design process. The stage will take on a discussion of the research methods applied throughout the master's thesis, as well as other relevant theoretical and methodological discussions. The stage will emphasize the academic discussions instead of continuing the on-going discussion of the design carried out throughout the master's thesis. At a higher level of abstraction, this deviation from SSM can be understood as a way in which the principles of Argyris and Schön (1978), regarding the reflective practitioner, is carried out. During all stages except stage seven, emphasis is put on the reflection *in* action, and in this stage emphasis is put on the reflection *on* action (Argyris & Schön, 1978).

2.4 DELIMITATION

This master's thesis is delimitated by solely focusing on the consultations between young people living with RA and Rheumatologists. In order to create an understanding of the problem situation, it is necessary to create an overview of which the stakeholders involved in the situation are. They will be elaborated in the following section, followed by a *rich picture* that presents a visual overview of the problem situation that has been made on the basis of qualitative research (Dix, 2003a). The methods and analysis made in order to create the rich picture are presented in stages 2 and 3.

2.5 STAKEHOLDERS

The following stakeholders, in relation to the consultation, were located: Nurses, Rheumatologists, young people living with RA, Daman, FNUG, relatives, receptionists at the hospital and chiropractors.

There might be more stakeholders related to the consultations but they were not discovered by the qualitative research due to the delimitations that have been made. Before dividing the stakeholders into categories, some are excluded. This is because their relation to the system are of a peripheral character, meaning that they are only related to the system through one of the other stakeholders. The excluded stakeholders are: *Relatives, receptionists,* and *chiropractors*. Another selection was made based on the system's focus solely on the consultations between Rheumatologists and young people living with RA. The nurses are left out as well. However, further research into the nurses' role in consultations is a relevant topic for future work, which will be elaborated in the discussion section.

2.6 RICH PICTURE

In order to create an overview of the consultations and the activities related to it, a rich picture (figure 2) was made. It visualises the stakeholders and their requirements in relation to the consultation. It serves the purpose of showing the context in which this master's thesis operates.





The picture was made from the empirical data and the analysis that will be explained through stage 2 and 3. It pinpoints the activities that have an influence on the consultation between Rheumatologists and young people living with RA. The collared circles represent the stakeholder requirements of each of the stakeholders directly related to the consultation. The rich picture shows that the consultation is centred around two screens that both the Rheumatologist and the young people focus on. This implies that a digital device on a screen is a format that can easily be adapted into the context without causing too much disruption.

The information on the screens consists of information provided by both the clinical staff and the young people, HAQ-questionnaire results, blood sample results, patient journals and so on. A HAQ-questionnaire is a clinically validated set of questions to assess functional capabilities of people with Rheumatic disease (Danbio, 2013). The Rheumatologist is in possession of all the

information, including the information provided by the young people mediated by the HAQquestionnaire. In relation to patient empowerment this does not serve the young peoples interests, as the Rheumatologist exclusively dictates the consultation. It is only when the young people have questions that they are the ones to provide information directly to the event. However, if the young people provide information that, from the Rheumatologists view is too time consuming to interpret during a consultation, it is no longer considered valuable. A noteworthy point revealed in the rich picture is that both the young people living with RA and the Rheumatologist require the young people to prepare for the consultation. As just mentioned the information provided may not be too detailed.

Stage 1

Definition of Problem Situation

This stage consists of two parts. The first elaborates the context in which this study is carried out. It consists of a description of already existing systems supporting people living with Rheumatoid Arthritis.

The second will discuss relevant literature about topics related to RA and smartphone use in various contexts. The discussion will be based on a systematic search about relevant topics via the most adequate databases. It has been found that:

- Smartphones prove as suitable technological systems for selfmeasurement among people with chronic disease.
- Literature lacks research regarding consistent user involvement in mobile health apps development.

3 STAGE 1: LITERATURE REVIEW

This stage elaborates the context in which this design process is carried out. The first part consists of a description of already existing systems supporting people living with RA.

The second part of this section will discuss relevant literature about topics related to RA and smartphone use in various contexts. The discussion will be based on a systematic search about relevant topics via the most adequate research databases.

3.1 INTRODUCTION

The following literature review will rely on an approach to literature reviews called Interactive Literature Review Process (Combs et al., 2010). The main goal of this approach on literature reviews is to ensure that the review will not only serve as a separate operation disconnected from the rest of the master's thesis. The Iterative Literature Review Process framework emphasises a reflexive approach to literature reviews. The reflexivity of literature reviews is comprehended by interacting with not only the literature at hand, but also the supervisor assigned to the thesis (Combs et al., 2010).

The ILRP approach combines the overall iterative design methodology described in the framework (section 2.3) with the way in which this literature review will be carried out. This literature review covers both relevant papers but also applications, relevant for the inquiry into the design context.

As a consequence of the iterative review methodology, certain highly context specific papers, which will become necessary to cite later on in the thesis, are not present in this section.

3.2 Purpose

The literature review will act as a valid basis to state that the research carried out is this master's thesis is relevant and sought to be unique for the field of research it is supposed to benefit. Thus, validating the search process is key to this literature review in order to make sure that a possible knowledge gap identified in the existing literature, as well as in existing technologies, is not a consequence of a literature search process lacking consistency. A model based on the Iterative

Literature Review Process approach has been developed to describe the iterative approach to literature reviews (Figure 3).



Figure 3 - Iterative Literature Review Model

3.3 Search strategy

The strategy for this search relies on principles from Zins (2000). This approach states, among other points, the necessity of choosing the most comprehensive resources for the literature review. The resources in this case are the databases and app repositories in which the search process will occur.

The field of research in this master's thesis is considered interdisciplinary, as it covers systems development with an overlap of health related research. Due to this, both databases covering specific fields of research and multidisciplinary databases will be used in the search process. Two specialized databases, ACM (Association for Computing Machinery, n.d.) and PubMed (NCBI, n.d.) have been chosen as the necessary specialized databases for this literature search. ACM is a database devoted to texts covering technology related topics. It will be used as the database covering all relevant topics within the main field of research, human computer interaction (HCI). PubMed, a database covering health related topics, was chosen to ensure consistent results when searching for articles involving RA, or in a broader perspective, chronic disease. On top of the two highly specific databases, three databases with a broader academic scope have been chosen; Scopus (Elsevier B.V., n.d.), SpringerLink (Springer Science+Business Media, n.d.), and Google Scholar (Google, n.d.). Both Scopus and SpringerLink were chosen due their academic breadth. They cover most resources regarding academic peer reviewed articles, thereby providing a solid foundation for a systematic review of the articles found. Google Scholar has not been a substantial part of the search process, however, it has been used as a reference search engine during the process, as it searches across all databases. Hence providing the necessary breadth when looking for a specific paper. These are the five sources used for retrieving articles. In order to maintain a steady pace during the review, almost all aspects of the search log have been left out (appendix 1). In other words, only the queries, which led to the desired results, will be discussed here, not all the initial queries are included.

The apps subject to exploration in this section will, to the extent possible, be found using a systematic search strategy, such as the one explained above, covering papers. However, as the largest app repositories, App Store and Google Play, both lack transparency regarding search queries, a subset of apps will be picked as representatives of the field of existing apps for RA.

3.4 Comparable systems

The assessment of comparable systems will be carried out as a positioning of apps of interest on a scale derived from a review paper about smartphone assessment for Rheumatic Diseases (Azevedo et al., 2014). Positioning the app developed in this master's thesis within the already existing field of RA apps provides an opportunity to pinpoint the uniqueness of this app, thus being able to make sure that the design proposed in this master's thesis is not a replica of an already existing system.

As mentioned in the introduction (section 1) the number of apps devoted to chronic disease management has increased at an incredible pace over the last few years (Martínez-Pérez, de la Torre-Díez, & López-Coronado, 2013). Therefore, a complete elaboration of all apps devoted to chronic disease management and more specifically RA is not performed.

Theoretically self-management has commonly been used as a term to describe a desire for behavioural change among people living with chronic disease. In this master's thesis self-management is understood as a term used within the field of health care. It covers the act of letting patients take part in their own treatment (K. R. Lorig & Holman, 2003).

Apps developed for healthcare professionals will not be taken into account, although both App Store and Google Play contain a vast amount of this type of apps. This is because they are solely aimed at health care professionals. Another reason for this delimitation, described previously, is the lack of transparency when using search queries in the main application repositories.

Because most RA self-management apps serve a variety of purposes, it is complicated to meaningfully place the apps in categories, like the papers chosen for the literature review. Instead a review article inquiring usage of smartphone apps in health care will provide a more comprehensive framework for discussing apps designed for Rheumatic Diseases (Azevedo et al., 2014). This framework distinguishes the apps by the way in which they are meant to intervene, either; *educational and psychosocial, lifestyle or treatment* (Azevedo et al., 2014, p. 8). These distinct categories have an underlying span reaching from *treatment*, advocating for more compliance to *educational and psychosocial*, advocating for more patient empowerment, as can be seen in figure 3. Compliance is: "[...] *the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice*" (Conrad, 1985, p. 1). Thus, compliance and treatment are linked as technologies encouraging patients to commit to prescriptions from physicians is the essence of compliance.

Figure 4 is a visual representation of the fundamental difference between compliance and empowerment, which lies in the opposite understanding of the causal relation between well-being and correct treatment (Feste & Anderson, 1995).



Figure 4 -Compliance/Empowerment Scale

The first app picked from App Store that is not dedicated for healthcare professionals is an app called RoA (Roche SAS, 2015). The app is designed for managing a certain type of medicine, developed by the same company that has developed the app. This app must be placed at the leftmost end of the diagram, due to the explicit focus on compliance regarding a specific type of medicine: "*It is possible for the patient to schedule injections and the app has a reminder option which reminds the patient to take her injection as prescribed by the doctor*." (Roche SAS, 2015). It is a specific app devoted to one type of medicine, focusing on this particular type of medicine it is designed for, instead of acknowledging RA as a pervasive condition impacting all aspects of life.

Another app, which is discussed by Azevedo et al., (2014), MyRA (Crescendo Bioscience, Inc., 2014) aims to embrace all facets of the life with RA. This app emphasizes the idea that more knowledge about oneself and the insights from data about the implications of a life with RA might strengthen oneself, thus providing better conditions for an explanation to the surroundings regarding the invisible disease that RA is (Crescendo Bioscience, Inc., 2014; Sanderson et al., 2010). MyRA puts it this way: [...] "*MyRA is a revolutionary app which lets you track your RA, create visual snapshots of your data, and communicate about your RA like never before. Now you can track what is important to YOU, whenever, wherever.*" (Crescendo Bioscience, Inc., 2014). MyRA takes a holistic view of the people living with RA, leaving it up to the users to decide what is important to them regarding their disease, thus positioning the app on the rightmost part of the scale, due the empowerment approach this app takes.

The two apps presented above provide an adequate understanding of the span explained by the model, ranging from empowerment to compliance.

The app being developed in this master's thesis differs from the two apps above, as it provides a bi-focal approach. Instead of focusing solely on the person with RA, the design in this master's thesis also provides an elaborate understanding of the necessary precautions when designing a system, which must also appeal to Rheumatologists. Encompassed on the same scale as the two other apps, it will lie on the right side of the scale. Although designed to provide extended patient empowerment, a trade-off made in order to reach that goal, is to acknowledge the requirements of Rheumatologists, as the system inevitably will be designed into an already existing practice.

3.4.1 REVIEW OF PAPERS

The following review of relevant papers has been divided into four categories; Apps supporting RA, Smartphone self-assessment, Visualisation and Patient empowerment. These four categories alltogether sum up the field of interest for this paper. The previous figure (figure 2) providing an overview of the literature review presents the way in which this approach to literature reviews must be understood. The research has been carried out as an open exploration into papers capable of providing useful knowledge about the issue of designing smartphone apps for people living with chronic disease. Each category brought into the review provides additional knowledge of important aspects of designing apps devoted to people living with a chronic disease. After an elaboration of apps supporting RA, the next step in the literature review, is to broaden the scope and look at smartphone self-assessment, as the amount of papers specifically looking at self-assessment for people with RA was considered to be sparse. Visualisation is brought into the equation as the literature proved insufficient when it came to visualisation of personal health data. Examining visualisation provided knowledge about how information is perceived when it is presented visually, leading to an argument that comprehensive visualisations can lead to stronger self-awareness in a health related context. This fosters patient empowerment, due to the stronger incentive to believe that it is possible to control the disease oneself.

It is important to keep the iterative approach of this thesis in mind. The implication of this approach is that certain texts, which are not included here, can be referred to further on in the master's thesis, due to new input from the participants that requires additional knowledge.

3.4.2 APPS SUPPORTING RA

Because this master's thesis is carried out on the basis of a specific case, the initial literature review of scientific papers started by exploring papers about this very specific interdisciplinary field derived from the case: Smartphone based self-assessment tools for young people living with RA.

The articles in this section were found by searching the medical database PubMed as well as the interdisciplinary database, Scopus. A series of queries were made (Appendix 1) although only one proved to deliver relevant papers. *("rheumatoid arthritis" AND "smartphone")* provided the seven main articles which will be elaborated in this section. The additional four articles discussed in this segment of the literature review (Goeppinger et al., 2009; Goeppinger, Armstrong, Schwartz, Ensley, & Brady, 2007; K. Lorig, Ritter, & Plant, 2005; K. R. Lorig, Ritter, Laurent, & Plant, 2008) were found via the references of a review article by Azevedo, et al. (2014)

It became clear that articles covering all aspects of the case are specialized and significantly rare. In fact, out of the total number of eleven articles of interest only two were found during the entire search process that covered all the previously mentioned aspects of the case.

Both papers discuss the potential of integrating qualitative data provided by the user combined with information about gait patterns derived from smartphone sensors (Nishiguchi et al., 2014; Shinohara et al., 2013). The aim of the paper by Nisiguchi et al. (2014) is to try and predict certain factors pruning for outbreaks of inflammatory incidents. In a broader perspective, the goal of the study was to prove if a system based on a smartphone could be developed in a manner, which could give RA-patients an opportunity to assess their own disease without consulting a Rheumatologist. One strength of this paper is that it aims to give the participants of the pilot study an objective output; a parameter for their disease level at the moment. Furthermore, the study excels, because it proves that a concept based on a non-invasive measurement can provide relatively valid data about disease levels compared to clinically applied measuring methods. Thus, providing empowerment by letting them become managers of their own disease.

There are, however, certain implementation aspects that can be discussed. The study is based on a pilot study of 67 participants, for whom the average age is 63,1 years (Nishiguchi et al., 2014). The sampling criteria seem comprehensive from a clinical perspective, however from an HCI perspective, it seems incomprehensive that no precautions have been made regarding the technological background among the participants. Especially given that the participants are 63,1 years on average, and equally problematic, that the smartphones they test the system on, are not the participants' own. The research in this master's thesis, on the other hand, will be carried out focusing on the user's own smartphones, eliminating that potential pitfall. Especially when focusing on smartphones that are considered a personal device, testing a system on the users' own devices are important.

Shinohara et al. (2013) also experimented with a smartphone based gait analysis tool, which should work as a self-assessment tool for RA patients. In this case the sampling criteria have obviously been made with an emphasis on clinical validity as well. The study is very similar to that of Nisiguchi et. al. (2014), leaving room for a variety of improvements when it comes to the developmental approach. Both these studies use a minimal effort, looking at user-friendliness of the system being developed. They even stress that it is an overlooked area of the research into self-assessment tools for RA patients.

The two articles emphasising the use of gait patterns as a variable in the measurement of disease activity (Nishiguchi et al., 2014; Shinohara et al., 2013), both serve as a proof of concept that non-invasive disease activity measurement is possible. Gilek-Seibert, Prescott and Kazi (2013) back up the point that patient driven outcomes of disease measurement is becoming more important. It is stated that the emergence of smartphones as assessment tools will provide more frequent and accurate modes of measuring disease, which, albeit being completely patient-driven, still upholds medical validity. The medical validity is kept by relying on the disease activity measurement concept, which is designed to work without neither involvement of physicians nor the necessity of a blood sample (Gilek-Seibert et al., 2013). Thus, smartphones have until now proven to be an emerging technology with a great potential in relation to RA, at least when it comes to the generation of valid disease activity measures

Papers focusing on tools for assisting the broader target group, Rheumatoid Disease patients, have also been published. They have a more user-centred point of view. These papers are accepted although they inquire a more generic group of arthritis patients. Three papers have been found with the common denominator that they inquire technological implementations in the health care situation of Rheumatoid Disease Patients (Gauthier, Lindwall, Davis, & Quinet, 2012; Hughes, Done, & Young, 2011; Lee et al., 2013). Two of the papers (Gauthier et al., 2012; Lee et al., 2013) focus on systems devoted to appointment reminders for consultations. Both papers outline a significantly higher degree of technological openness among younger people with Rheumatic Diseases (Gauthier et al., 2012). None of the studies, however, inquire or assess the feasibility of smartphones in particular as reminder systems, leaving space for further inquiry. Although these papers look at reminder systems, one important conclusion might be applicable in this master's thesis; according to Gauther et. al. (2012), young people, or generation Y as they are named in the paper, are the only segment in the study which show no preferences regarding reminder modality. The rest of the participants in the study tend to prefer analogue modalities like phone calls. Thus, the young people might be more likely to accept the use of smartphones for medical purposes.

The review article mentioned in the beginning of this section (Azevedo et al., 2014) clearly outlines the point that smartphones, given the fact that they are categorized as a pervasive technology, bring an entirely new dimension to self-assessment and self-management tools. In short, Azevedo et al. (2014) explains the potential of using smartphones this way: "[...] RD selfmanagement interventions can empower patients to become effective health care consumers in addition to improving clinical outcomes." (Azevedo et al., 2014, p. 4) A series of other articles assessing the technological approach to Rheumatic Diseases exist. However, they tend to lean more on clinical validation of a computer-mediated self-management tool than on context-aware systems development. Arthritis Self-Management Program (K. Lorig et al., 2005; K. R. Lorig et al., 2008), Arthritis Self-Help Course (Goeppinger et al., 2007) and Arthritis Self-Management Tool Kit (Goeppinger et al., 2009) are systems presented as solutions, which are proven to impact the lives of patients living with Rheumatic Diseases in a positive way. All studies rely on the user's willingness to sit down by a computer and type in data on a regular basis. That the participants of the studies overcome the work load involved in such activities, presents an interesting point. People living with chronic disease are willing to do a lot of work, in order to become more on top of their own disease.

These papers do show significant improvements in healthy behaviour when using the tools presented, however this leaves a relevant discussion regarding success criteria of the results. The premise for these results, in order for them to be considered a success, is to accept that there is a set of correct behavioural patterns when suffering from RD. On the other hand, the papers still present results pointing towards the efficiency of self-management programs in RA, regardless the platform.

So far the literature review provides a clear understanding that more research can be done in terms of understanding the potential of smartphones as a pervasive technology in relation to selfassessment among RA patients. In this master's thesis focus will be to uncover how this pervasive and effective self-monitoring technology, which a smartphone is, can adequately be designed for people living with RA to adopt it.
3.4.3 SMARTPHONE SELF-ASSESSMENT

Several topics are related to self-assessment via smartphone, however some tend to be more relevant when recognizing the scope of this master's thesis, which is to develop a system devoted to support RA patients benefit more from their consultations with their Rheumatologist.

Because self-assessment and smartphones are the central terms in this master's thesis, the first search queries that gave results of interest, were made based on those two words. A series of search queries were executed in the ACM Digital Library (Association for Computing Machinery, n.d.)(Appendix 1). The articles presented were found by the following queries: *("self-assessment" AND "smartphone") and (PublishedAs:journal OR PublishedAs:proceeding OR PublishedAs:transaction)*. Furthermore it was decided that the search query must occur within the abstract of the article in order to stress that the main focus of the articles must be on smartphone self-assessment.

Three papers of relevance were found covering smartphone self-assessment. Two articles describe a system named MONARCA, a system designed for bipolar patients. Its purpose is to generate insights based on tracking data as well as user-contributed data (Bardram, Frost, Szántó, & Marcu, 2012; Frost, Doryab, Faurholt-Jepsen, Kessing, & Bardram, 2013). The MONARCA papers examine how bipolar patients can dodge events of mental illness breakouts by being extraordinarily conscious about Early Warning Signs based on the user's behaviour. Awareness of these signs is pursued through a combination of sensor smartphone data, as well as users providing data to the MONARCA app, which in a synergetic process, through some mathematical predictions, enables the system to predict an outbreak of mental disorder. The exact data entities will not be elaborated here because they are considered too contextually imprecise to be of benefit in this master's thesis. However, the two papers about MONARCA do contribute with particularly interesting insights. The studies show that bipolar patients become more self-aware as the app provides visual representations of the data, showing changes in illness patterns. They even stress the value of such synthesized visualisations providing more complex insights about their illness. Another valuable insight is that the bipolar patients explicitly prefer visual representations on their smartphones contrary to a website presenting more complex and detailed representations. The finding is explained in the following quote:

[...] not all the self-reported data or the objective data was visualized on the phone, but was only shown on the website. But all the patients found this highly annoying; they wanted to be able to get access to all data on the phone, and the visualization needed to incorporate all data.

(Bardram et al., 2012, p. 29)

More than just encompassing an emphasis on the importance of the modality of the data visualisation, this also outlines that even the scientists of the MONARCA project seem to have presupposed something about data visualisation; in short that the complexity of data visualized is proportionally equal to screen size. During their study the presupposition was falsified. The MONARA scientists were not the only ones to get this conception wrong, Sunyaev et. al also outlines this understanding as well: *"While mobile phones can be well suited for data entry, we doubt whether they are the best choice for data exploration and visualization, and whether an accompanying PC program or Web site could be a better solution."* (Sunyaev & Chornyi, 2012, p. 5)

Although most papers were about treatment of bipolar disorder, another article was found during the search process that discusses principles for developing health care smartphone apps for chronically ill people (Sunyaev & Chornyi, 2012). The paper gives an opportunity to transfer some of the knowledge found from papers focusing on bipolar patients to the field on RA, due to the fact that both illnesses are chronic. This far in the literature review, various approaches to data visualisation revolving around the use of a relatively small smartphone screen as mediator of structured, statistical data, has been presented

Despite this discussion, the papers about self-assessment in smartphones seem to strengthen the argument that smartphones, regardless of screen size, show a great potential for self-assessment for people with chronic disease. By proposing such an antagonism against the idea, that complex visual representations of data must be presented on a large screen, a further inquiry into data visualisation is found necessary.

3.4.4 VISUALISATION

Next step in this exploration of the research field is to get a more thorough understanding of concepts related to the visualisation of data in the context health and smartphones. By searching for *("health information" AND "visualisation" AND "smartphone")* in Scopus and ACM, a series of articles were found, that proved a potential to strengthen the knowledge base for this master's thesis. One in particular; a review article about visualisation of health information (Faisal, Blandford, & Potts, 2013) proved interesting. Papers discussing this topic were found in the Scopus database, although ACM was also used for the initial search queries. ACM, however, gives no articles of interest due the high degree of specialization within the field of computer science, which lies outside the academic breadth of this thesis.

The article discusses various challenges in the field of visualising health data in a meaningful way. A considerably interesting point found during the review, was how merging quantitative health data with qualitative data about every day life can be help to reduce the gap between health professionals and patients. It is not only possible; it is also overlooked in the existing literature:

The information may take the form of readings and values generated from monitoring devices, medication time logs, or diaries in which they document health-related issues. Because patients are the ones who live with and manage these health conditions, representing the pure medical facts is not enough. The supporting health-care technologies must be designed in a manner that bridges the gap between medical needs and everyday life circumstances. (Faisal et al., 2013, p. 212)

From a social constructivist point of view, these findings make sense, due to the way in which it has been found that visualisations only makes sense in cases where the person subject to the visualisation finds the data meaningful. Linking these findings to those of the MONARCA studies further underlines the importance of acknowledging the preferences of the users; if the users find their own smartphone adequate for complex visual representations, those must be considered adequate regardless the screen size.

Another paper backing up this point is focusing on understanding the underlying concepts behind the practice of translating visual representations of information into insights. The study aims to understand how visualisations of information can be to the benefit of the user. It is called InfoVis in the paper (Yi, Kang, Stasko, & Jacko, 2008). This paper extends the argument by Faisal et al. (2013), by proposing the argument that visual data can not only shorten the interpersonal gap i.e. patient, Rheumatologist, but also bring new insights within a person, by tying complex health data to the world of a persons everyday life: One of the benefits of InfoVis is that the visual representation of data can decrease the gap between the data and the user's mental model of it, thereby reducing cognitive load in understanding, amplifying human recognition of familiar presences, and linking the presented visual information with real-world knowledge. (Yi et al., 2008, p. 4)

The MONARCA project works with both quantitative sensor data and data derived from user input, which could have been qualitative data. However, the project avoids the uncertainty of qualitative data by categorizing the qualitative measures in static quantifiable categories (Bardram et al., 2012; Frost et al., 2013), thus enforcing the aim to cognitive load for understanding, as proposed by Yi et al (2008).

RheumaBuddy, on the other hand, provides a diary function that requests non-quantified diary input that must be approached differently than in the case of MONARCA.

Linking qualitative and quantitative data has, however, been tried in a paper inquiring how personal communication patterns can be visualised and understood retrospectively (Zhao, Ng, & Cosley, 2012). During the study a system, visually representing personal communication in combination with keywords automatically retrieved from the correspondences, has been developed. A key finding is how users manage to make sense of the past by linking patterns seen in the visual representation with keywords derived from the same period: *"All participants linked keywords and patterns in the visualization to life events."* (Zhao et al., 2012, p. 29). Further on in the paper, it is argued that albeit the research design had put an effort into inquiring the user's ability to gain insights from broader patterns over time, the details remained central for the explanation of the past: "[...] *people use specific incidents and events as a fundamental way of reminiscing, reflection, and understanding the past, and that even if the goal is seeing a "bigger picture", details are important"* (Zhao et al., 2012, p. 30).

These papers inquiring about visualisation all present the idea that visualisations are able to bring new insights into the lives of oneself, thus giving more self-awareness to people. In the context of chronically ill people, this self-awareness is closely linked to the term *patient empowerment*, which relies on the concept of patients, in this master's thesis referred to as *people*. Thereby, the next step in understanding how these visual representations of qualitative and quantitative data can benefit the participants in this master's thesis, is to get a more thorough understanding of the term patient empowerment in relation to smartphone apps, and in relation to this case.

3.4.5 EMPOWERMENT

Within empowerment lies the assumption that a person living with a disease is the main source of information when trying to understand disease activity. The reason for this is that the person with the disease is the only person who is able to perceive the impact of the disease on the body. A review on the usage of empowerment explains the term empowerment in relation to *powerlessness*, which refers coping with the difficulties in a compliant treatment. Empowerment is, as a direct opposite, when the patient is able to manage diverging requirements from the health care professionals and their own personal goals (Aujoulat, d' Hoore, & Deccache, 2007).

These two diverging concepts about treatment rely on radically different ontological points of view. Compliance is based on a positivistic approach, emphasising *correct treatment* as a term referred to. If the treatment clinically enhances the wellbeing of the patients, treatment has worked. Opposed to that, empowerment approaches well-being differently by acknowledging that the only person able to assess the outcome of treatment is the patient. The following quote by Feste et al. describes the extended concept of well-being: *"Successful chronic disease management requires that patients be able to make choices that will help them achieve their personal and health-related goals."* (Feste & Anderson, 1995, p. 140). Achieving personal goals is a cornerstone in empowerment, as this is a clear statement that the person being treated is the owner of knowledge about what is important in relation to treatment.

Recent studies, however, have stressed that changing perspective from compliance to patient empowerment is more than a change of view. Medicinal practice must be radically changed as well, in order for patient empowerment to take place. This is explained in the following quote from a qualitative study of patient empowerment in Diabetes 1 treatment by Booker, Morris and Johnson (2008). They explain how maintaining empowered patients is manageable by taking a variety of actions:

Information and education provide some skills that an individual can use to develop and maintain a sense of control regarding their diabetes management, but psychological skills training is required to ensure that control is maintained across all aspects of their life. (Booker et al., 2008, p. 42)

Empowerment requires diverse initiatives to be carried out, as explained above and expanded upon below by Feste and Anderson (1995). However, certain aspects of implementing empowerment can be met by the technologies as described above in the literature review.

In a chronic disease model, many pieces contribute to that larger picture. These pieces include, but are not limited to: a skilled and caring healthcare team, including as its key member, the activated patient; medications and equipment necessary for managing or adapting to the disease; and disease-specific education that communicates to the patient what the disease is, why it needs to be managed and how to manage it. (Feste & Anderson, 1995, p. 143)

A central notion in the quote is that *the activated patient* is important for empowerment to arise. That part of enhancing the autonomy of young people living with RA, to become activated as patients, is what this literature review has revealed is possible. Extending the self-awareness of the patient by providing useful visualisations, on the basis of a comprehensive self-monitoring process, will be a part of empowering young people living with RA.

3.5 SUMMARY

The literature review has emphasized the work done in the fields of research that this master's thesis operates within. It has given valuable insights that have formed an informed basis for conducting the context specific research of this master's thesis. The following is the key findings from the literature review:

- Digital self-monitoring technologies can provide empowerment for people with chronic disease, by providing more self-awareness.
- Smartphones are particularly well suited as technologies for self-monitoring due their pervasiveness and sophisticated level of technological development.
- Smartphones are adequate hardware for health information visualisation. Users prefer even complex visual representations on their smartphone, due the pervasiveness of the technology.

During the literature review it was found that there is a lack of research literature into how smartphone health applications can adequately be created in collaboration with the potential users.

The next section will elaborate stage 2, which provides an explanation of how the detailed description of the problem situation has been researched and what the results have been.

Stage 2

Detailed Description of Problem Situation

Qualitative research has been conducted in this stage. Focus group interview, contextual inquiry and interviews have created the basis for determining the following main findings answering:

What are the main challenges of a consultation between young people living with RA and Rheumatologists?

- RA affects almost every aspect of everyday life.
- Young people with RA tend to have a negative attitude toward their Rheumatologist and the consultations.
- Consultations between Rheumatologists and the young people are focused on information presented on computer screens and
- Rheumatologists rely on simple and recognizable information because of sparse time allocated for each consultation.

4 STAGE 2: DETAILED DESCRIPTION OF PROBLEM SITUATION

This stage builds upon both the research questions as well as the findings from the initial research into the design field carried out in the literature review. Rheumatologists and potential system users, or as described in the section about participatory design, *participants*, will be brought into the research. Qualitative research is emphasized in this second stage of the design process. The stage will consist of a focus group interview, a series of observations of rheumatologic consultations followed by interviews with two Rheumatologists. The data gathered from those three qualitative research methods will then be coded for further analysis, which will take place in stage 3.

This section serves the purpose of generating a detailed description of the problem situation. In order to do so a detailed understanding of the consultations was needed, together with insights on matters that might have an impact on the consultations. In other words the qualitative research was initiated in an explorative manner by letting the participant discuss rather general questions regarding their condition and their use of IT. This was done to understand the situation from as many different perspectives as possible. The focus group interview was a divergent activity, as it explored potential influential factors regarding the consultations. The focus was then on converging as the focus was narrowed down to understanding the consultations from both the young peoples', the Rheumatologists' point of view, and from observations.

Each of the various activities performed, as part of the qualitative research design, will have its own section. It will present a focus at the beginning including one or more questions that will be researched by the chosen method. All questions will be marked with a number. The answer to the question will be pursued in the analysis results subsection followed by a summary of the findings.

The first part of this section will explain how the participants of the design team were recruited.

4.1 SAMPLING / DESIGN TEAM

In line with the participatory design approach, the design process has been conducted with a main focus on developing a system in close collaboration with potential users. They are the experts and therefore their knowledge and insights are key in terms of creating a useful and valuable system (Spinuzzi, 2005).

The recruitment for the design team was made together with FNUG with members in the age span of 12-35. This could have been a natural delimitation in terms of sampling the participants for the design team. Working with people above 18 is comprehensive due the focus on their relation to Rheumatologists. If some participants had been below 18, they would have been assigned to a Rheumatologist working with juvenile idiopathic arthritis (JIA). Thus not being within the scope of this master's thesis.

A team of six members of FNUG was recruited. They were all given informed consents to sign (Appendix 2) i.e. giving them information about the purpose of the study and how the data gathered from their participation would be used. The team consisted of one male and five females age 20 to 28. The scope of this master's thesis is not to investigate or uncover differences in preferences for mobile apps across age spans or gender. Hence, the sample is considered comprehensive for generating knowledge about smartphone usage in consultations.

The members of the design team agreed to participate throughout the whole design process that involved a focus group interview, a workshop and one user test session. However, working with humans involves risks of dropouts, which was also the case in this process. One of the members did not show up for the focus group interview. For the workshop four members announced their presence but one never showed up. For the user test four people announced their participation and they all showed up. There was no way to determine the reasons for the dropouts.

Given the qualitative nature of this research, the diverging number of members is not seen as a challenge. Because that the initial focus group interview had the highest number of participants, this provided a solid basis for covering the implications for young people living with RA.

The participatory approach to design had a lot of advantages, as mentioned in framework (section 2.2) It gave the designers an option to qualify the work that had been done on the basis of the finding and insights gathered from the participants, thus ensuring that the work was as close to the participants' needs as possible. This is a central part of validating the data. This overruled the risk that the results might get unified due the small sample of people that were to give feedback on the on-going design process, together with the findings from the other activities during the

qualitative research. The scientific point of view also prescribes advantages of studies with qualitative depth in comparison to studies emphasizing quantitative breadth in the sampling.

4.2 CODING STRATEGY

This following section will provide an overview of how the empirical data that was gathered as part of the qualitative research will be processed throughout the analysis.

The empirical data of this master's thesis consists of transcript text of all utterances from the focus group interview and the interviews with Rheumatologists. It also includes field notes from the contextual inquiry carried out at consultations with Rheumatologists. The field notes have been translated from keywords and phrases into understandable sentences. In order to carry out the analysis, the data has to be organised. This is done in a process of coding by labelling the content based on appropriate foci. (Coffey & Atkinson, 1996). The idea is to synthesize the data into categories. The purpose is to *"facilitate the retrieval of data segments categorized under the same codes"* (Coffey & Atkinson, 1996, p. 28). The coding has been carried out using an inductive approach, in the sense that neither categories nor codes are chosen in advance but rather, the researcher focuses on the actors and generates categories from their utterances with the research question in mind (Coffey & Atkinson, 1996).

The coding process made in this stage is an inductive process. It was made with the scope of the research questions in mind. The empirical data collected through the focus group interview, the contextual inquiry, and the semi-structured interviews; each of the data sets were separately coded. This was done with an exclucive focus on determining tendencies relevant for answering the reaserch questions. This approach ensured that all aspects of the data were analysed. Not only the data describing the consultations, but also the influential factors surrounding them, such as general knowledge about being young living with RA. The coding will be documented through the following stage 2, forming the basis for creating a detailed description of the problem situation.

The empirical data from the qualitative research is produced in Danish but whenever it is brought into the master's thesis it will be translated into English. The reason for this is that all of the people that were a part of the research design speak Danish as their first language. This of course impacts the original utterances, but the translations will strive to be as true to the utterances and at the same time to the English language.

The transcriptions of spoken utterances do not include pause words but otherwise, the transcriptions are true to the actual utterances word by word. Leaving out pause words does not affect the quality of the data, as focus does not encompass how a statement is presented but merely on the substance of it (Stewart, Shamdasani, & Rook, 2007).

Nvivo is used as a technical tool for organizing and analysing the empirical data. Its force lies with the ability to easily create codes that can be used across various sources of data (http://www.qsrinternational.com/about-qsr.aspx). Nvivo was used to transcribe the empirical data. It was then used to conduct the inductive coding. The software eased the process of sorting and searching through the data.

The first activity of the qualitative research was the focus group interview. It will be elaborated on in the following section.

4.3 FOCUS GROUP INTERVIEW

This following section is a thorough elaboration of the focus group interview carried out as part of the detailed description of the problem situation. Focus group interviews are collaborative interviews, in which a set of participants are encouraged to discuss a set of predefined questions. The questions are by no means sought to strictly determine the outcome of the focus group interview; they are used as guidelines for the discussions. A facilitator leads the discussion. The role of the facilitator is both to support the discussions as well as to keep the discussions on track, in relation to providing insights about the topic of the focus group interview. The purpose of conducting a focus group interview is to enhance the construction of knowledge in collaboration in comparison to individual interviews (Stewart et al., 2007).

4.3.1 Focus

As the literature review showed, more research into the specific case of supporting young people living with RA was needed. It was necessary to obtain a broader understanding of not only the consultations, but also to get more general knowledge about how the young people live their lives. The questions that have been explored through the focus group have contributed to answering the research question mentioned above. The topics, which the participants were to discuss during the focus group interview, derived from the overall research question:

What are the main challenges of a consultation between young people living with RA and Rheumatologists?

In order to do so meaningfully, a series of sub questions were made. The answers to these did altogether answer the research question just mentioned. They were as follows:

- 1. How is everyday life living with RA?
 - a. This question must be answered in order to ensure that requirements are not left out in the initial research of the problem setting.
- 2. How do the young people living with RA perceive their consultations with their Rheumatologist?
 - a. As the main purpose of this master's thesis is to understand how the young people can benefit from a smartphone app in consultations, this questions aims to narrow down the scope from everyday life to the specific situation of a consultation.
- 3. How do the patients use their smartphones?

- a. This will uncover whether the young people have different smartphone usage patterns compared to young people in general.
- 4. How can IT support consultations? Is it done already?
 - a. This research question is proposed, as it will provide insights into the already existing practices among the young people regarding technologies to support them.

4.3.2 Setting

The focus group has been held in a conference room at Daman in Copenhagen. This setting was chosen due to the fact that the facilities were available, but also because this master's thesis had no scope for considerations regarding where in Denmark the participants live, thereby legitimising that all participants live in either Copenhagen or nearby areas.

The setting is considered adequate, as FNUG is already a costumer at Daman. However, both FNUG and Daman might have shared interests in exposing Daman as a compelling company. The argument that this setting is still suitable, is that the intervention, regardless of the setting, would be biased by the fact that the research in this master's thesis is done in collaboration with Daman.

4.3.3 INTERVENTIONS

The focus group interview was recorded on an audio recorder as focus was on the topics that were discussed rather than the mood or the tone surrounding it (Stewart et al., 2007). It is acknowledged that the attempt of keeping the situation as welcoming as possible was to some extent compromised by recording the event. This, however, was not regarded as a problem because the stimulation and excitement of the discussions seemed to overrule the awareness towards the presence of the recording equipment.

An interview guide was made together with a playbook (Appendix 3). The playbook consisted of time estimates for the various topics together with a section providing an overview of the expected outcomes from the various topics. The interview guide served the purpose of providing an overview of the questions that were to be discussed during the focus group interview.

4.3.4 CONSIDERATIONS

Methodological considerations played a role in the decision to choose focus group interviews as one of the three methods for data generation. Focus group interviews, in the way they were carried out here, did emphasise a social constructivist approach to the data, which could be derived from the session.

Although the outcome of this focus group is not aimed at bringing new insights about group dynamics per se, the literature mentions an opportunity to end up with a more sufficient data set, if the group of people involved in a focus group is, to some extent, like-minded. Stewart et. al. (2007) describes it like this:

"The more cohesive the group, the more power the members have and, therefore, the greater the influence exerted over each other. This means that the cohesiveness of a focus group is a critical element in ensuring interaction. Thus, a sense of cohesiveness may facilitate discussion of even the most sensitive topics." (Stewart et al., 2007, p. 26)

Being both similar in terms of suffering the same chronic disease, the participants also have their ages in common, and even more, they are part of the same patient organization. These are strong predictions that the participants are willing to contribute to the discussion.

Willingness to share experience on sensitive topics is imperative to this focus group interview. The participants are supposed to discuss a pervasive chronic disease, impacting all aspects of life: "[...] *RA has an important impact on everyday life, with not only physical consequences, but also important social and psychological implications for the individuals and their families* [...]" (Kristiansen et al., 2012, p. 30). Thus emphasising even more the importance of a particularly homogenous group for this type of focus group interview, in order to reduce the risk of participants feeling stigmatized by their sensitive statements. This is explained in Stewart et al.: "*Similarly, in culturally and racially homogenous group situations, it may be easier to encourage member participation.*" (Stewart et al., 2007, p. 22). Hence, pursuing a homogenous group of participants is considered from an ethical perspective, as sensitive statements will occur during a focus group about a chronic disease.

4.4 ANALYSIS RESULTS

The outcome will be presented in this section by emphasizing the tendencies found throughout the focus group interview. The structure follows each of the research questions mentioned at the beginning of the section *focus* above:

1. How is everyday life living with RA?

The participants were encouraged to describe to a person not living with RA, how everyday life is affected by the disease. The following quote explains that morning stiffness is one of the challenges that a young person with RA has to deal with. Not only does the quote explain the physical challenge of stiffness, attention is also paid to how other people might not understand the situation, although it is a physical matter:

P1: Something that, like, arthrithis patients probably feel, which you probably don't feel, is probably morning stiffness. We are very affected by weather, such as humidity and cold and heat and so on and so on. That was also why we, for example, said that now the winter is over while we were in there, if you know what I mean by that.

(Appendix 4, p. 2)

Another major challenge is fatigue:

P2: I think it is the fatigue, the enormous fatigue that you can have, always. That is, regardless of whether you sleep for twelve hours or not, you can still wake up and be completely devastated, and you can fall asleep at 8 PM for no good reason. So fatigue and a kind of restlesness in the body if you sit still for too long. Where your knees, or somewhere else, simply start hurting and need to move.

P3: I also think the fatigue has been the worst. You can live with the thirty minutes that pass each morning before your body is, like, warm and working and so on, but the fatigue, that's just all the time.

(Appendix 4, p. 2)

The persistent and yet inconsistent situation of feeling tired is considered even worse than the stiffness mentioned above.

Young people living with RA have to take a lot of medicine to live a tolerable life, but this is not without consequences:

P5: And then there's all those pills

(laughs)

P4: And all those damn side effects that you aren't told about anyway until you discover them on your own.

P5: And then there's all the pills you need to take because you're taking pills.

P4: Yes exactly, the pills you have to take because you get some side effects

(Appendix 4, p. 2)

The quote shows an example of the young people stressing side effects as a challenge, partially due to the fact that sometimes the young people have to take medicine in order to deal with the side effects caused by another type of medicine.

Finally the biggest issue of being young and living with RA is the psychological pressure that the above-mentioned challenges raise. An example of this is shown in the following quote:

P1: I think what I'm dealing with the most is frustration and anger. A lot. I'm living in a dorm, so I have a lot of people around me all the time, right. And they jump and dance around. And then I come trundling along. Limping on my right leg, right. That can lead to some complications in my head, right. There's a lot of that.

P6: Having to say no without really wanting to say no. That can also be really frustrating

P2: That is by and large a lot of it. It is recognition in various ways. Recognition of your own limitations and other peoples' recognition of your illness and the limitations you have, without questioning them so much

(Appendix 4, p. 7)

The quote shows that the young people have to say no even though they want to participate in a given event. Being together with others also challenges them when they have outbreaks of inflammation. As seen in an earlier quote, the young people seem to presume that other people are unable to understand their conditions, since it is invisible, yet highly inconsistent. Literature supports the finding that young people are more prone to psychological impacts of living with RA (McDonagh & Kaufman, 2009).

2. How does the patient perceive their consultations with their Rheumatologist?

The young people explain that the standard time span between consultations is three months but it varies depending on, for example, new medicine, changes in the intensity of the disease, and frequency of outbreaks. Throughout the focus group interview a tendency of a negative attitude

towards the Rheumatologist came up time and again In the following quote, the participant imitates the Rheumatologist:

P2: It's not going so well. I'm in pain. Oh. Okay. Your blood samples look fine. So give it another half a year. And then you're almost out the door again. You get your prescription renewed and then you can walk away again. That's roughly how it happens. Oh you have swollen joints, no you don't, then we'll continue.

(Appendix 4, p. 14)

Another example of the participants' negative attitude towards Rheumatologists is shown in the following quote. The participants show dissatisfaction when they feel that their Rheumatologists do not care about the outcome of the consultations:

P4: To present a nice picture to the public, that they actually care about what happens. I can remember from my consultations, nothing happened at all.

P2: I don't think it does at mine either. It takes at most ten minutes. Then I'm out the door again. And the only reason it takes ten minutes is because it takes him five minutes to figure out the electronic prescription system, he can't figure that out. Like. That's about it.

P4: The other five minutes, they're spent on that little thing he speaks latin into, which you don't understand a single word of anyway.

(Appendix 4, p. 16)

The quote exemplifies how the consultation is almost over before it is started due to the Rheumatologist rushing the event. Another example is related to the change from youth to adult:

P6: Like, I'm in the transition from youth to adult department. And my. The way I've been welcomed at the adult department has been shit, to put it mildly. Like, the woman I met at my first consultation at the adult department. She seemed completely disinterested in who I was and what I had to say about my illness. It was just like. Come in. How are you. Well I feel like this and this. Well then she took a look at this and that and then I was out the door again. There was no conversation involved and you didn't actually feel like she cared at all about who you were. And how, like. How things could have triggered eachother. And how your illness had developed. I missed that a lot, the sense of closeness, that they actually cared.

(Appendix 4, p. 18)

There seems to be a significant change in the amount of investment from the Rheumatologist in the patient when it comes to the difference between the two departments. An example that the Rheumatologists, according to the participants, do not care about the questions that they bring to

the consultations was another topic of interest for the participants. An example is shown in the following quote:

P4: It is a little difficult to prepare for something when. When you then come in if you've prepared yourself what. When I went into the youth department at Rigshospitalet I always had a book with questions. But the doctor didn't care.

INT: Were those prepared beforehand?

P4: Yes

P3: I've done the same.

(Appendix 4, p. 19)

The example shows a tendency that the young people perceive that their expectations for the outcome of consultations are less important than the Rheumatologist's schedule. There are also doubts about whether or not the Rheumatologist read the patient journal before the consultation:

P4: No no. They know more. I've been in the back. What the doctors say when they're making rounds. That's what they've been told by the nurses to say. The doctors don't know shit. They don't read journals and stuff. It is the nurses who say this patient so and so. I think we should do this and this. What do you think about that? Fine. Well, then we'll do this and this. Could you please say that.

(Appendix 4, p. 20)

A lack of interest in the patient from the Rheumatologist was a big part of the concerns regarding the consultation. Discussing merely professional health related topics in a manner, which is sufficient for the Rheumatologist is not considered adequate for the patients to feel taken seriously. However, there were some inconsistencies with regards to the perception of the Rheumatologists professionalism. This can be seen in the following two examples:

P2: I don't think it does at mine either. It takes at most ten minutes. Then I'm out the door again. And the only reason it takes ten minutes is because it takes him five minutes to figure out the electronic prescription system, he can't figure that out. Like. That's about it.

(Appendix 4, p. 16)

And the opposite statement is made here, within the same discussion:

P3: Like, I'm always in there smalltalking with my doctor for a few minutes. Five minutes while I'm there. I've always thought it was a bit strange until, actually, last time I was there. Then afterwards I received a mail saying that my muscular figures were too high, but that I shouldn't be too concerned about that since I just started doing badminton. So that was probably why.

(Appendix 4, p. 16)

This contradiction towards the Rheumatologist's work has to be taken into account and it was made subject for consideration in the following activities of the qualitative research design.

3. How do the patients use their smartphones?

The usage of smartphones was not any different from what could be expected from a young person not living with a chronic disease. The use of smartphones plays a central role in their lives. It is used to store and plan activities, as tools for communication, keeping up to date with news, and as entertainment through music and games:

INT: what do you use them for on a daily basis, not like arthrithis stuff, just

P5 everything

P6: my whole life is in my smartphone, almost

P2: I was just about to say that. It is the daily planning, mails, texts, calls, facebook, news, music.

[...]

P4: frost
P2: frost oh yes, games
P1: and you make it sound like we're the weird ones.
P2: it's a good way to wind down and just sit
(Appendix 5, p. 1)

There was only one example of one of the participants using the smartphone in relation to the disease, explained in the following quote:

P1: I use one called health and fitness a lot, where I go in and look at different workout schedules, and there you can, there's a lot where it's like, at home workouts where you don't need any equipment. But then you can sit and do some pilates or whatever you feel like at home, and can strengthen the joints on a rough winter's day or something. That's what I use, for example.

(Appendix 5, p. 1)

P1 has used an app on his smartphone as an inspirational source for choosing exercises that help him minimize the morning stiffness.

4. How can IT support consultations? Is it done already?

Only one of the participants uses her smartphone to support her in consultations. She uses RheumaBuddy but the others support her arguments about how RheumaBuddy can help in relation to consultations. Two central elements are expressed as benefits from using a smartphone in consultations. The first is to become more self-aware by having an overview of the disease activity. The second is to have a tool which can provide insights to the Rheumatologist via visual representations:

P6: Like, I've used it a lot when I had an iPhone. Now I've changed (phones, red.). And it made a difference in terms of being better prepared and having a better overview of my disease which was awesome. So it's been a massive help for me.

P2: but it appears a little better when you show at the Rheumatologist's, that you can like, show him and say, look at this. I don't know. If you could get like, charts or something like that. Like, this was when I felt really bad. That you could see that you actually. That it's legitimate and you aren't just making up that two months ago you felt really bad, and have to sit there and try to remember roughly how many days it lasted and so on.

P4: And on which level it roughly was, whether it was a good 5er or if we were up in 9, where you're in fetal position and just about to cry, or whether you're down to 3, right.

P3: Yes and it could also help oneself to like, straighten your back in front of the doctor and say that it was like this, and you can see that there. Whether otherwise you might have forgotten.

(agreement)

(Appendix 5, p. 5)

She explained the value of bringing information that was visualized on the basis of self-assessment data. It gives the young people enhanced arguments in the consultation both because it provides a visual presentation of the activity of the disease but also because it helps them to remember episodes that they otherwise would have forgotten.

4.4.1 SUMMARY

The main findings were that almost all aspects of life are affected for these young people living with RA; spanning from physical constraints to physiological challenges caused by the limitations of everyday activities, pain level, and a lack of understanding from their surroundings. There is a divergent attitude to how the consultations with the Rheumatologist are perceived by the participants. However, they all agree that there is room for improvements. The young people demand that the Rheumatologists do not rush the consultation and that they take more interest in personal and clinical matters that are exclusive to each individual. Some of the young people felt that their Rheumatologist displayed a lack of interest because they did not engage in small talk, while others did not perceive this as a problem. The usage of smartphones does not differ from what could be expected from young people not suffering from a chronic disease. They use their smartphone all the time to communicate, plan activities in their calendar, play games and listen to music. Thus suggesting that no special precautions must be made when designing to this specific target group.

These were the findings from the focus group interview. The insights will be supported by the findings from observations of consultations, as well as the Rheumatologists' point of view, and these points will be presented later on for the design team to validate the findings.

4.5 CONTEXTUAL INQUIRY AT GLOSTRUP HOSPITAL

The following section will unfold the fieldwork done in order to get a detailed description of the problem situation. Insights from the young people living with RA created some knowledge but in order to get as close to understanding the situation as possible, observations were conducted in order to get a detailed understanding of the setting surrounding the consultations. During the consultations the observer strived to stay as unobtrusive as possible. However, between consultations contextual interviews were made in order to deepen the understanding of the activities that observation alone could not explain (Gold, 1958).

4.5.1 Focus

There were several reasons for doing contextual inquiry in the field. The purpose was to supplement the knowledge about the consultation gathered at the focus group interview, in order to be able to understand the situation in more detail. Observations ensures that the research does not lack important details of the problem situation, as it is known that participant sometimes do not describe the events as they actually happened. This can be caused by both a tendency for participants to elaborate on what they might think is the most interesting for the interviewer to hear, and that their familiarity with the situation causes them to leave out certain details (Swenton-Wall, Mosher, Giacomi, & Blomberg, 1993).

This section will gather information for answering the following question:

What happens at the consultation between young people with RA and their Rheumatologist?

4.5.2 Setting

The setting was chosen to be "Videncenter for reumatologi og ryglidelser" at Glostrup Hospital. The contact was made through Daman. The gatekeeper was a chief physician with whom patient recruitment was coordinated. This was done by sending a patient protocol (Appendix 6) together with an informed consent that needed to be signed by the patients who were willing to participate (Appendix 7).



Figure 5 - Observation Setting

The setting is pictured in the figure above (figure 5). It shows a representation of the physical objects present at the consultation together with a visualisation of where patient, Rheumatologist and the observer was placed. The observer was placed away in the distance in order to cause as little attention as possible. Additionally the positioning made it possible to observe the Rheumatologist's computer screen. This was deemed important because the understanding of already existing technological devices in the consultation must be understood. Another thing worth noticing was that the computer screens were the center of dialogue between the patient and the Rheumatologist. Not only in the sense that the Rheumatologist did look a lot at the screens, but the patient was also invited to look at the screens. This indicates that bringing in a smartphone to the consultation might not cause too much change in the norms of a consultation, leaving some chance that a smartphone app could be adapted in the context.

4.5.3 SAMPLING

A gatekeeper, a chief Rheumatologist, curated entrance into the field. Daman had a connection to a Rheumatologist that referred to what came to be the gatekeeper of the field. He picked two Rheumatologists that invited the researchers into their consultations.

4.5.4 INTERVENTION

The qualitative research sessions were performed as contextual inquiry. This allowed the researcher to participate in the field and obtain insights from the observations themselves but also by conducting contextual interviews. This interview technique can uncover what observations might not show. It is important, though, to keep in mind that it interrupts the person's everyday routines and the interruption must be subject to consideration (Dix et al., 2004). The researcher did not interrupt the consultation itself but questions with regard to specific aspects of the consultation were asked between consultations.

Choosing this methodological framework gave the opportunity to map the consultations with all actors that had an influence on the setting. This made it possible to obtain a detailed understanding of the consultations, creating a basis for a greater understanding of the knowledge gathered from the focus group interview, but also the interview with the Rheumatologists regarding their experience of the consultations.

The observations were recorded on neither audio nor video. This had to do with the emphasis on understanding the situation without focusing on the individuals as such. Sticking with note taking also preserved the privacy of the consultation to a greater extent than it would be possible with recordings.

Making field notes is an individual activity. It serves the purpose of recalling memories of the situation after the event has passed (Blomberg, 1993). The structure of the note taking was that the notepaper was divided into two columns, *factual observations* and *interpretation of the action*. Afterwards the notes were processed into actual text that was subject to the following coding process, fostering the opportunity to include segments of the data into the Master's thesis.

4.5.5 CONSIDERATIONS

The observational role will strive to be as unobtrusive as possible (Blomberg, 1993). In reality this is not possible because the observer will always have an impact on the situation by simply being present. One way of minimising this issue is to be given a culturally appropriate role allowing the observer to *hang around* (Blomberg, 1993). In practice this is done by providing the observer with white coats and inform the patient that the conversation is confidential and the information obtained is not being linked to each individual but solely used to try and get an understanding of the consultations as such. Although the presence of an observer inarguably has an impact on the situation, that is not invalidating the data from a social constructivist point of view, because there is no such thing as an objective and unspoiled consultation.

It is a known fact that patients expressed personal facts during consultations and it must be taken into account that the presence of the observer might influence this (Blomberg, 1993).

The fact that Daman provided the contact to the outpatient clinic at Glostrup was not considered an issue as none of the Rheumatologists had participated in any activity related to Rheumabuddy. Nor did they know of the Rheumabuddy project at all.

4.6 ANALYSIS RESULTS

The findings from this intervention can be seen in section (2.4) where the rich picture is displayed. As the findings from this intervention have already been presented, no analysis results will be presented here. The reason for this structure is that the rich picture made on the basis of this intervention serves as a part of the structural framework for this master's thesis. Instead, this section served to provide methodological knowledge about how the data for the rich picture was created. This argument also explains why a summary in this section will not serve any purpose.

4.7 Semi structured interviews - Rheumatologist

Another intervention consisted of two interviews with two Rheumatologists. The methods and findings will be elaborated in the following section.

4.7.1 Focus

The interviews were made in order to understand the consultations in more detail and to gather insights from the Rheumatologists, as they have to, at least to some degree, be open towards adapting the system. The research questions that were to be answered by this activity is as follows:

From the perspective of the Rheumatologist, what is the purpose of the consultation? And what are the optimal conditions for a successful consultation?

4.7.2 INTERVENTION

The interviews were made as semi-structured research interviews. This means that the interviews were kept as conversations but with a certain focus. To ensure that the focus was kept, an interview guide was created prior to the interviews. The guide was made as an actionable version of the research question for this section, which is listed above (Appendix 8) (Kvale, 2009).

4.7.3 CONSIDERATIONS

During the focus group interview, sentiments questioning the professionalism of the Rheumatologists were expressed. Although the theme kept occurring during the focus group interview, disagreement was found among the participants, which might indicate that the procedures in consultations vary a lot according to which Rheumatologist is consulted. This consideration is addressed by relying on a variety of qualitative data sources. Conducting contextual inquiry as well as interviews with Rheumatologists will provide additional knowledge about how consultations occur.

4.8 ANALYSIS RESULTS

The point from the two interviews will be reviewed in this section. The Rheumatologists both mentioned the evaluation of medicine as the main purpose as an appraisal of the patient's condition, when asked what the main purpose of the consultations were:

RH1: Yes, it is to evaluate the actual effects of the treatment, as well as the disease activity. To see if there is a need to adjust the treatment. Improve it if there is activity in the disease. But also generally just to hear how things are going. If there are other problems that need to be solved. There can be some social issues. There can be a need for training. There can be a need to contact the municipality. But primarily that's. The reason for regular control is to keep an eye on whether they can handle the treatment. That is also why they have blood sample checks all the time.

(Appendix 9, p. 1)

The other Rheumatologist answered:

RH2: Medicinal updates and blood sample control. As in how are things with the patient's disease. Because some patients, for example, feel like they're doing fine, or neglect their disease. But they don't want to increase their medication. Or. Many different reasons, so it's good to say, like, aren't those joints swollen? Is that something that's like, additional? As a symptom.

INT: Then it's different how. Where you experience the difference between what the patients want to achieve and what you want to achieve.

RH2: But you try to negotiate expectations. I do that sometimes as well, when I feel. There's a lot of communication in body language. And a lot of things like that. But I feel like they're a little, like. Dissatisfied and I can see the confusion in their eyes. So I ask, like, did you expect. Like, what would you like? Is there something else we should do? Like, talk about. Is there anything you'd like to ask me about? So I try to finish the consultation by sending them onwards.

INT: Is there anything

RH2: And then of course, like, when you have these chronic patients, then we've seen them a few times before. So we have a rough estimate of their needs. So you know that, like, this patient wants to know their medicine thoroughly. Some patients want a little back and forth.

(Appendix 10, p. 1)

The two statements outline how the Rheumatologists focus mostly on medical procedures when describing the desired purpose of a consultation. An interesting point is that one of the Rheumatologists mentioned a more nuanced view on the purpose of the consultation. This includes a focus on more personal aspects of living with a chronic disease. The tendency of the two interviews was clear in relation to questions aimed at determining the optimal conditions for a consultation from the Rheumatologist's point of view. Emphasis was on the short amount of time allocated for each consultation. An example of this is shown in the following quote:

INT: What would more detailed information, like, help you with in the consultation? Would it be helpful to you in any way over time, if a diary had been kept, for example.

RH2: No.

INT: It wouldn't.

RH2: No. It is. It is too time-consuming to go through it.

(Appendix 10, p. 1)

The Rheumatologist explained that detailed information would be too time consuming to include in the consultation. However, there are some indications that the Rheumatologists acknowledge the need for more information about their patients, at the same time stating the necessity of simplicity of this data:

INT: Back to where we talked about if you agreed with a patient that keeping a diary would be a good idea. What's the format? What should they write down?

RH2: As little as possible. As clearly as possible. Because you don't have time to read it. Because when the patient comes in with a stack of papers like that and says. Listen to this. Or expects that, like. Now you need to read how everything's been since the last time, and you have 25 minutes. That's not going to be a very thorough reading.

(Appendix 10, p. 3)

The Rheumatologist emphasises the importance of making the information uncluttered, stating approachability towards the idea of being presented with patient data:

RH2: As I said, like. I don't know, like. As clearly as possible, so that, what should I say. Not too much reading.

INT: No, so that if it was visually presented in som way, you'd be able to talk about it. That could be very.

RH2: And then you could elaborate from there. And say, what's that there?

INT: But that. Does it make sense to do that in all consultations, if you did that?

RH2: No.

INT: No, it doesn't. Okay. No, that's fine.

RH2: Yes maybe if you chose no details. Like I see it now, then no. But you're open for the possibility.

(Appendix 10, p. 3)

In order for the Rheumatologist to adapt or relate to more information the format has to be recognizable and simple to create value. Although this tendency is the most prevalent, the Rheumatologist also expresses the possibility that other information sources might contribute in understanding the patient:

RH2: No. I could imagine that they looked like something I was used to looking at. Like. So that in some way was reminiscent of. So that if you had a DAS-28 CRP calculated. You could't do that of course Because you'd have a CDAI where a CRP isn't a part of it. Hehe. But that's doctor-nonsense. So there is something. Like. No, but like, some kind of other way for me to measure it. But in reality it might be some entirely different things you would need to know to hear how the patient is doing, right. So this is something fairly well validated, which has been made in cooperation with patients, but. But something so you'd get an overview, right. And it shouldn't be too complicated. Like it would have to be something where you'd be able to look at it and say. Okay. You felt bad then. Then you have to ask. Like. You don't have time to read diaries, right?

(Appendix 9, p. 2)

The findings in this section will be summed in the next section, providing a brief overview of the outcome of the interviews.

4.8.1 SUMMARY

The Rheumatologists mentioned evaluation of medicine as the main purpose of the consultation. This is the basis for appraising the patient's condition and to plan further treatment. With regards to optimal conditions for a consultation, the Rheumatologists emphasised the limited time allocated for each patient as a constraint for optimizing or changing events in the consultation. However, the Rheumatologists are open to the idea of getting more detailed information about their patient as long as it is kept simple and is recognisable. They stated that they might even benefit from more data.

From this elaboration of the detailed description of the problem situation, the following section takes on the scope of systems thinking about the world towards the findings from the qualitative research analysed.

Stage 3

Generate Root Definition for the System

This main purpose of this stage is to apply a technological focus as an elaboration of how the system thinks about the world. It will answer:

Which aspects of the consultation does the system need to support?

The main findings are that the system has to:

- Support the young people by giving them insights about their disease activity over time, empowering them in their every day lives and in consultations with their Rheumatologists.
- Generate simple and recognizable visualisations of data in order for the Rheumatologist to allow it into the consultation.

5 STAGE 3: GENERATE ROOT DEFINITIONS FOR THE SYSTEM

Focus in this stage is narrowed down, locating the requirements of the various stakeholders and relating them to how a system could support these. The activity was initiated in order to analyse the data more focused on the basis of the knowledge from the detailed description made at stage 2. The overall purpose of stage 3 is to generate root definitions for the system and thereby contribute to answering the research question:

Which aspects of the consultation does the system need to support?

In order to answer this, an analysis of stakeholder requirements will be conducted in order to determine the actors involved in the consultation and to pinpoint their requirements.

5.1 ANALYSIS OF REQUIREMENTS

The stakeholders have been presented in the framework (2). They will, in this section, be placed into categories defining how they relate to the system.

The categories that the stakeholders will be placed in follows the CUSTOM approach, which divides them into four categories: Primary, secondary, tertiary, and facilitating (Dix, 2003a). The CUSTOM approach will only serve as inspiration for the categories for placing the various stakeholders. This is because the CUSTOM approach is focused on organisations and workflows between work groups inside these (Dix, 2003a). The focus of this master's thesis lies with the relation between Rheumatologists and young people living with RA. Therefore the Soft Systems Methodology, used as framework for this master's thesis, is considered more adequate at covering this relation due to the fact that it is not focused on a particular context. However, the categories that CUSTOM presents in relation to stakeholders are useful and therefore used in this section.

Stakeholders categories:	Stakeholders:
Primary - refers to the end-users who will be using the system	Young people living with RA.
Secondary - are the stakeholders who provide input to the system or receive output from it. These do not directly use the system	Rheumatologists.
Tertiary - the stakeholders who are dependent on the success or failure of the system	DAMAN, FNUG.
Facilitating - stakeholders involved with design, development and maintenance of the system	DAMAN.

The stakeholder requirements were determined on the basis of the coding process of stage 2. This gave the advantage of not only being able to stress the requirements of the stakeholders but also to link the requirements to research areas, known from the literature review, providing knowledge towards principles for supporting them.

The following section will provide an overview of the requirements of each of the stakeholders, exemplified by a quote from the empirical data.

5.1.1 YOUNG PEOPLE LIVING WITH RA

These are the primary stakeholders as they are the ones to primarily use the system and furthermore exclusively the ones to provide input to the system (Dix, 2003a). Overall, a total of seven requirements were found and they will be examplified one by one.

1. Comprehension from the Rheumatologists

The young people require their Rheumatologists to believe them when they elaborate on how they are doing. Their point being that they are the ones with RA and therefore the only ones who know how that affects them.

The following quote shows an example of an agreement towards the lack of comprehension met when attending consultations. The young people found it difficult to get acknowledged due the rarity, inconsistency and invisibility of their disease. The participants articulate how their Rheumatologists react when presented with information about their condition:

P3: I also think that if you've got something when you show up. Then I feel like the doctors sometimes have a hard time believing that that's what you've got. That you can feel the difference between one thing and the other or something like that. They don't believe that, for example.

P4: Are you sure?

P2: How does it hurt?

P3: No, exactly.

P2: No, I'm not sure that that's arthritic pain.

P3: Yes, it's probably something else.

P4: It's really like you're told. You're told. are you certain. I don't think so. But it's my body for crying out loud

P2: I've gotten that reply many times. It's not arthritic pain.

P3: As if you don't know how it feels, really.

P4: It's just like. Which one of us has arthritis on a daily basis?

(Appendix 4, p. 15)

This indicates that one of the requirements the system has to fulfil is to somehow support the young people in a way that gives them something to strengthen their arguments when attending consultations. The system might help to suppress the challenge described in the requirement. If successful, a system that can support this will promote a better relation between the young people and their Rheumatologists.

2. Online HAQ-questionnaire

This was a point stressed by one of the Rheumatologists; that some of her patients had asked for the possibility of answering the HAQ-questionnaire at home:

RH2: Young people. Yeah, that happens often. They want to have like, can't you do that from home?

INT: Okay. But you can't do that?

RH2: You can't. I think it's a good idea to have it on the actual day.

(Appendix 11, p. 1)

This was a point mentioned by one of the Rheumatologists on behalf of the young people. The point was nevertheless taken into account and presented for the design team, giving them the chance of disqualifying the statement if they disagreed.

This requirement has to do with making a mandatory obligation that comes with living with RA as convenient as possible. A system that can support an online HAQ-questionnaire will also empower the patient in the sense that they are the ones who determine when, on the day of the consultation, they will fill in the scheme. It might sound like a minor improvement but it will nonetheless strengthen the autonomy of the young people.

3. Individual preparation prior to the consultation

The HAQ-questionnaire did not suffice in terms of targeting relevant difficulties among all patients. It was found to be too generic. I.e. a person suffering RA in the lower back will not benefit from answering questions regarding tasks dependent on the functionality of a person's upper extremities. The following is an example of an utterance towards individualized preparation. It was suggested that the Rheumatologists should somehow prepare a personal questionnaire for each person:

P1: Then it could maybe. It's maybe difficult to just specify a questionnaire just for me. That's almost how it should be done, that my rheumatologist should finish a questionnaire for each patient in relation to that patient's situation.

(agreement) yes

P1: So you're more like, yes, user-oriented for each person.

(Appendix 4, p. 25)

This requirement encompasses the need of the young people to be acknowledged as an indivdual. Not as a generic definition of a patient living with RA. It also suggests a willingness of the young people to perform self-management if it is individually designed.

4. Dating back information about their condition

The young people elaborated the need to discuss the status of their condition on a more nuanced basis, rather than relying on information about how they are doing at the moment. They want the information to be based on events dating back in time.

P1: Well then he has like. He's got the results immediately when I enter. And he goes through them rapidly to see if it's gotten worse or better. But for crying out loud, that's just. I can only tell how I'm feeling on that specific day like that. They rarely go back very far, those questionnaires. It's very much a snapshot of the moment. And that can vary.

(Appendix 4, p. 24)

It is elaborated further in the following quote:

P1: It would be nice if they asked how things have been the past month or three months, because I have a consultation every three months, right.

(Appendix 4, p. 25)

The HAQ-questionnaire and the consultations refer to how the patients are doing at the moment but the young people want to refer to events dating back up to three months.

The young people showed that they do not find the measuring of the current state of their disease activity sufficient because it only refers to how they are doing at the moment. A system that can support self-assessment over a longer period of time will not only ensure that the activity of the disease will be tracked over time, it will also strengthen the empowerment of the young people due to the fact that they will be the ones with the detailed information about their condition.

5. Differentiated intervals between consultations

The young people experienced an arbitrary correlation between the frequency of consultations and their own perceived state of disease activity. They wanted the time between consultations to be subject to individual needs rather than standardized intervals. They do not see the point of attending a consultation for ten minutes stating that nothing has changed:

P2: It's actually why I think that a questionnaire that's better, as MI says, adapted individually, so that you could answer it. And if you're okay with seeing a doctor often, then you should do that, but like, I think it's a damn waste of time to go to Gentofte to be there for 10 minutes and then leave again. I spend more time waiting for blood samples than talking to my doctor that day.

(Appendix 4, p. 25)

A possibility for a system to support this requirement could be that intervals between consultations were based on the young peoples' self-monitoring of their condition over time. This could help to reduce the number of consultations where the condition has not changed thus making the consultation unnecessary. In supporting this requirement comes a discussion toward the fact that the young people would have the opportunity to manipulate the data in order to get fewer or more consultations depending on their agenda. Although this is a concern, it is not considered a problem as consultation frequency relies on more than input solely derived from the people living with RA, because the Rheumatologist will also do some clinical assessments of this.

6. Comprehension from the surroundings

A major challenge for the young living with RA is the lack of understanding from their surroundings. They are often met by the assumption that Arthritis is only something that elderly people suffer from:

P4: Like, for example, I know it can sound whiny, but if you're having a bad day and you can't use your legs, and you're sitting in the bus, then many people have that sort of "there's an old lady, she wants your seat and you get up"-thing. I've had several arguments with people because it might well be that you've got arthritis, but so have I

(Appendix 4, p. 6)

The surroundings are also having trouble understanding how the young people can perform certain activities one day, and do nothing the other. This is a stressful and frustrating episode for the young people to explain time after time:
P2: Why can't you stand up in the bus or why can't you walk? You could do that yesterday. Why can't you take a walk today?

P4: Yeah, what have you been doing since then that means you can't do it now?

(Appendix 4, p. 6)

This requirement was strongly represented in the data. As such, it does not directly link to consultations. However, the issue was important to the young people and because they were a part of the design team, this requirement was kept in order to present it and work on the issue at the workshop in stage 4. It was considered important to keep this requirement because bringing it into the next step of the design process ensures that the young people feel that their utterances have been listened to and taken seriously. The young people at the workshop disqualified the requirement but their trust to the fact that they are actually a part of the design was considered strengthened by letting them decide whether or not to support the requirement.

7. Medicine reminder

Another issue that was stated was the large amount of pills that the young people have to administer every day:

P5: I had one of those, and then at the same time I had my calendar, where I'd just written from day to day when to take pills, so it would beep because I always forgot to take my pills.

P2: Mine is on the kitchen table.

P5 It could be on the kitchen table and I'd walk past it twenty times and still forget to take them.

(Appendix 5, p. 4)

It is important for the young people to remember to take their pills but as the quote shows it can be a challenge to remember to do so.

There is no doubt that the young people were affected a lot by their medicine. However, the degree of how big an issue the medicine reminder is, was not clear. The young people had diverging opinions on the matter. A medicine reminder can fairly easily be incorporated in a system's design. Because it was unclear how important the issue was, it was included in the next step of the design process for qualification.

5.1.2 RHEUMATOLOGISTS

They are secondary stakeholders because they are not the ones who will directly be using the system but they will receive the output from it during the consultations. A total of five requirements were determined.

1. Data has to be recognizable and represented in a simple way

The Rheumatologists stressed the limited time allocated for each consultation as an important factor when considering bringing new information into the consultations. They acknowledge the benefits of bringing in information about the young people's activities related to their disease. However, they emphasise that if the information is to have any chance of being relevant, it should be both recognisable and easy to interpret:

INT: Back to where we talked about if you agreed with a patient that keeping a diary would be a good idea. What's the format? What should they write down?

RH2: As little as possible. As clearly as possible. Because you don't have time to read it. Because when the patient comes in with a stack of papers like that and says. Listen to this. Or expects that, like. Now you need to read how everything's been since the last time, and you have 25 minutes. That's not going to be a very thorough reading.

RH2: As I said, like. I don't know, like. As clearly as possible, so that, what should I say. Not too much reading.

INT: No, so that if it was visually presented in som way, you'd be able to talk about it. That could be very.

RH2: And then you could elaborate from there. And say what's that there? And what does that mean?

(Appendix 10, p. 3)

In the quote above, the Rheumatologist stresses that letting the patient bring in too much information might cause a conflict because the Rheumatologist does not have time to process the information.

The following quote is another example of the matter but it explicates what the rheumatologists mean by recognisable information:

RH1: I'd say, it would be a lot to have to consider many points on, like, a chart during a single consultation. But of course it would be relevant to say. Hang on, what happened that day, right? What did you do about it? Can you see that as well? What can they do about it?

RH1: No. I could imagine that they looked like something I was used to looking at. Like. So that in some way was reminiscent of. So that if you had a DAS-28 CRP calculated. You could't do that of course Because you'd have a CDAI where a CRP isn't a part of it. Hehe. But that's doctor-nonsense. So there is something. Like. No, but like, some kind of other way for me to measure it. But in reality it might be some entirely different things you would need to know to hear how the patient is doing, right. So this is something fairly well validated, which has been made in cooperation with patients, but. But something so you'd get an overview, right. And it shouldn't be too complicated. Like it would have to be something where you'd be able to look at it and say. Okay. You felt bad then. Then you have to ask. Like. You don't have time to read diaries, right?

(Appendix 12 p. 2)

Another interesting point was that the Rheumatologist acknowledges that the simple, recognisable values might not be sufficient in order to understand the condition of the patients thoroughly. The rheumatologist explains how certain measures of disease activity are dependent on data that can only be provided by health care professionals, e.g. blood sample and professional assessments of joint tenderness and soreness (Gilek-Seibert et al., 2013).

The Rheumatologists put a lot of emphasis on the small amount of time allocated for the consultations. This fact made them particulaly cautious about expanding the amount of information used as basis for the consultation. This fact is considered the key point into bringing a system into the consultation. This means that if the system should have any chance of being accepted by the Rheumatologists it has to, at least to some degree, be incorporated on their premise of providing data that is recognizable and presented in a simply way.

2. Intervals regarding notifications

There were some concerns in relation to encouraging the young people to perform self-assessment. The problem is that people who are observant towards their condition all the time might not benefit from self-assessment because they need to try to get their thoughts around other matters:

RH1: Yes it definitely would. It would be. I can. Like I said before to Niels, then I'd just be like. Having to walk around and constantly noticing how they feel. Because then you start to become very focused on whether you're in pain right now.

INT: So maybe make the intervals longer?

RH1: Yes. Like. Because in reality you want people not to think that they're sick. If their treatment was going well, then they shouldn't be thinking: "I've got chronic arthritis. That sucks." Then that's the only concern. So, like, I definitely think it could be useful.ja. altså. Fordi man vil jo i virkeligheden gerne have at folk ikke tænker på at de er syge. Hvis de nu var velbehandlede så skal de jo ikke gå og tænke. Jeg har også kronisk leddegigt. Det er også noget ged. Så det er den eneste bekymring. Så altså jeg synes det kan man sagtens bruge til noget.

(Appendix 12, p. 1)

However, people living in denial about being chronically ill could benefit from getting to know more about themselves and their disease:

RH1: Patients are very different, right. Because some care a great deal about being ill. Like, their whole identity is based on the fact that they have chronic arthritis. And others nearly deny it. It could be very useful for them to type things into a screen every now and then.

(Appendix 12, p. 1)

This requirement does not directly concern the consultations. However, it pinpoints a concern when patients are asked to perform self-assessment.

3. Patients have to fill in a HAQ-questionnaire on the day of the consultation

The HAQ-questionnaire plays a central role given that the whole consultation is dependent on the results of it. It has to be filled in on the day of the consultation:

RH2: No, then we'll just do it together. But there is a requirement for it, just like there is for all patients who come here. It has to be fully filled in at two visits on a yearly basis. But we don't do it because it's a requirement. It's because it's better, like, when it comes to understanding. It's actually a good tool to, like, quality control. It creates some discussions with the patient based on the data. And then helps form an understanding of the treatment. So it's a good tool for communication.

(Appendix 11, p. 1)

As the Rheumatologist elaborates in the quote above, the HAQ-questionnaire is mandatory at Glostrup Hospital because it ensures a certain degree of quality. It acts as a tool for dialogue and for both understanding the condition and the current treatment.

This requirement shows that the Rheumatologists are dependent on the HAQ-questionnaire being filled out on the day of the consultation. This knowledge is of great value because the system that is to be designed in this master's thesis will somehow have to relate to this. The information about how important the results from the HAQ-questionnaire is, shows how important the information that comes from the young people themselves is. This indicates that information from and about the young people is highly prioritised, leaving a chance for a system to be adopted into the context of the consultation.

4. Patients to prepare questions

The Rheumatologists encourage their patients to prepare questions prior to the consultation. This is mostly suggested to new patients, but not exclusively. It helps the patients when recalling their situations. The patients are also advised to bring an assessor:

RH1: But I guess that's what the patients should do. And then it's a very good idea. We tell them often, especially new patients, that if they have any questions, write them down. Then they can remember. Because it can be. Especially when you've received a new diagnosis, then you're a little dazed, right. You get a lot of information the first time you're here. So because of that we need to pay closer attention. But they're more than welcome to write them down. They're also welcome to bring a friend or relative who can help them remember. Because there are a lot of things that can worry you.

(Appendix 9, p. 1)

The requirement shows that the Rheumatologist actually encourages some of their patients to do self-assessment. This is another hint that data based on self-monitoring has a fair chance of being adopted into consultation.

5. Comparison of values

The observation revealed that the Rheumatologists depend on the value DAS-28. It is a value generated from a blood sample, a pain-VAS, and an expert assessment of each of the joints harmed by RA. Pain-VAS is a scale represented by a number plus a colour. It ranges from near remission to high severity of the disease activity. The colour that follows goes from green to yellow to red, as the number gets closer to high severity (Appendix 13). This number showed to be crucial as the Rheumatologist used that value and compared it to the value from the last consultation. This gave an instant indication of how the consultation should be focused.

The requirement shows how the current practice is. The Rheumatologists rely on a comparison of one number that is accompanied by a colour. This is useful knowledge when designing a new system because it is important to support an already existing practice instead of creating a new one. If this is successfully done the chances of the system being adopted and used are much higher.

These were the identified requirements of the Rheumatologists. The following will pursue the requirements of Daman and FNUG before providing an overview. These requirements are gathered as general knowledge obtained when working with both Daman and FNUG. Therefore the requirements are not a direct consequence of the qualitative research and that is why the requirements are not presented with formal documentation.

5.1.3 DAMAN

Daman has a single requirement.

1. Profitable system

Daman is both a tertiary and a facilitating stakeholder. The company is dependent on the success of the app. This is because they need to make profitable products in order to have a healthy economy. They are also the facilitating stakeholder, as they are the ones who have developed the original RheumaBuddy app and they are still working on improvements. The reason that they are considered a facilitating stakeholder in this design process is because they might be adapting the findings from this master's thesis into the next version of RheumaBuddy. This requirement reveals that the system will only be fully developed if Daman considers the system to be a profitable improvement.

5.1.4 FNUG

The patient's organisation focuses on helping their members cope with their disease.

1. Supporting their members

The patient organisation is categorised as a tertiary stakeholder. This is mostly because of their partnership with Daman in relation to RheumaBuddy. The reason that they are placed in this category in this master's thesis is that they showed a lot of willingness to participate in this project. This is due to the fact that they have a general interest in optimising their members' quality of life. It includes initiatives for supporting the members in any way possible when attending consultations. An example of this is the guide made by FNUG called *The good consultation* (FNUG, 2013). It strives to educate the members prior to, during and after the consultation. Finally, FNUG is also the gatekeeper in relation to gaining access to the young people.

This requirement shows that if FNUG consider the system that is developed in this design process to be supporting their members when attending consultation, there might be a chance that they will be funding the project. The fact that FNUG members have been a part of the design process increases the likelihood of this happening.

5.1.5 TABLE OF REQUIREMENTS

The following table shows an overview of the stakeholders and their requirements:

Stakeholder	Requirements
Young people living with RA (Primary)	1. Comprehension from the Rheumatologist
	2. Online HAQ-questionnaire
	3. Individual preparation prior to the consultation
	4. Dating back information about their condition
	5. Differentiated intervals between consultations
	6. Comprehension from the surroundings
	7. Medicine reminder
Rheumatologist (Secondary)	1. Data has to be recognizable and represented in a simple way
	2. Intervals regarding notifications
	3. The patients have to fill in the HAQ-questionnaire on the day of the consultation
	4. Patients to prepare questions
	5. Comparison of values
Daman (Tertiary, facilitating)	1. Profitable system
FNUG (Tertiary)	1. Supporting their members

The table shows the results of the focused analysis of the data from stage 2 from the scope of a more technical character. It has revealed a set of stakeholder requirements related to the problem situation. Not only has the process made it possible to determine the requirements, but the system's design strives to support as many of the above-mentioned requirements. The requirements were prioritised, leaving primary stakeholders the most important and the tertiary least important.

5.2 ROOT DEFINITIONS FOR THE SYSTEM

The generation of root definitions is the last activity of the stage. This section will define the core of the system, or at least how the core is thought to be at this time in the design process, based on the analysis of the empirical data generated until this point. The root definition will define *clients, actors, transformations, weltanschaung, owner* and *environment* (Dix, 2003a). It is important to keep in mind that this section provides an attempt to define the root definitions. They will be indirectly challenged in the workshop at stage 4. The reason that this challenge is indirect is due to the fact that the findings, or more precisely the challenges connected to the requirements of the young people, are being qualified during the workshop. Because the root definitions derive from those challenges it is possible to modify the root definitions, if needed, by letting the young people qualify them. Therefore the root definitions will be indirectly challenged. The root definitions at this point are as follows:

- *Clients* are the ones that benefit from the system. In this case these are the young people and the Rheumatologists. The young people will provide input to the system and both the young people and the Rheumatologists will receive output from the system. The young people will get the information directly and then present it to the Rheumatologist.
- *The actors* of the system are the ones who perform activities directly within the system. These are the young people providing input as just mentioned.
- *Transformations* refer to changes in the knowledge base in the consultation, as a consequence of the data provided by the person living with RA. The enlarged knowledge base will become available for the person living with RA, as well as the Rheumatologist.
- *Weltanschauung* refers to how the system is perceived. In this case the young people can empower themselves through self-monitoring when attending consultations with their Rheumatologist.
- *The owner* of the system is Daman. An owner is defined as the one to whom the system belongs and who can change the system.
- *Environment* is the surroundings in which the system operates. The environment includes influential factors that the system must relate to.

5.3 SUMMARY

This stage has determined the stakeholders related to the consultation. The stakeholders have been categorised in terms of how they relate to the system and what their requirements are. The stakeholder requirements have provided an overview of what is required of the system in order to be valuable in supporting the young people living with RA during their consultations. This value will be achieved if the system can foster comprehension from Rheumatologists and contribute to making a more personalised preparation prior to the consultations.

In order for the system to support the requirements of the young people, it has to be adapted into the consultations with the Rheumatologists. The system will inarguably bring new information into the consultation. This leads to the requirements that the Rheumatologists have for the system. The information provided by the system has to be presented with as little detail as possible and the data must be recognisable from a clinical perspective. Finally, the Rheumatologists have requirements with regards to the importance of maintaining correlation between new data and the data from the already implemented DAS-score. They acknowledge that they might benefit from additional information about their patient's current state of disease activity.

Stage three ultimately determined the root definitions of the system at the current point of the design process. The finding that rheumatologists seem to acknowledge a possible improvement of the consultations with the right data presented by the patients, made a set of root definitions possible.

The analysis of the data material, from the scope of the systems thinking, gave a deeper understanding of the system requirements. It has been considered a viable solution to change the research design slightly. Instead of two iterations of user testing involving the participants, one of the user tests will instead be carried out with the Rheumatologists. This change has been made as it became clear through this stage, that the requirements of the Rheumatologists were more important for the system to be adapted into the setting of the consultations than assumed prior to the analysis.

Stage 4

Conceptual Models and Prototyping

This main purpose of this stage is to generate conceptual models in collaboration with the young people followed by the development of a prototype on the basis of those. This will answer:

How can a smartphone application, from the perspective of the users, most comprehensively support a consultation?

The application has to:

- Include the possibility of adding measures of pain, fatigue, mood combined with notes.
- Include a Rapid3-score, which is a clinical value calculated from the self-monitoring made by the young people, to enhance patient empowerment.
- Follow a linear path in order to withhold the users attention and ensure data quality.

6 STAGE 4: CONCEPTUAL MODELS AND PROTOTYPING

During this stage the requirements discovered in stage 3 will be translated into a prototype for user testing. Central to this stage is the requirements found above, which will act as the basis for a workshop conducted in collaboration with the design team. The findings from the workshop will be extrapolated into a set of UML-diagrams serving as documentation of the functionalities necessary to carry out the tasks required to meet the refined requirements of the system. The diagrams will finally be translated into a visual representation of the system, in the shape of an interactive prototype made through a system called UX-pin (UXPin, 2015). This stage serves the purpose of answering the following question.

How can a smartphone application, from the perspective of the users, most comprehensively support a consultation?

The purpose of this stage is to transform the system as a boundary object into a more concrete epistemic object (Ewenstein & Whyte, 2009). During this process, a deeper understanding of the user requirements is sought.

The rising complexity of the design process is a circumstance of participatory design, thus the users cannot take part in the final conceptualizing parts of the prototyping process. The users will provide the main design ideas and sketches of the system. The UML-diagrams as well as the visual prototype will be designed without the participants involved.

6.1 **CONCEPTUALIZATION WORKSHOP**

The analysis of stage 3 has uncovered a set of stakeholders and their requirements. Stage 4 once again invites the users into the developmental process. This stage is a collaborative stage between the designers and the participants, as the participants will not only be asked questions, they will also be encouraged to bring concrete design ideas into the design process.

This stage is a part of the continuous validation of the analysis based on the data produced in collaboration with the participants. As explained in stage 3, the requirements will, in this stage, be translated from requirements into challenges, which the users will then have to validate as important, imprecise or inconsequential. In fact, that particular task of validating the translated requirements is a part of the iterative process of doing participatory design, by continuously evaluating temporary results with the users.

6.1.1 SAMPLING

During this fourth stage of the design process, the same participants that participated in stage 2, are brought back into to the design process. Continuing to work with the same participants provides a higher level of expertise into the situation, as the participants can both draw on experiences from their everyday lives as well as reflect upon knowledge generated in the focus group interview. "And it is iterative, allowing workers and researchers to critically examine the impacts of these incremental redesigns in progress." (Spinuzzi, 2005, p. 167).

During the design process, the sampling size has shrunk from six participants to three, albeit this is no concern due the approach, which emphasises strong ties to the design process over the size of the sample. Regarding the quality of the new sample size, the participants in this second intervention are considered representative of the group; All three cope with different types of RA outbreaks, yet none of them are near remission (Appendix 4). This qualifies them as an adequate design team.

6.1.2 Focus

Qualifying the requirements found during stage 3 and processing these into concrete concepts for further development is the main focus of this workshop session. Although the ideas proposed during the workshop are important to the design process, another important purpose of carrying out a workshop is to bring the participants closer to the system being designed. By continuous collaborative sessions a partnership is sought, rather than the strictly divided user/designerrelationship. By letting the participants propose concrete design ideas, the probability that they will adopt the final design, as if they are owners of the system, is more likely. An outcome like that is emphasised, as it will provide an incentive for the end users to use the system.

6.1.3 SETTING

The setting was the same as in stage 2. The workshop took place at Daman, however the setup was slightly different due a variety of diverse tools for creative processes i.e. permanent markers, post-it notes, and blank paper. The setting will be more thoroughly elaborated in the description of the four intervening stages in the workshop.

6.1.4 INTERVENTION

This section will describe in-depth which activities were carried out during the workshop. However, no comments will be put on the output of these interventions, as they will be analysed in the following section.

The workshop consisted of three interdependent activities, all providing insights for the next activity accordingly: Evaluation of challenges, dream scenarios, and visualisation of solutions (Appendix 14). The outcome of each of the three activities will constantly be assessed as a part of the design process. When something is proposed during one activity, it is brought into the next activity, thus being assessed due the iterative design approach.

6.1.4.1 EVALUATION OF CHALLENGES

As described earlier, a main goal of participatory design is to make the requirements of a system, and in the end the system itself, recognizable to the participants: "[...] introduction of a new system is liable to change the work context and organizational processes, and will only be accepted if these changes are acceptable to the user." (Dix, 2003a, p. 466) Therefore, the requirements discovered in stage three have been translated into a set of challenges, which the users were presented with during this initial part of the workshop. By presenting them with these challenges, it is possible to determine whether they are either relevant or important to the participants. This assessment of the ideas will eventually qualify a set of the challenges for the next activity, where dream scenarios will be made based on the challenges.

Some of the requirements from stage 3 have been translated into more than one challenge, due to an assumption that those contained more than one challenge. The requirements and their subsequent form as challenges are presented in the following diagram:

Requirements	Challenges
Comprehension from the Rheumatologist	Lack of comprehension from the Rheumatologist The Rheumatologist is not comprehensively prepared for consultations
Digital HAQ-questionnaire	The HAQ-questionnaire has to be completed in the hospital prior to the consultation
Comprehension from the surroundings	Lack of comprehension from the surroundings
Individual preparation prior to the consultation	Consultations are not adjusted for individual disease profiles Getting a blood sample is inconvenient. The HAQ-questionnaire is too generic
Medicine reminder	Forgetting to take medicine Insufficient knowledge about the medicine

Seven out of the nine challenges are derived from requirements found when looking at data from the participants. However, two challenges are constructed on the basis of the participants. The decision to include challenges, which were not provided by the participants themselves, has been made from a designers' point of view. The two included seemed to have great potential in terms of being assisted digitally. Therefore they will be presented to the participants, in order let them assess whether they are actual challenges. The two are; *The HAQ-questionnaire has to be completed in the hospital prior to the consultation* and *Getting a blood sample is inconvenient*. The two challenges not provided by the participants will be presented during the workshop alongside the remaining seven, in order to prevent bias.

6.1.4.2 DREAM SCENARIOS

In the second part of the workshop, the participants were asked to look at the challenges that they have just qualified. The participants were then asked to imagine ways in which these challenges could be turned into dream scenarios. Afterwards the participants had to include technology to realise their dream scenarios.

This type of workshop is called a future workshop (Mogensen, 1994), as it is supposed to facilitate a process in which participants of the workshop are forced into conceiving ideas as to how the future of a given practice could be; in this case how living with and managing RA could be enhanced by using digital technology.

In order to facilitate the development of dream scenarios, a set of large posters were produced (figure 6). These acted as the framework, into which the participants could place the challenges that were written on post-it notes. As the image illustrates, the participants were encouraged not only to write down their dream scenario, but also to propose functionality to support fulfilling the scenario. Furthermore, the participants include the actors that were a part of the scenario.



Figure 6 - Dream Scenario Poster

Mogensen (1994) outlines the importance of understanding the role as facilitator when carrying out a future workshop. Therefore, a set of technology cards were presented to the participants (figure 7). The technologies shown in figure 6 were, however, not the only ones. Altogether more than 20 technologies were proposed. Listing all of them is not necessary, due to their facilitating role rather than being cards determining the path of the development process however, some of them can be seen in figure 5. These were made to change the focus of the participants from remembering different smartphone functionalities, to remain focused on the task of developing potentially feasible design proposals. Moreover, the use of technology cards has proved to stimulate creative processes, as they can help participants transform abstract concepts into ideas by conceptualizing them with the help of technology cards. This approach is derived from a methodology called inspiration card workshop (Halskov & Dalsgård, 2006) in which they use different types of inspiration cards:



Figure 7 - Inspiration Cards

The main purpose of the Inspiration Cards is to inspire this creative process, and as such, the cards may be used both directly i.e. "*This specific technology may alleviate that specific problem in the domain*"(Halskov & Dalsgård, 2006, p. 5) and indirectly i.e. "*This application of technology embodies a style that we wish to reproduce in the domain*"(Halskov & Dalsgård, 2006, p. 5).

At the end of the session, the posters were kept for the final activity, which relied directly on the ideas just produced.

6.1.4.3 VISUALISATION OF SOLUTIONS

During this phase, the participants had to become more specific in their elaborations about the system's visual representations. Until this point they have only been asked to think about solutions as ideas and concepts.

The iterative process continued as this activity begun. The participants now had to assess their ideas through a discussion of whether their dream scenarios could feasibly be translated into a visual representation as a mock-up. This approach is aligned with the way in which Spinuzzi (Spinuzzi, 2005) proposes a participatory design process is carried out. In his terms, the process has now entered the third stage of the development, prototyping. In terms of Ewenstein and Whyte (2009), the instrument, in terms of the ideas generated in the two activities prior to this, is to be transformed from a boundary object into an epistemic object, which is a visual representation of a set of ideas. This representation then acts as the basis for discussing the functional properties of the system, which is valuable in the subsequent steps towards a functional prototype.

In order to provoke the participants to create these models of their dream scenarios, they were provided a set of A4 sheets, which were decorated to imitate a smartphone (figure 8). Thus bringing into the situation a set of well-known objects that should catalyse the creative process of drawing the functionalities of the future system. At the end of the session, the proposals are discussed in plenum, in order to maintain the iterative nature of the process by reflecting upon the ideas, sketches and mock-ups that have been developed during the session. These drawings, alongside the sentiments provided by the participants, will become the primary empirical source of data for further development of the system, from UML-diagrams straight through to, eventually, a working prototype.



Figure 8 - Mock-up Smartphone

6.1.5 CONSIDERATIONS

As explained above, the workshop draws inspiration from a combination of more than one type of workshop. The reason for this is that none of the workshop methodologies used were found to be sufficient on their own. If only the future workshop was applied, the participants would not have been able to cross the gap from a boundary object, in form of their dream scenarios, to the epistemic objects, which were first created during the second part of the workshop. During the second part, where they were encouraged to draw sketches of the system ideas proposed, they got an opportunity to concretise their ideas. Thus providing themselves a set of sketches which were more purposeful in terms of negotiating the ideas: "[...] as material instantiations, we see them as a crucial dimension of the epistemic object as it is with these that practitioners interact when they develop knowledge" (Ewenstein & Whyte, 2009, p. 12) As this point, when developing as much knowledge as possible during the developmental sessions is important, it was decided that an extension of the future workshop had to be a part of this fourth stage of the design process.

6.2 ANALYSIS RESULTS

The outcome of the workshop will be presented as a combination of statements made by the participants during the workshop, alongside images of the illustrations made by the participants. Similar to the way in which the activities within the workshop was described above, the analysis will be carried out chronologically, as the findings from each part of the analysis brings insights relevant for the next part.

6.2.1 EVALUATION OF CHALLENGES

The challenges described previously were assessed in collaboration with the participants during this activity. The outcome of that activity will be discussed below, in relation to existing knowledge provided during the stages before this.

When presented with the first challenge, they quickly accepted the premise and discussed whether they were able to recognise it as a challenge of importance. The first challenge, which they were presented with, was the following: "The HAQ-questionnaire is too generic". They did recognize that as a problem:

INT: Do you recognise it?

P1: Uhm, that was the one you showed us last time. I.

INT: That was the DANBIO thing.

P1: That was actually what we were talking about.

P2: I think so. It actually fits quite well.

P1: We talked about the need for specialisation for each different patient, kinda. As opposed to targeting a very wide target group. So yes. I agree with you.

P2: Yes.

(Appendix 15, p. 1)

Not only did they agree that the statement was a challenge, MI also elaborates in which way he considered it incomplete.

The next challenge they were presented with also related to the HAQ-questionnaire: "The HAQquestionnaire has to be completed in the hospital prior to the consultation". However, a unique property of this challenge is that it did not derive from the participants themselves, instead it was a challenge mentioned by the Rheumatologists. Exactly that fact is why they could not recall that they had stated something about that, themselves. It is interestingly, though, that they do agree

that it is a problem. KA even backs her agreement by reflective arguments based on prior experiences herself:

P1: I don't remember that. But yes, I definitely agree. It should be answered.

INT: No, but the challenge is that it has to be.

P2: Yes, that happens often. Because I actually thought that it might be quite nice, maybe, if you could do it at home.

P5: That's what I was.

P2: Because when you're sat there prior to your consultation, and you might be a little late, then you'd have to rush through it. Did you remember everything and so on. In that case i might be an advantage if you could answer it at home, where you might. Where you might also have the time to think about the questions. If there was something you'd forgotten. (Appendix 15, p. 1)

Not only is this point important, due their immediate acceptance of a challenge generated on the basis of a statement by a Rheumatologist. It is also important insofar as it reveals that Rheumatologists and young people living with RA can agree on a requirement for the system being developed in this master's thesis.

A challenge regarding medicine was also presented to the participants: "Forgetting to take medicine". Although this challenge was derived as a requirement of the users in stage 3, there seems to be no consensus among the participants. The challenge is not completely diminished among all participants, but there seems to be no pattern regarding difficulties about medicine consumption:

P2: That you forget to take your medicine.

P5: You do.

P2: I don't have that problem.

INT: It was with regards to some boxes?

P2: Yes, I have some boxes.

INT: Tiny boxes.

P2: I don't forget that.

P1: I sometimes deliberately choose not to take it. But I never forget. If I.

P5: Yes, I've always got it written down on my cellphone. Then there's a popup about it. You need to take it now. I can walk past my medicine and still forget to take it.

P2: For me it's a routine.

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P1: Same for me.
(Appendix 15, p. 1)
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Although no consensus was found, ST still has a point regarding the use of a smartphone with the inbuilt ability to remind the user to take medicine correctly. The sample size might, in this case, be too small to conclude something about the significance of forgetfulness regarding medicine consumption.

One of the main challenges of living with RA as a young person has turned out to be that the surroundings do not believe that young and seemingly agile people suffer a disease which is commonly related to elderly people. Thus, the challenge: "Lack of comprehension from the surroundings, once again echoed total consensus among the participants."

INT: It's difficult to write down on a post-it.

P1: But it's true enough.

P2: Yeah, it is. Yes. Yes. People don't get it. And then you're treated to that: "Oh how awful for you." Thing.

P1: Yeah, and: "Aren't you a little young for that?" and stuff like that.

P2: "You're much too young!"

P5: It's what, half an hour ago. Someone asked me if I couldn't give up my seat for an old lady. I was like: "No, I really can't."

(Appendix 15, p. 2)

Not only is the point that young people suffering from RA do have problems related to how other people perceive them. It has been stressed in stage 2 during the focus group, in various papers inquiring everyday life of people with RA, and once again in this fourth stage. It seems to play a major role in the lives of young people with RA.

Before people with RA attend consultations, they have to have a relatively new blood sample, meaning that it is mandatory to get it in close proximity to the consultation. Addressing the implications of the inconvenience of getting a blood sample was considered a requirement for the participants, thus the challenge: "Getting a blood sample is inconvenient". However, the participants immediately denied that it was much of an inconvenience to them; either because other things are considered more inconvenient, or because it simply is not an inconvenience from their point of view. Whatever the matter, they denied the existence of that challenge:

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P2: Blood sampling is bothersome.INT: Not particularly.P2: No.P1: No.(Appendix 15, p. 2)
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Similar to the challenge about medicine, this was also a challenge made on the basis of quotes from the participants, which did not exactly express the challenge itself. That might be why they did not accept it as a real challenge. However, as part of the iterative design process, evaluating findings from parts of the analysis in which the participants did not participate is important. Otherwise, the final results could become imprecise, illustrated well through this example of correction of an analysis by the participants.

The next challenge: "Consultations are not adjusted for individual disease profiles" addresses two interesting points. First of all, the participants, immediately after they are shown the challenge, tend to neglect the importance of the challenge. They find that consultations held at times of low disease activity, which they perceive is the case most of the time, is a circumstance of living with RA that cannot be changed:

P2: It makes no sense for every single consultation. It's like that for most people from what I hear. When you have your regular consultation, you never have issues. It's always immediately before or after. It's never when you're scheduled.

P1: But like. You don't get a lot of new information at one of those checks. It's just to check if you. Whether you can still take the medicine, or if you need something else. So that's almost the only thing they check for.

(Appendix 15, p. 2)

The second point stressed by this challenge was that they could be provoked to think differently. Facilitating the process of discussing beyond current limitations gave another, less definitive answer. KA did actually start to reflect upon the challenge as if it could be changed, hence they did change their approach and acknowledged that it was a challenge which should be met, and which is being inquired in Gentofte:

INT: What if you, somehow, could make it so that the consultations were scheduled better in relation to the more problematic periods?

P2: There is a way to do that, actually. By getting tested. At Gentofte.

INT: Interesting.

P2: They're testing something that we in FNUG call the Bristol-model. Which is something that a hospital in Bristol tested, that the hospital in Gentofte are now testing. You can. You can opt in. You can choose. That's what you can do in Bristol. You can choose one of two things. Either you can choose to continue as you would normally, with regular consultations. Like, every six months. Or you can choose the other way, where you don't have fixed consultations, but where you can call if you experience any difficulties, and then you can book a consultation within a very brief amount of time. Like, within a couple of days. And then you can also, if you have questions, then you can call them and they'll get back to you quickly. So that you save some consultations. So that people only show up when they feel there's a problem. And then of course you have to keep an eye on blood samples and such. But so that it's a little better adapted to when you feel like there's a problem. They're testing that right now in Gentofte. And it works really well in Bristol, so it's nice that they're testing it in Denmark now.

(Appendix 15, p. 3)

P2 actually presents a model trying to solve the problem of adjusting the treatment to the patients, rather than forcing the patients to adapt to the treatment. An interesting approach, however not something for further inquiry, as it is too closely related to the papers already discussed in the literature review about reminder systems for RA patients.

During stage 3, it was discovered that the participants have difficulties navigating the vast amount of medicine they were prescribed. When presented to the challenge "Insufficient knowledge about the medicine", they all agreed:

P1: Is that us?

INT: Like, is it a challenge that you're not really informed about (the medicine, red.)

P1: Yes.

P2: Yes. That's actually quite descriptive.

P1: That's not all of it. You don't really feel like you're informed when you start taking new medicine.

P2: No. And if there are any side effects that a lot of people experience. Then you don't necessarily get informed about them. Then it's not until you, after a while, start thinking:"Wait a minute, that's a little odd." Oh, by the way, that's probably it.

P5: The doctor also frequently forgets to tell you that you need to take some pills for the other pills you're taking.

(Appendix 15, p. 3)

This definitely shows a concrete space for improvement. The participants find this frustrating as they are experiencing known side effects of medicine on themselves, and not being told about them by a healthcare professional.

As it was the case with the challenge regarding differentiation in consultations, knowledge about the challenge: "Lack of comprehension from the rheumatologist" was constructed during the discussion. In the beginning, the problem did not seem to bother the participants. However, when KA participates, it became clear that there was an alternative to practice as it is at the moment. This way of putting perspective on current practice, seems to invoke a change of opinion regarding the challenge:

P1: Like, you get more and more. The more patients a doctor has, the more superficial they become. With regards to their patients. So a lack of comprehension, basically. I don't expect my doctor to be greeting me with arms wide open when I show up. I expect to be treated like a patient just like everyone else. So. A lack of comprehension. That's.

P2: But it's also just.

P1: It's difficult.

P2: But I don't actually know that it is. Like, I don't think they're very good at it at the hospital. But, like, I go to a private practitioner, although it doesn't happen very often. But when I go there. Then she's very open and happy. And. Oh how good to see you, how are you

doing? And. Oh, I thought about you the other day when I saw a program about arthritis. Like. I don't know. I think it might just be the person.

P1: Yes. That might be. But from the doctor's perspective, I reckon that's probably our specialist. Our rheumatologist.

P2: Sometimes then.

P5: Probably him. I think. Because I've tried calling him and told him that I couldn't walk because of fluids. He'd rather not remove it. But in the end he had to remove it. And then he had to admit that he had to get another two syringes. There were two syringes in each knee. He could remove.

(Appendix 15, p. 3)

This quote is an example of how interaction and dialogue can change perspectives on things. MI goes from denial of the challenge as neither important nor present, to an agreement that in fact Rheumatologists might lack comprehension.

The creation of knowledge in cooperation proceeds into the next quote, where it becomes even clearer that the participants had to get a common understanding of what the challenges actually meant to them, before they were able to assess them:

P2: I think sometimes it's lacking. I sometimes experience a lack of comprehension when it comes to the demands you make for your own life. And as a result for your treatment. Like, the lack of comprehension that you're not old mrs. Jensen, who sits at home all day. But that you might be living an active life that you'd like to carry on living. That's the comprehension I find lacking.

P1: Yes.

P2: That you're a young person with a life you'd like to live in a somewhat normal way.

INT: That's very interesting.

P1: Actually, I can understand that. You stand there and it's completely hopeless to talk to the doctor because there's so much you want to do. He's just like, calm.

(Appendix 15, p. 3-4)

They are clearly frustrated that their Rheumatologists do not acknowledge them as human beings beyond their disease. In the end, this is what they, through collaboration, end up thinking about the lack of comprehension from the Rheumatologists.

The last challenge: "The doctor is not comprehensively prepared for consultations" was interpreted by the participants in the same way as the challenge above. They did agree that it was a problem that doctors did not prepare for consultations. Not only do the participants recall

situations in which they felt they wasted their time, they also felt uncomfortable as a consequence of the missing flow due to lack of preparation:

P2: Yes. You can have that experience.

INT:Yes.

P1: Like. Yes. Like. Again. It's like. You come in there as a patient among so many others. And. He just sits at his computer and clicks. "So Michael. This was when you were last here." Does a quick check through your file. That's what mine normally does. Quickly. Taps me on the knee. Checks a bit. And just says. You're doing pretty well

INT: So you don't get the impression that the doctor has read your file before you arrive?

P1: No. No.

INT: Ok.

P5: I think mine reads it while I'm there.

P2: I think mine reads while I'm there as well.

P5: I frequently visit an ear specialist. My ear specialist knows everything about my arthritis. And my rheumatologist doesn't know anything about my ears.. And it's like. It should be like.

P2: I don't know. No. It's quite descriptive. Sometimes it's a little strange that they sit there and read while you're there.

INT: Yes.

P1: Yes. Because then there's a bit of silence while they sit and you just have to.

P2: And you have 10 minutes, right. If they then spend the first couple of minutes reading your file.

(Appendix 15, p. 4)

One conclusion to this part is taken from a methodological standpoint. Participatory design works as intended. The participants both recognized sentiments from the focus group interview, which were first translated into requirements and then into challenges. This emphasises the idea of collaborating with the same people over and over again. Another point that can be added to that matter is how exposing the participants to challenges made them reflect upon their initial relation to the individual challenges. They did actually change their minds on some of the subjects after discussing it.

The most consistent acknowledgements rose when they were exposed to challenges regarding how others perceived them as individuals, i.e. the lack of comprehension from both Rheumatologists and their surroundings

6.2.2 DREAM SCENARIOS

The second activity in the workshop was devoted to solving the challenges discussed above. Solving the challenges was approached by letting the participants formulate a set of dream scenarios based on the most interesting challenges. Only two dream scenarios were created during this second activity. The two scenarios created by the participants are described separately. They are discussed on the basis of pictures of the scenarios, which will be supported by statements from the participants.

6.2.2.1 DREAM SCENARIO 1

The first scenario proposed from the participants attempted to encapsulate the difficulties regarding the lack of understanding from the surroundings. As the walkthrough of the challenges above uncovered, that particular challenge turned out to be one of the main difficulties when it comes to living with RA. Therefore, the participants chose to address the problem during this workshop.

However, it quickly turned out that solving the problem of lack of comprehension was not considered immediately feasible from a technological point of view. The participants did not even propose a solution before they discarded the idea that the problem could be solved with a smartphone application. Several quotes explain how the challenge was discarded:

P1: Yes that's incredibly difficult because. It can't. From my perspective it's impossible for my surroundings to understand.

P2: They can't. No. Because you. It's difficult to understand if you haven't been there yourself.

(Appendix 16, p. 1)

In the beginning they completely deny that any solution might change the situation at the moment. Further on in the discussion, the argument did, however, evolve from complete denial to an acknowledgement that a technological solution might be a comprehensive solution in the process of changing the view of young people. Instead, the conclusion was that only enough information might change other people's views on young people with RA:

P2: No, I'd say that's not an easy one. Because.

P1: But. Of course there are ways of making an approximation without them getting a full, 100% understanding of it.

INT: Yeah? What're you thinking of?

P1: It could probably be useful in some way.

(Appendix 16, p. 1)

Even after the participants attempt to solve the challenge, they ended up in a consensus that the work being done in the design process of this master's thesis cannot meaningfully enhance the situation regarding lack of comprehension from their surroundings.

Although this dream scenario was discarded, it still serves an important role in fulfilling the purpose of this workshop. It is supposed to provide insights about how the participants would prefer a digital solution to support them in their consultations. Therefore, discarding a solution, which was not found feasible from a technological point of view, provides an opportunity to focus on solutions which are possible within the solution space of this master's thesis. The challenge cannot be brought any further into the design process, as it was not possible to even create a boundary object. If that is not possible, it is difficult to provoke any further constructive dialogue regarding that particular problem. Thus, the next dream scenario is the main focus of this workshop.

6.2.2.2 DREAM SCENARIO 2

The second dream scenario turned out to be more useful in terms of evolving from diffuse ideas to more concrete solutions to the problem. The scenario was named as a combination of the two challenges from which the scenario was derived: "Lack of comprehension from Rheumatologists" and "The Rheumatologist is not comprehensively prepared for consultations." The participants ended up calling the scenario: The good consultation (figure 9). As the image shows, there are various variables involved in getting to the dream scenario proposed. The four variables, written with green and red permanent markers in the cloud in the middle of the poster, represent almost direct translations of the challenges into solutions Therefore they are paid less attention to, because the solutions proposed will require actions outside the scope of a smartphone app. I.e. fewer patients per rheumatologist, which would require structural changes to treatment strategies. Hence, the post-its representing technologies supporting these solutions will be paid more attention to.



Figure 9 - Dream Scenario 2

The technology cards show a tendency towards an emphasis on technologies which support dialogue between the Rheumatologists and the patient. Four of the six technologies used to support the dream scenario can be related to dissemination: Note field for pain map, info box, graphs, and checkbox for deciding what the rheumatologist can see.

The participants expressed the importance of being in control of data about themselves:

P2: If you said that you could, like, get things in there. Say. What do I actually want to send to my doctor, right..

P1: So it'll be like he can see everything or?

P2: No, that's exactly my thought. Maybe it could be made so that you could tick off that I'd like him to see my rating system, and I'd like him to see the pain map, or whatever it's called. And then maybe a. Yeah. I might see it as a graph. And then you could maybe. If it's because you don't uset his for anything beyond just. Like. Just. Playing football. Then maybe you could choose to send the notes for that particular day. So he might get an idea why. I don't know. But so that you had the option. The choice regarding what to send to him. So he doesn't get everything. Or can see everything.

(Appendix 16, p. 1)

Although no reason for maintaining control of information is given, it was still stressed throughout the workshop, that it was important to be the exclusive owner of information about oneself. Moreover, a way of representing the data was considered important. In fact, one participant argued that the data could not only be valuable in consultation settings, it might be beneficial in the understanding of the system user's own disease: P5: I think I would as well. Because then you could also. If you go in there and write every time it hurts or something like that. You have a reason for it hurting. Then, longterm, you could also say. Last time I did this, it actually started hurting. So you'd know what kinds of things to.

P2: To maybe try and avoid or scale down a bit.

(Appendix 16, p. 2)

Another participant also acknowledges the point. They seem to believe that longitudinal data about their own disease might provide new insights about causal relations between outbreaks and a certain type of activity. From a design perspective, that point is very important, as the everyday benefit of using a system must have a potential. Otherwise, it might be difficult to motivate the users to keep using the system.

This scenario proved to be the most feasible for the participants to propose a design for. Therefore, the scenario was kept until the third stage of the workshop, in which the participants were encouraged to create visual representations of a system that can bring them closer to their dream scenario. The transition from this second workshop activity to the third workshop activity is where the design is changed from a boundary object to an epistemic object. Within this transition, negotiations regarding the functionalities proposed for this dream scenario will be carried out.

6.2.3 Sketching the system

As the participants were encouraged to sketch the system, they provided three views, which visualised the system as they wanted it to look. The elaboration of these views will start with a view that visualises how the participants want the data provided to the system to be showed to their Rheumatologist (figure 10).



Figure 10 - Check Box Sketch

Because the scope of this master's thesis is to design an app primarily used by people living with RA, emphasis is on functionalities, which occur within the app itself. The view outlines how the participants want the data to be integrated into a view, which Rheumatologists has access to. Pushing data directly to the medical journal of Rheumatologists is, however, not found feasible for this design process, as it would require integration with a system outside the system being designed here. The view is not completely discarded, however. The data which the participants wanted to push to their Rheumatologists was proposed as an option for the system users to help prepare the Rheumatologists for the consultation. This idea rose as a consequence of the participants' acknowledgement that no system could automatically make sure that Rheumatologists would be more comprehensively prepared for consultations.

Therefore, only the types of data which the participants proposed as important for their Rheumatologists to know prior to consultations will be taken into account further on in the design process. The types of data are what have been written on the poster with a green permanent marker. The data types are: spare time activities, job/education, marital status and medicine. As the participants consider these types of data important for a better consultation, the system must support functionalities giving the users the opportunity to include these types of data in the system.

The second view (figure 10) represents the same constraint regarding the interoperability systems. The design proposed here also implies that data must be forwarded directly to a system the Rheumatologists are already using. This can be seen in the lower right corner of the poster, where a button has been drawn, describing how the user of the system must be able to send certain curated data to the Rheumatologist. As mentioned earlier, this is outside the scope of this master's thesis. Therefore emphasis will instead be on supporting the underlying requirement of the participants, which lie in this idea. The system being designed here will instead approach the challenge by providing a comprehensive way of storing data for consultations. Although it is not possible to forward data directly to the Rheumatologist, another important design principle within this view will instead be emphasised.



Figure 11 - Forward Info Sketch

The third view was made in order to explain how data should be presented visually. As can be seen in figure 11, users want a view in which quantitative and qualitative are presented at the same time. The graphs are representations of quantitative i.e. pain measures over a period of time. At the same time, the participants articulated a wish to merge the quantitative data with notes about their everyday lives. This particular functionality was emphasised in an attempt to try and merge the, from the participant's point of view, objective measures with events occurring in their everyday lives. Context specific notes, revealing more about what created certain anomalies, which can be read on the graph, should enhance the quantitative measures.

To sum up the visual representations of the system functionalities found during this third activity of the workshop, two concepts were considered central for the system. One was the ability to remain exclusive administrator of data. Both in terms of determining which data Rheumatologists must see, but also in terms of being able to manipulate data comprehensively. The participants continuously expressed the importance of a checkbox functionality, providing that particular control of data. The second central point found during this activity was the importance of a comprehensive functionality enabling the participants to combine quantitative and qualitative data. They wanted to be able to reinforce the insights from a graph consisting of quantitative data, by adding contextual notes to points of interest. Not only was this point stressed in relation to the consultation setting, it was also important in terms of giving the participants a better understanding of themselves.



Figure 12 - Graph View Sketch

The findings from this workshop will, in the next section, be translated into a design proposal for a system that is aimed at fulfilling as many of the design ideas proposed by the participants as possible. Though, as mentioned earlier, only design solutions considered feasible within the scope of this master's thesis will be included in the final design proposal.

7 Systems design

The next section of this master's thesis is devoted to systems development. The system's design process is divided into two sub-sections. The first is the technical documentation of the system functionalities. This is carried out using UML-diagrams. The second part of the systems design is the creation of a visual representation of the system. These are two distinct sections, as they serve different purposes. The first UML-diagrams will provide a sufficient overview, in order to be able to create the prototype. The prototype as visual representation serves the purpose of making a product which potential users can test. The prototype will be designed on the basis of a set of chosen design principles.

Another important notion to make here is that some elements of the prototype derive from the already existing RheumaBuddy app. The main menu, the colour scheme, and four self-monitoring variables have been transferred into the prototype developed in this master's thesis. Because the main menu is taken from the RheumaBuddy app, some of the functionalities in the menu have been disabled, as they are not a part of the work carried out in this master's thesis. However, the importance of these four specific variables derived from RheumaBuddy, *pain, stiffness, fatigue* and *mood*, have all been addressed as important measures by the participants during the focus group interview and the workshop. Therefore, incorporating them has not been considered as a means of lack of reflection. Instead it is an acknowledgement that the research design of which RheumaBuddy is originally designed provides findings similar to those found in this master's thesis.

7.1 UML DIAGRAMS

As explained in the beginning of this fourth stage, a set of UML diagrams will be constructed in order to document the ideas of the system that this master's thesis is designing. The UML diagrams will serve as technical visual representations of the system. They are the epistemic objects necessary for any further development, whether it's the visual prototype or a functioning app further on in the design process. The diagrams are the framework on which the arguments for the architecture of the system are applied.

In order to get a comprehensive understanding of the UML diagrams, given their technical level of abstraction, the core concepts of the methodology, UML diagrams, will be elaborated below.
7.1.1 OBJECT ORIENTED APPROACH

UML diagrams are a standard used within the field of systems design. The standard relies on a concept called *Object Oriented Design* (Whitten & Bentley, 2007). This approach has the purpose of closing the gap between systems design and systems development, thus bridging the gap between design and coding. A central element is that every entity within the system is to be considered as an object; i.e. actions carried out, actors and classes.

UML consists of a diverse set of diagrams, which all belong in either of two categories. For this master's thesis the fundamental distinction between the two main points of view must be understood. One being the behavioural point of view, the other being the structural. For this master's thesis, emphasis will be on the behavioural point of view, thus supporting the argument of focusing on two types of diagrams; *use case diagrams* and *sequence diagrams*. However, a third type of diagram will be introduced; *class diagrams*. These serve as the structural, static, description of the system, which describe how the system has to be divided in terms of databases and coding structures (Whitten & Bentley, 2007) as they are outside the main focus of this master's thesis, they will be less emphasised here.

By focusing on the behavioural diagrams, focus can be maintained on the interactive parts of the system being designed. This is pursued, as the scope of this master's thesis is to get a thorough understanding of how the interaction between humans and a system can change a practice. Therefore, emphasising behavioural diagrams, which represent the dynamics of a system, is comprehensive in this setting.

7.1.2 USE CASE DIAGRAM

The most basic of diagrams within UML are the use case diagrams. They are diagrams deciphered with the least technical expertise. The purpose of use case diagrams, is to "[...] *specify the behaviour of some entity such as a system or a subsystem*." (Bennett, Skelton, Lunn, & Choules, 2005, p. 21). The use case diagram for this master's thesis consist of five types of artefacts: The *use cases* (1) themselves, *actors* (2), *generalization arrows* (3), *dependency arrows* (4), and *packages* (5). An example of a use case diagram is shown below (figure 13).



Figure 13 - Use Case Explained

The actors within a use case diagram, are the humans involved in an operation. Such actors can have different levels of generalization relevant for different purposes (Whitten & Bentley, 2007). I.e. in this master's thesis, a person living with RA is at the highest level of generalization. The same actor can at the same time, represented by a generalization arrow, be a patient in the setting of a consultation. The dependency arrow describes how one use case might be mandatory for another use case to be carried out, thus making the second use case dependent on the first. The last term that must be explained is packages, which encapsulate use cases within a specific technical setting. In this use case scenario, the three use cases are divided into two different packages; *before consultation* and *consultation*, because there might be an alternative platform for presenting the data from the system when used in the setting of a consultation. The first two use cases are carried out on a smartphone, and the last might be carried out in a web application or with a printed representation of the data generated from the application.

The use cases are fundamental for all UML diagrams. They give a brief overview of the actions a system must be able to carry out, in order to meet the requirements discovered earlier in the design process.

The use case diagram of this design is derived from the findings during the workshop, as the participants outlined and qualified a set of ideas for further inquiry. These have been translated into three use cases as the diagram illustrates (figure 14):

The diagram illustrates how a use case called *self-monitoring* is the initial stage before the use case *prepare for consultation* can happen. Therefore, the self-monitoring covers all activities

related to putting data into the system. Without these data, the preparation for a consultation cannot take place. That is why the two use cases are related by a dependency arrow, going from *self-monitoring* to *prepare for consultation*.



Figure 14 - Systems Use Cases

The third use case found within the second package *consultation* is a use case that is highly dependent on the system user's behaviour during the consultation. As it is not considered feasible to make a prototype with functionality to use in an actual consultation, this third use case, which will take place in the consultation setting, has been deemed out of scope. The reason why creating a fully functioning app is deemed out of scope, is that it would require high level coding skills and a lot of hours spent on coding. The prototype being developed in this master's thesis will be designed horizontally in terms of functionality. It will describe and show a vast amount of functions. However, it will not be capable of carrying out any of the back end tasks in terms of i.e. storing data input in the correct databases, which is what would have been a vertical approach to prototyping. Therefore, bringing the prototype into the consultation would not make sense in this case. As the interaction between human and computer is key to this master's thesis, visual representations of the system, rather than fully functioning parts of the system, have been prioritized. As a consequence of this, no sequence diagrams will be produced that will encompass the details of the use case of collaborative assessment of the data between Rheumatologists and patients.

The next type of diagram presented is the class diagram.

7.2 Systems architecture

Before providing an explanation of the interactions that are possible in the system, an elaborate understanding of the static structure of the system must be understood. The explanation of the architecture of the system will be presented in two parts. One, which is a brief overview of the system, visualising the entities involved. The second part of this section will provide an explanation of the system, presented through a class diagram. This type of diagram will be explained when it is used.

As figure 15 shows, the system consists of three elements: a database, a program and a view (User smartphone). The database and the program will be explained by the class diagram and the view will be described by the prototype. The relation between these is that all data is stored within the database, handled by the program and presented to the end user in the view. Handled means that data from the database is manipulated in a variety of ways i.e. a set of data points is translated into a graph. As the figure shows, the architecture of this system is rather simple. However, an important point to keep in mind when discussing the architecture of this system is how the usage of the system is applied. As the figure shows, the user smartphone is the only device showing the



Figure 15 - Arcitechture Overview

content of the program. The young person living with RA is only one user of the system. This is represented with the double-sided arrow between the user and the smartphone. The Rheumatologist is not supposed to manipulate the system but is only able to see the output. This is important as the young person living with RA has to be the owner of the data, in order to support the empowerment of the young people.

7.3 CLASS DIAGRAM

The explanation of class diagrams derives from the works of Whitten & Bentley (2007). Class diagrams are used for presenting how the objects in a system are interrelated. They serve as the static overview, covering how the system should be built, as well as how the data is related to the user interface, with which the end user interacts. Below is the entire class diagram of the system (figure 16).



Figure 16 - Class Diagram

The class diagram is built using a framework called model-view-controller (mvc), which is a framework applied in systems design to support a more systematic coding process (Dix, 2003a). Mvc consists of three elements: models, views and controllers. In this case, there are five models: SavedView, bullet, painMap, user and program, all of which are classes as well. The reason is that they are labelled models in the mvc-framework and classes in a class-diagram. The first four are

devoted to storing data and the program, which is connected to the controller, is devoted to the manipulation of data. Program is the model that carries out actions requested by the controller. The view, as the name suggests, is the part of the system with which the user interacts. Throughout the elaboration of this class diagram, emphasis will be on explaining the models, as the technical details of the controller and the view is outside the scope of this master's thesis.

7.3.1 CLASSES

First of all the classes will be explained. Classes are divided into three parts: name, attributes and properties. However, an entity within a class does not necessarily need to have all attributes or all properties. I.e. an entity within bullet can have only the attributes: userId, date and pain, as a data input might not contain more information than the three attributes. Bullet (figure 17) is a class in this system. It consists of all data from the self-monitoring use case. As the figure shows, this class does not have any properties, as it cannot do anything but store the data. A bullet would be created when a system user has monitored the daily mood on a scale from 1-10. This entry is then stored as a bullet with the following attributes: Userid, depending on which user submitted the mood score, date of the entry and finally the mood score itself. This is an example of how an entry within a class does not necessarily have any attributes.

bullet
userld:uint date:int pain:uint mood:uint fatigue:uint stiffness:uint questions:uint condition:uint note:string

Figure 17 - Classes

The program class, on the other hand (figure 18), has no attributes; the class does not have any content. However it does have properties, since it is capable of manipulating all the data in the system. The get and set properties represent the capability of the class to either store data entries or retrieve them, i.e. to store entries in the bullet class or to retrieve bullets from the bullet class.



Figure 18 - Program Class

The program class has a property named calcRapid3. This property is central to the entire system. Rapid-3 is a simplified value for measurement of disease activity, which derives from the DAS-28 score that the Rheumatologists currently use as reference point in their treatment of RA patients.

Due the importance of the Rapid-3 score in this system, a thorough elaboration of the concept behind the score is necessary. The score is calculated on the basis of a specific set of data, which is what this system supports. Rapid-3 is based on the following equation: (MDHAQ / 3.33 +painVAS +PtGA VAS)/3 (Gilek-Seibert et al., 2013).

The MDHAQ, is the questions:uint which is a series of ten clinically validated questions about everyday activities, providing knowledge about disease activity when used in combination with the other input from the Rapid-3 equation. The following is a question taken from MDHAQ: "Over the last week, were you able to: Wash and dry your entire body" (Pincus, Yazici, & Castrejón, 2012, p. 31). MDHAQ consists of one single value between 1-10. This value is calculated on the basis of the ten questions, which can be scored between 0-4 points. Each question can be answered from "without any difficulty" (Pincus et al., 2012)(0 points) to "unable to do" (Pincus et al., 2012)(4 points). Hence, MDHAQ as a variable in the equation, refers to the sum of all answers.

The questions referred to above are described in the by Pincus et al. (2012). This paper documents Rapid-3 as an almost clinically validated disease activity measure. However, certain

precautions must be taken when referring to this paper as Pincus et al. (2012) alongside being authors of the paper are also copyright owners of the Rapid-3 score. This financial interest might impact the validity of the findings. Rapid-3 as a valid disease activity measure is acknowledged because other papers discuss the usage of Rapid-3 assessing it as a valid score (Gilek-Seibert et al., 2013). The most important aspect though is that the Rapid-3 score is accepted and found adequate by the young people and the Rheumatologists in this master's thesis.

PainVAS, is calculated as a weekly average of all scores of severity of pain, on a scale from 1-10 as well.

Before continuing, VAS needs to be explained. VAS is an abbreviation of visual analogue scale (Stinson et al., 2014). Although the scales in this prototype are not analogue, they still emphasise the same concept of a slider used to assess a certain measure. In fact, conducting self-assessment on a digital device automatically time-stamping entries has proved to be more precise than similar activities carried out using pen and paper (Sunyaev & Chornyi, 2012).

The last variable within the equation is PtGA VAS. It is the patient's global assessment, compared to how the disease could have affected their overall condition, on a scale from 1-10. This variable is calculated on the basis of a weekly average as well. When all variables are present, the Rapid-3 score can be calculated. The program provides a score from 1-10 describing the disease severity based on the user's input.

In class diagrams, the classes have relations. These relations describe the associations between the different classes. As associations can imply various dependencies between classes, multiplicity must be explicitly claimed as in the example below (figure 19). Multiplicity describes how many of one class must exist for the other class to exist. In the example above, the logic is that in order for a bullet to exist, it must have exactly one user, described by the 1 on the left side of the line linking the two classes. As bullets are data points provided to the system by users, it is necessary to claim one unique user for the bullet class to exist. The opposite dependency is that a user can have zero to infinite amount of bullets, seen by the 0..* notation. This is necessary as new users obviously have no bullets and they will over time add bullets by using the self-monitoring functionality.

The aim of this elaboration of the static composition of this system, is to bring an understanding of how the data provided by the user will be stored, eventually processed, and finally presented in the user interface. Below, the sequence diagrams explaining the operations carried out in the system will be elaborated.



Figure 19 - Multiplicity

7.3.2 SEQUENCE DIAGRAMS

Sequence diagrams are used for explaining users' interactions with the system. The technical purpose of the system is to "[...] model the interaction between object instances by showing the sequences of messages that are exchanged by the object." (Bennett et al., 2005, p. 158) The diagrams have a strictly vertical structure, outlining the spatial properties of the actions carried out (figure 20). Each sequence diagram represents one or more use cases, as described above. Although sequence diagrams tend to look complex, the purpose is to maintain a clear overview of the outcome of any manipulation of the system, within a given use case. However, an important rule when creating sequence diagrams, is that they are always created on the bases of the presumption that the user manipulating the system intends to carry out the use case. Thus, the diagram represents the ideal outcome of a use case scenario.

All numbers in the following list refer to the image below (figure 20): The box named *sd self-monitoring* (1) refers to the use case which the content within the box visualises. As mentioned in the beginning, all actors, actions and classes are understood as objects in object oriented design, which is what UI (2) and the three other boxes refer to. They refer to different objects. Whether or not an object is active at any given state is expressed by the narrow rectangle (3) covering the dashed line going from each of the objects in the top. The box within the diagram, which is labelled *Loop VAS* (4), describes a set of sequences, which are repeated a specified number of times; in this case four times. The arrows either pointing from left to right (5) or from right to left (6), are among the most important parts of a sequence diagram. They explain how manipulations of the system are translated into messages forwarded through the system until they are fed back to the UI, which is where the user meets the system. Solid arrows from left to right represent an immediate action

taken by the system, and dotted arrows from right to left represents replies to the messages sent the opposite way. Text is applied to support the arrows, as well as notes (7), when it is considered necessary to explain a sequence more thoroughly.



Figure 20 - Sequence Diagrams Explained

The next step is to describe the two sequence diagrams representing the two use cases chosen for further inquiry. The diagrams will be presented chronologically, in relation to dependency described in the use case diagram. Thus, the sequence diagram *self-monitoring* will be elaborated first.

7.3.2.1 EXPLANATION OF DIAGRAM

Arguments about why the system has been developed will be elaborated prior to all sequences within the diagram. This structure is chosen in order to give an understanding of how the research with and without participants has contributed to the design proposal below.

Like papers about RA, the focus group interview and the workshop have shown a main issue for people living with RA. They do not feel acknowledged by their Rheumatologists. They feel that Rheumatologists tend to emphasize the clinical aspects of living with RA too much in comparison to how much they feel their everyday well-being matters to the overall picture of what it is like to live with RA. Therefore, the participants demand that their Rheumatologists change behaviour. However, facilitating a cultural change among Rheumatologists is not considered feasible within the scope of this master's thesis. Instead, emphasis has been on providing a knowledge base as equal as possible between the Rheumatologists and the young people. This is pursued by designing a system that provides a tool to generate data, which meets, not only the main requirement of the participants, but also some of the requirements of the Rheumatologists.

The qualitative research has uncovered that the only way in which new information will be adapted into the consultation is when the Rheumatologists consider the information viable.

In order to meet the requirements of the Rheumatologists, yet maintain a focus on the participants, a compromise must be made. The Rheumatologists stated that if they should accept any more information in their consultations, only limited and recognisable information should be included. The participants, on the other hand, did, as mentioned above, want more information about their everyday lives to be included in the consultation. Herein lies the most important juxtaposition between the two actors.

Overcoming this contradiction is pursued by designing a system, which enables the user to gather longitudinal data. This feature is both deemed valuable from the perspective of the participants and the Rheumatologists. In order to adequately meet the requirement of the Rheumatologists, given that they want easily interpretable data, the Rapid-3 score has been introduced in the design proposal. This score will be one of the main parameters in the visual representation by the system on the basis of the data provided by the users. Thus, Rapid-3, alongside other values demanded by the participants, will be included in the final visual representation of the data. A graph is added to this visual representation that has the ability to push optional notes about events. This ability to merge data demanded by the participants with notes about everyday activities, and finally by integrating Rapid-3 will be an opportunity to challenge the crucial discrepancy between requirements of participants and Rheumatologists.

By providing the participants with a tool to replicate a value that Rheumatologists rely on, alongside demanded information, a change in the situation at the consultation is sought, supporting patient empowerment.

The following will provide a step-by-step walkthrough of the two sequence diagrams, outlining how the pursued purpose of the system is carried out from a technical perspective. The first diagram that will be explained is the sequence diagram called: *sd self-management* (figure 21). As mentioned earlier, the chronology of a sequence diagram is shown vertically, and goes from the top to the bottom:



Figure 21 - Sequence Diagram Use Case 1

The beginning of the diagram, *Choose sm*, is an abbreviation for the user choosing a menu option to begin self-monitoring. As the following arrow shows, a request is sent to get the Rapid-3 score, which is stored within the database of the system. This score, which is the score from the user's self-monitoring from the last week, is presented to the user before the user is able to begin the self-monitoring session. As soon as the user starts the self-monitoring, stated by the arrow *start sm*, the sequence enters a loop. The loop is set up to describe how the user is repeatedly asked one of four questions at the time. Each of the questions has to be answered with a dot on a slider, representing

a value between 1-10. Every one of the four values; *mood, pain, fatigue,* and *stiffness,* accordingly, are stored in the database for use later on. After the four iterations in the loop are finished, another loop begins, which is a loop of 10 iterations, explaining the ten questions required to produce the Rapid-3 score. After the 10 iterations, one last slider is presented to the user, which is a question regarding well-being compared to the optimal state of wellness.

As the structure of this sequence diagram reveals, the users cannot do anything else than answer the ten questions within the use case being presented. The path through the interface in this use case is linear. By designing a system that leaves no other choice but to answer the questions being asked, a high data quality is pursued. As the user can either answer all questions or none, a complete data set for a day is produced, or no data is produced. However, this ensures that all variables to produce the Rapid-3 score are present when the user finishes the use case scenario.

The second sequence diagram, *sd consultation preparation* (figure 22), is a direct extension of the sequence diagram explained above. This relation between the two sequence diagrams can also be seen in the use case diagram, in which the two use cases in the package *before consultation* are illustrated with a dependency arrow connecting them.



Figure 22 - Sequence Diagram Use Case 2

As the participants proposed during the workshop, they wanted an option to choose which entities of the data provided by themselves should be presented during a consultation. This second sequence diagram elaborates a use case in which this requirement is operationalized. First of all, the user selects *choose prep*, which brings forth a check-box view, in which the three right-pointing arrows right below each other represent the boxes that can be checked. The last, however, represents an option to get the graph overview presented as a synthesis of the data provided. This view is elaborated more extensively in the next section, in which the prototype is described. When the graph view is requested, the app calls the database for the Rapid-3 score, which is a combination of some of the data points provided in the first sequence diagram. This data is then transformed into one single value, using the :Rapid3Api. As the diagram shows, all data necessary to provide both Rapid-3, graphs and notes are fed to the UI, though the only data being provided to the user immediately is the Rapid-3 score. Both notes and graphs require the user to either toggle graph or toggle notes, in order for these to show up on the graph view. This construction is chosen as it thus emphasises the Rapid-3 score, which is central in the mediation of information between patient and Rheumatologist. Though, as will be shown later on, both graphs and notes, which are optional, are shown on the same graph view as the Rapid-3 score. The reason therefore is that the participants in the design team desired an option to toggle whether certain data should be hidden in the view that their Rheumatologists should see.

When the notes have been toggled, an option has also been made to individually choose which of the notes made will be present in the view for the Rheumatologist. This option is made to meet the requirement of complete control of data. The last option during this sequence diagram is to save the edited graph view for a consultation. When saving the view, the user is given a confirmation that the view is saved for purposes later on.

This elaborate explanation of the actions carried out during the sequence diagrams is a leap towards a visual representation of the system, which is the next part of the design process.

7.4 PROTOTYPING

The prototype aims to be functioning in a way which enables the participants to properly assess the design ideas. Therefore focus is put on the visual representation of the system rather than on creating a fully functioning system. The aim of the prototype is to make it an epistemic object which the participants will be encouraged to propose improvements for, when they interact with it.

The prototype itself will be elaborated in two steps. First of all, a set of usability heuristics used for this design case will be explained. Afterwards, the prototype will be presented with screen dumps, explaining both use cases elaborated in the sequence diagrams.

7.4.1 USABILITY HEURISTICS

The heuristics will work as a theoretical framework for the design principles applied in the making of the prototype. Two main sources are used as basis for these heuristics. The first is Dix (Dix, 2003a), which covers all basic usability heuristics. The second is Zapata et al. (2015), which is a context specific paper covering usability heuristics particularly relevant when creating mobile health apps.

Zapata et al. (2015) has assessed the operability of mobile health apps, and found that certain precautions must be taken. Operability refers to the ease with which users can manipulate a system. I.e. it was found that an operability concern regarded "difficulty in performing swipe gestures" (Zapata et al., 2015, p. 19). However, there have not been made any particular precautions in this design process, as all participants have responded that they are daily users of smartphones. Thus they are used to the typical gestures on a touch screen. Focus has been put on understandability and on learnability (Dix, 2003a; Zapata et al., 2015). The prototype has been developed with a high degree of understandability, as the users of the system should be able to adopt the ideas behind the system immediately. Therefore, it is beneficial for the understandability of the system that the questions asked in self-monitoring functionality are derived from the HAQ-questionnaire. This is beneficial because some of the participants have expressed that they are familiar with the HAQ-questionnaire. Learnability is addressed by providing an extensive description of the purpose of the self-monitoring use case, as soon as the user initiates the process of self-monitoring.

A major part of the use case self-monitoring occurs as a linear path. This should create predictability, another important usability heuristic, as the user would be able to grasp the path quickly due its simplicity. Another effect of this linear design is that the user should find the design consistent, as graphic elements are adopted throughout the self-monitoring process. The graphical consistency can be seen in the figure below, explaining the path through the self-monitoring use case. Aside from the emphasis on usability within the system's design, focus is also on maintaining a high degree of data quality. The concept of data quality in this master's thesis is derived from the works of Pipino et al. (2002) who have developed a set of criteria for assessing data quality. Two of the central criteria are met by this design: completeness of data and appropriate amount of data. They are both concepts aimed at producing data that can produce valuable output. In this case, the valuable output is a graph view, presenting the data to the user. This will be elaborated below. How these data criteria have been met alongside the usability heuristics presented, will be discussed on the basis of an explanation of the prototype visualised in the following figures. All functionalities in the prototypes are presented in Danish, as the prototype is developed for Danish people. Hence, descriptions of the prototype will include Danish words from the views in the prototype.



7.4.2 Self-monitoring - explained

Figure 23 - Prototype Use Case 1

The path through the app is visualised by the green arrows (figure 23) between all the screen dumps of the prototype. The green numbers will be used as reference numbers, when describing the prototype.

The self-monitoring use case is initiated in the main menu view (1), in which the user, by pressing "Hvordan har du det i dag?" is led to the second explanatory view (2) providing a description of the Rapid-3 score. After pressing start in view (2), the user is led to the first of the four VAS scales, mood (3). When mood has been set by moving the scale in the view, the smiley in the middle changes accordingly to the chosen value; if mood is low, the smiley looks sad and if the mood score is high, the smiley changes to a happy face. When pain is chosen the user is led to the pain-VAS (4), which has the additional feature that the user can explain in details, where the pain has occurred on a pain map (4a). After pain-VAS, the user proceeds to the monitoring of fatigue and stiffness, which are not represented in the model, as they are completely identical with regards to interaction as mood and pain. The next view (5), after completing the initial four VAS scores, is the HAQ-questions. This view will present ten questions to the user. As soon as the user answers a question it is automatically substituted by the next question. This immediate and similar response after each question provides consistent systems design. When the ten questions have been answered, a "næste" button appears (5a). This will eventually lead to the final VAS score (6). This VAS score is corresponding to the PtGA-VAS, which is a part of the Rapid-3 equation. When this value is set, the user is led to the final input option of the use case, additional notes (7). This view presents three options for entering notes. The user has the opportunity to write a title for the note, choose pre-defined topics describing the day and finally write a note about the how the day has been. These predefined topics derive from the original Rheumabuddy app. When this activity is finished, the prototype provides an encouraging feedback for the user in the form of a pop-up message (8) explaining that the user's efforts have provided a more solid basis for him or herself when attending the next consultation.

This use case serves the purpose of providing sufficient data about the user, in order to be able to do two things. First of all, it is possible to generate a set of graphs on the basis of the data, which would eventually lead to the users getting a better understanding of their own disease. This improved overview might even lead to an extended understanding of which factors impact the disease activity. The user becomes more self-aware through this, with the intention of empowering them. The second purpose of the self-monitoring is to provide the data input needed to calculate the Rapid-3 score. Although still important for the users, the main purpose of providing Rapid-3 scores is to have an opportunity to provide a value, which might improve communication with the Rheumatologists.

A more thorough explanation of the second part of the prototype will be elaborated below.

7.4.3 PREPARE FOR CONSULTATION - EXPLAINED

The image below (23) is a visualisation of the second use case in the prototype. The first view presented is the main menu (1). From this view, the user can click on "overblik", which leads to another navigation view (2) that displays four options. The third option, "forbered konsultation", leads to view (3) in which the user is able to determine how far back in time the graph view should be. Moreover, the user can determine whether or not the pain maps should be included in the graph view. When the user has decided the properties of the graph view, "graf over sygdomsaktivitet" must be pressed in order to bring up the graph view (4). Per default, the graph view shows nothing more than the calculated Rapid-3 scores. These are represented by a coloured value combined with a matching background. As Rapid-3 scores express disease activity, being close to zero shows how close the users is to being in remission. Therefore, the graph view has been designed with lower values closer to green and higher values closer to red. Above the actual graph view there are five buttons consisting of the first four VAS-scores; mood, pain, fatigue and stiffness plus notes. In the next view (4a), the buttons fatigue and pain has been toggled. If smertekort has been toggled in the previous view (3), the user will be able to access a pain map at each of the peaks on the pain graph. Mood and stiffness can also be accessed by toggling their respective buttons. If notes are toggled, a thin grey line appear (4b) for each note entered in the first use case. If a user has entered a note on a certain day, these can be reached by tapping on the small grey bubble in the bottom of the graph view. By doing this, the note will, as shown in 4b, be presented as a box lying on top of the graph view. In these boxes, each note can be toggled, determining whether or not a given note should be saved with the view graph view. The same goes for all four graphs; toggling them does not only display them or hide them. Toggling the graphs also determines whether these should be a part of the saved view. When the user is satisfied with the view, "gem" is pressed, thus bringing up a pop-up box that explains how the user can see the view in "gemte konsultationer".

The actions carried out in this use case give the user an opportunity to prepare for consultations by determining, which parts of the data gathered through the self-monitoring that will be presented to the Rheumatologist.



Figure 24 - Prototype Use Case 2

7.4.3.1 Comparison with requirements

The two use cases elaborated in this section have a dependency. Prepare for consultation is dependent of self-monitoring, as all graphs, Rapid-3 scores and notes, presented as a part of the preparation for consultation, rely on data provided by the user. Therefore, understanding how this prototype meets the requirements of the stakeholders, will be the main focus of the second use case, prepare for consultation.

The workshop carried out in this stage stressed the importance of a system capable of providing more time and comprehension from Rheumatologists. Meeting this requirement is pursued by designing a system that is able to provide a compact yet complete overview of relevant parameters related to RA. By giving the users an opportunity to create systematic data about their disease activity, the users might bring themselves into a better position in regards to being comprehended by the Rheumatologist. All requirements in the table below will be compared to the prototype developed in this stage.

Stakeholder	Requirements
Young people living with RA (Primary)	1. Comprehension from the Rheumatologist
	2. Online HAQ-questionnaire
	3. Individual preparation prior to the consultation
	4. Dating back information about their condition
	5. Differentiated intervals between consultations
	6. Comprehension from the surroundings
	7. Medicine reminder
Rheumatologist (Secondary)	1a. Data has to be recognizable and represented in a simple way
	2a. Intervals regarding notifications
	3a. The patients has to fill in the HAQ-questionnaire on the day
	of the consultation
	4a. Patients to prepare questions
	5a. Comparison of values
Daman (Tertiary, facilitating)	1b. Profitable system
FNUG (Tertiary)	1c. Supporting their members

The requirements will be assessed chronologically. Through this system, the participants are able to gather extensive amounts of qualitative and quantitative data about themselves. Via this continuous self-monitoring, over time the young people will be able to express their needs to their Rheumatologists more clearly (1 & 4). The graph view will provide an opportunity for the participants to meet some of the requirements of the Rheumatologists (1a & 5a), as they will be able to generate a set of values, which the Rheumatologists will acknowledge. A point that was stressed by the young people in relation to the comprehension from the Rheumatologists, was that they had the experience that the Rheumatologist did not prepare for the consultations. This triggered a feeling that they were not taken seriously. It is not possible to change the workflow of the Rheumatologists, ensuring that they actually prepare for the consultations. Instead, the young people are provided with a tool that makes them capable of presenting easily interpretable data. This gives the Rheumatologists a quick overview, prepared prior to the consultations or not, thus giving them the additional information. This will ensure that the young people will have the impression that the Rheumatologist are up to date with regards to their condition. Although the Rheumatologists stressed the importance of keeping information brought into the consultation at a minimum, they did mention that questions asked by people living with RA (4a) could be valuable in some situations. This requirement is partially met due to the functionality, which provides an opportunity for the user to write notes. The two requirements related to the HAQ-questionnaire (2 & 3a), will not be met immediately. People with RA fill out a HAQ-questionnaire prior to consultations. This might possibly be substituted with the MDHAQ presented within this prototype. However, at the moment this is not possible, and as such these requirements have not been met. The participants addressed the problem of lack of comprehension from the surroundings (6), yet the problem was deemed impossible to solve by the use of an app. Another finding was that the participants could not agree that medical reminders (7) were an important functionality to incorporate in the prototype. Therefore, medical reminders have not been included. Another requirement, which has not been included, is the participants' wish that intervals between consultations could be planned individually (5). As this was found to be beyond the capabilities of this prototype, it was not included. The revenue of an app cannot be determined on the basis of a visual prototype, hence determining whether the requirement of Daman is met can be difficult. The requirement of FNUG to support their members (1c) has been met in case the statement of the participants correlate with a broader reception of the app developed in this master's thesis.

7.5 SUMMARY

During this stage it was found that requirements of young people living with RA and Rheumatologists could be combined. This was found in the initial activity of the workshop, where the participants were asked to qualify a set of challenges derived from requirements found in stage three. Furthermore, this stage has provided an extensive elaboration of the system architecture for a prototype able to support young people living with RA in their consultations with Rheumatologists. The system's design revealed that the dependency between the two use cases could be overcome by designing a prototype with a short linear path through the first use case. The prototyping also revealed that it was possible to merge quantitative and qualitative data by combining a graph view, with pop-up boxes presenting notes. A Rapid-3 score calculation was added to the prototype in order to transform a part of the self-monitoring data input from the user into a clinically validated disease measure, which will provide a simple and recognisable value useful for the Rheumatologist in consultations.

Stage 5

User Testing

This main purpose of this stage is to conduct a series a user tests providing knowledge about:

How do the participants of the design team perceive the prototype?

- The participants had only few requests related to changes in the design.
- They had a homogenous experience of the prototype.
- They found the Rapid3-score precise in terms of describing how they were feeling.

8 STAGE 5: USER TESTING

In this stage the prototype will be assessed by the participants. The stage will also provide a set of improvements of the system based on the findings from the user test carried out.

8.1 USER TEST

The evaluation of the prototype will be carried out as a cooperative evaluation which is a constructivist interpretation of a think aloud test (Dix, 2003a). The method is normally carried out on a lab session where users are highly encouraged to elaborate verbally on what they see, do and think when carrying a set of predefined tasks out. In this case, it has been decided that emphasis is on creating knowledge collaboratively, thus arguing that asking the participants questions during the session can be beneficial.

This activity consists of a combination of two separate activities. One being the cooperative evaluation (Monk, 1993), the other being a discussion among all participants. This provides more knowledge about how the participants interpret the prototype (Dix, 2003a). A more thorough evaluation is sought by assessing the prototype like this. It lets the participants express their personal ideas about the prototype to the rest of the group for further discussion.

8.1.1 Focus

The aim of this stage is to produce knowledge about the outcome of the design process. By presenting the prototype to the participants, it will be uncovered how they perceive their own ideas that have been conceptualised into a prototype. Asking the participants to evaluate the system makes it possible to gain insights into whether or not they are able to understand the concepts. The section serves the purpose of answering the question:

How do the participants of the design team perceive the prototype?

This stage strives to discover if the participants are willing to use the prototype to fill in the necessary information about their condition. This insight will be used to determine what needs to be redesigned.

8.1.2 SAMPLING

This intervention was carried out in cooperative sessions with four of the original six participants of the design team. It is sufficient to say that the group participating in this activity can be considered collaborative designers (Spinuzzi, 2005), as they have all participated in other activities of the design process.

8.1.3 SETTING

The activity consisted of two settings, both located at Daman. One being a lab setting in which the participants, one at a time, were asked to complete a set of tasks. The second setting was a discussion in plenum; a more informal discussion regarding the experiences of the prototype.

8.1.4 INTERVENTION

As mentioned above, a cooperative evaluation is practiced. From a social constructivist point of view, this method explicitly acknowledges the knowledge construction during a cooperative evaluation session. I.e. the presence of an observer was used actively by responding to the participants' questions during the test. Moreover, the qualities of using a cooperative evaluation method, as explained by Monk (1993) correlate with the aim of this stage: *"The aim is not to provide an exhaustive list of all the problems that could possibly be identified. Rather, it is to help you identify, with the minimum of effort, the most important problems to consider."* (Monk, 1993, p. 1). By emphasising this method, the output should most comprehensively consist of data about which parts of the prototype that need to be redesigned.

In each lab session the participants individually assessed the prototype by carrying out two tasks on their personal smartphone because the prototype was developed for smartphone use (Appendix 22). These tasks derive from the use cases proposed at stage 4, as they explain how the system should optimally be used.

The first task is to perform the use case "self-monitoring", which is the monitoring of the disease activity. The instructor kept track of the values that the participant chose during their self-monitoring. The prototype is not able to handle actual data input, thus it only imitates data input. By keeping track of the data input, the instructor will be able to calculate the Rapid-3 score and present it to the participants. This was done in order to assess whether the participants considered the output of the Rapid-3 score, which represents their disease activity, as being similar to how they actually feel.

The second task is for the participants to carry out the second use case, prepare for consultation. This was done to see if the participants understood the functionalities in the prototype, which should be able to support the participants in their consultations.

The data from the activity will be represented as transcripts of the conversations between participants and instructors during the analysis together with screen dumps of the prototype alongside screen dumps of the improvements made to cater the new requirements from the participants.

8.2 ANALYSIS RESULTS

Below, data from the cooperative evaluations will be used interchangeably, thus bringing nuanced insights into how and why certain aspects of the prototype need to be redesigned. The prototype has been assessed chronologically in terms of how the use cases are carried out, as this matches both the structure of the prototype as well as how the participants were exposed to the prototype.

The first view in the prototype is the main menu (figure 25).

This view was originally taken from RheumaBuddy. The view did not acquire a positive reception from the participants. The labels in the menu were too difficult to understand. Especially the second use case gave some difficulties, as some participants expressed that it was not logical how



Figure 25 - Redesign 1

they could prepare for consultations:

P1: I had a problem. The second question. Where i were supposed to prepare for consultation. I had no clue. On the front page. What to click on. I was apparently supposed to click on overview.

INT: Yes and it did not make much sense.

P1: I don't think so. I thought overview was more like. It was only an overview of how i have been. As long back in time as it is able to calculate. About mood and such. That what the overview it thought was an overview.

INT: Yes. What should be there instead in order for it to make sense to you. I can be pretty difficult. You might have a clue.

P1: I don't know. Consultation or something like that. Consultation with doctor.

INT: Okay

P2: Yes but then there must be two buttons. Because then there would both be one named consultation and one named overview if you just wanted to enter it over time.

P1: Yes yes. But then i would

P2: And see that overview right

P1: I would prefer an extra on the front page named consultation.

P4: Yes then when you click it. Then you have one named preparation and then you take that one and turn it into an individual menu item.

(Appendix 17, p. 1)

They address that the titles used in the menu are difficult to interpret. These issues were addressed by moving the "forbered konsultation" button from a sub menu onto the main menu. By doing so, the predictability of the functionalities of the buttons has been improved because both buttons are now placed in the main menu. Moreover, the users have saved a click, as they are now able to access preparation of consultation from the main menu.

One participant specifically stated that the process of clicking through self-monitoring was a cumbersome task. One of the pitfalls when designing a system is to cause the users to engage in long click-through (Dix, 2003a). Because of this, the statement was taken into account and has been addressed in several ways. The two figures (26a) and (26b) below are examples of views in the self-monitoring use case that have been removed, in order to provide a more efficient way through the use case.



Figure 26a - Redesign 2



Figure 26b - Redesign 3

Removing the intro image of figure 25 additionally improves the adaptation of the principle by Zapata (2015) that explains the importance of avoiding large chunks of text in one image. However it was considered important to give the users an opportunity to understand the underlying concepts of Rapid-3. Therefore, an info-button (figure 27), optionally providing a description of Rapid-3, was added to the final view in the self-monitoring.



Another benefit of proceeding directly to the next view after completing "ti hurtige" was that the inconsistent placement of the "næste"-button could be avoided. These changes are supported by statements below the images:

P2: I think the point where I go: "Oh, this is going to take forever". That was like where it started asking me all those questions about: "Can you do this" and "Can you do that?"

P4: Perhaps it's not necessary to do that every day.

As mentioned above, reactions about the self-monitoring process as being time consuming was not a widespread tendency throughout the dataset. It is still considered important to react upon the statement, as the users might have been impatient if they were asked to monitor themselves more than once during the usability testing. The fact that one of the participants pointed out that it might not be necessary to perform the monitoring each day correlates with the concern the Rheumatologists mentioned in stage 3. They are both arguing that it might not be advisable for the young people to perform self-monitoring too often, and that data from times of severity is the most important.

Due to the linear nature of the self-monitoring use case, any view removed within the use case will provide faster completion times for the users. Therefore, the screen which provides the users with an opportunity to write a personal note about what made the day special was removed. (figure 28).



Figure 28 - Redesign 5

Moreover, the note taking screen was removed because of a severe lack of understanding. The participants did not understand the idea of both providing a title as well as a note describing the day. Moreover, the fact that the screen required two free text input fields seemed to be a major issue for the participants. This findings correlates with the work of Zapato et al. (2015), who has stressed that system users commonly respond badly to free text input. Though, as it is seen in the image above, the substitution for the dedicated note view, was a pop up box allowing the participants to submit short notes about their day. This exact need was expressed in the data:

P4: That's an okay question. Perhaps it just needs to be rephrased a little.

P2: Maybe you could call it quick note. Or, I don't know. Something. In some way it is. I assume that it is what will appear as a note on the graph. Or what?

P5: Otherwise just extra note.

(Appendix 17, p. 2)

This is one of many examples of the users expressing negative thoughts about the note view.

Extending the discussion of how to create a path through the self-monitoring that is as smooth as possible, the new design of process bars will also be extended on the basis of quotes from the participants. The process bar made in the first iteration of the prototype did not work out in terms of providing the participants adequate feedback about their current status through the use case. The process bar did not include a dot for each of the ten questions asked in the use case, but was instead presented as one activity per dot. This was redesigned to show the actual amount of steps that should be carried out in order to complete the use case (figure 29). In particular one participant felt that the lack of transparency would become an issue if it was not fixed. Her expression is also backed by the heuristics proposed by Dix (2003a) about predictability within a system. Users tend to emphasise that systems must clearly express where the user is in the system:



Figure 29 - Redesign 6

Another improvement to the prototype was made on the basis of the lack of response by the participants. As none of the participants clicked on neither "smertekort" nor "aktivitet", which were sub-categories of the two VAS scores "smerte" and "træthed", they needed to be redesigned. However, "smertekort" remained in the system, because when the participants were shown the presence of it, they were positive towards it. On the other hand, "aktivitet" was removed from the prototype as no participants seemed to show any interest in the functionality. As the image below shows, the button for activating the pain map was kept in the second iteration. However, the appearance has been changed from a plus-symbol to a lightning-symbol (figure 30). Moreover, the lightning seen in the purple circle will, whenever a user touches the VAS-slider, rotate 360 degrees in order to catch the attention of the user, due to sudden motion in the image.



Figure 30 - Redesign 7

All the changes elaborated above relate to the first use case. The users tended to express the most concern regarding this use case. However, one important change was made to the second use case "prepare for consultation". This use case contains the graph view, presenting a visualisation of the data provided by the first use case. The temporal aspect of providing a visual presentation of the condition of the disease over a period of time, was not designed purposefully, as no temporal indications were to be found on the y-axis. The participants wanted dates presented on the y-axis, as they needed insights about the period that the graph represented in order to make sense of the patterns related to the graphs:

P2: I think that's missing. I need weekdates on there. But then I use calendars every day, so.

INT: Yes yes, exactly.

P2: I don't know if the others had.

P1: Yeah, I agree.

P2: Had that experience. (Appendix 17, p. 2)



Figure 31 - Redesign 8

As the image shows, three improvements have been made to the graph view. The y-axis has been improved by labelling the days of the week. A description of the view has been added, and "noter" has been re-styled from grey to purple, as especially one participant was challenged by the grey colouring of notes. They tended to disappear on her phone:

P5: It doesn't really show up.

INT: Try to click it again. It's because they're very unclear on your phone. They should be there.

(Appendix 17, p. 1)

Therefore, the colour was changed. Moreover, presenting "noter" in the same purple that is the signature colour of the app, emphasizes that it is an important functionality.

8.3 SUMMARY

This stage has discovered discrepancies between the participants' requirements and the prototype. The analysis has primarily been focused on concepts in the design that were not well received. However, this same analysis also reveals that the participants seem to acknowledge the overall design; their response to the prototype revolved primarily around minor details, such as navigational aspects of the menu and the process bar in the bottom of the screen. The only major issue regarding the overall idea behind the use cases was a concern in relation to answering the self-monitoring questionnaire too often. This is not a design issue, which is why it has not been addressed in this stage. One major point in this cooperative evaluation is that the participants tended to have a homogenous experience of the system, providing a basis to enhance the prototype in a way, which will support the input from all participants.
Stage 6

Cooperative Evaluation

This main purpose of this stage is to conduct cooperative evaluations of the prototype with Rheumatologists answering:

How can the prototype improve the consultations from the perspectives of the Rheumatologists?

- Minor changes have to be made to the user interface creating more exact explanations of disease related topics.
- They acknowledged the premise of the rapid3-score and they found the overview provided, which combines the Rapid3-score and other visualisations valuable.
- They found the prototype relevant to include in consultations as a tool for supporting dialog.
- The prototype can give additional knowledge related to regulation of medicine.

9 STAGE 6: COOPERATIVE EVALUATION

The focus of this section will be to test the prototype, which has been modified on the basis of the user test at the previous stage, with the Rheumatologists.

9.1.1 Focus

This stage will determine if the Rheumatologists can support to the premise suggested and thereby be willing to adapt the system into the consultations. The section will serve the purpose of answering the following research question:

How can the prototype improve the consultation from the perspective of the Rheumatologists?

One of the main goals will be to determine whether or not the rapid-3 score, which has been incorporated in the system to support their requirements, actually fulfils its purpose.

9.1.2 SAMPLING

The sampling consisted of two Rheumatologists from Glostrup Hospital. They are the same Rheumatologists that were interviewed during the qualitative research in stage 2. These Rheumatologists were chosen in order to be able to discover whether the design supported the requirements that were determined on the basis of their utterances.

9.1.3 SETTING

The test was carried out at Glostrup Hospital. This was the same place as the contextual inquiry and the two previous interviews with the Rheumatologist were made. The setting was chosen to be the same place where consultations normally take place. This was done so that the Rheumatologist would not have to make any considerations aside from relating to the system and to make the setting as realistic as possible.

9.1.4 INTERVENTION

The interventions were cooperative evaluations (Dix, 2003a) performed in the same way as the ones performed on the users at stage 5. The only exception was that the Rheumatologists were not gathered to discuss their experiences with the prototype after the cooperative evaluation. This is considered an advantage, as the Rheumatologists are asked to give their opinion as experts on the young people's behalf when using the self-monitoring functionality of the prototype. They were furthermore asked to evaluate if and how the prototype would add any value to the consultations. This was done on the basis of the final graph view that is supposed to be presented to them by the young people. Including the Rheumatologists was done by asking them to perform simple tasks using the prototype, telling them to evaluate continuously. The facilitator encouraged the Rheumatologist reflect critically on the prototype (Dix, 2003a). The method is considered valuable in this particular setting, as the interaction with the system is not supposed to be performed by the Rheumatologist, but by the young people. The role of the Rheumatologist lies in interpreting the data presented to them, visualised through the system. Therefore, questions like "what-if" and "why" where considered more valuable than simply providing a walkthrough of the system.

The Rheumatologists used the prototype on a smartphone, making the setting as realistic as possible. The sessions were recorded on audio.

9.2 ANALYSIS RESULTS

This section will provide an analysis of the data from the testing in two sections. The first will present the Rheumatologists expert evaluation on behalf on the young people. The final section will elaborate on the evaluation towards using the system in consultations from their point of view. The first section will provide further qualification of the functionalities in the prototype. Even though, due to the social constructivist approach of this master's thesis, it is not possible for an individual to mean something on behalf of others, it still serves the purpose of getting insights about the systems functionalities. The utterances will only be considered in comparison with the actual utterances from the young people. The last section will indicate whether or not the system has a chance of being adapted into the setting of consultations.

9.2.1 EXPERT EVALUATION

When performing the self-monitoring with the prototype, the Rheumatologists were excited about the pain map and the possibility of adding notes. The pain map gives the possibility of adding the exact joint that causes pain (figure 32) and adding notes (figure 33) makes it possible to enhance dialogue with regards to how and why a particular day has been affected by the disease:



Figure 33 - Pain Map



Figure 32 - Graph View

RH2: The note is a good thing. Sometimes when they've written that everything's awful, and they come in, it turns out to only be about the knee. Overall things are going well with their arthritis.

(Appendix 18, p. 1)

and

INT: There's a link to a pain map here. So you can click on that as well.

RH1: That thought. Okay, so then you can enter where it hurts.

INT: Exactly.

RH1: Clever!

(Appendix 19, p. 1)

An interesting point was that one of the Rheumatologists mentioned that some of the patients might not know what a HAQ-questionnaire is. At least some do not know that the questions they answer prior to their consultation is actually called a HAQ-questionnaire. Neither do all of them know that the Rheumatologist relies on a single value, DAS-28, when determining the severity of the disease:

INT: What do you think about this explanation?

RH1: It's probably not everyone that understands what a HAQ-questionnaire is, I think. So maybe it needs. It's probably fine.

INT: What would you call it to make sure that a patient gets it? What do they see it as?

INT: I'm actually not. It's very different. I'm not sure that they're all aware that it produces a number at the end.

INT: So they might not even know what happens in Danbio?

RH1: Well, they know the picture. It's not all who. Well, HAQ doesn't show us as anything other than a number, right. But what we tend to look at is DAS-28, and HAQ isn't even a part of that

(Appendix 19, p. 1)

This point correlates with a point from the workshop. It was not all the participants who knew that the questionnaire they were filling in was called HAQ. This is a valuable insight. The next step will be to expand or modify the explanation that is given in the following screen view (figure 34):



Figure 34 - Rapid-3 Explained

Another point was that stiffness might benefit from getting renamed into morning stiffness because it is more accurate simply due to the fact that stiffness only occurs in the morning. This was another point that correlated with previous findings; this time with the focus group interview. The young people articulated stiffness as morning stiffness. This is another issue that needs to be corrected in the prototype.

9.2.2 USE IN CONSULTATIONS

The second part of the testing session was focused on the graph view.(figure 35).



Figure 35 - Graph View 2

A noteworthy point was that when the Rheumatologists were presented with the graph view, their first reaction was of a negative character. Their negative responses were in relation to scepticism towards the concept in general, but also towards the view being too detailed and complex:

INT: If you look at this way of presenting it.

RH1: Then I might get confused as a doctor when I saw.

(Appendix 20, p. 1)

and

INT: If you're presented with it (the graph, red.), how would you. Do you understand the graph? Does it make sense to you?

RH2: No

[...]

INT: What about the number behind it? The Rapid-3 score? What do you think about that? Is it.

RH2: It is confusing.

INT: Is it confusing?

RH2: Yes

[...]

RH2: Yes of course. You need, like, if you are going to use it, then you need to take the time to understand what it is.

(Appendix 21, p. 1)

However, after a while their attitude changed. They were given additional information about the origin of rapid-3 and how it related to the other values that they use in consultations. This changed their judgment and they suddenly acknowledged the premise. They stressed that the rapid-3 score would provide an overview of the condition and that it would be relevant to use it in consultations. This relates to a point stressed by Soo Yi et al. (2008), they acknowledge that graphs might provide an overview, allowing a more comprehensive basis for grasping important areas of the data set, by enhancing the understanding of insights about patterns related to disease activity:

RH2: Of course it does. It does so in a way that has been decent. It's been a good week. And then you can see when the notes come up, that you've had a bad time because you've been out (drinking, red.). Have been tired the rest of the week. The pain was actually reasonable, but it's the tiredness. So in that way, yes. It could be useful.

INT: Then it becomes a little more recognisable, rather than simply being a graph.

RH2: Yes.

(Appendix 21, p. 2)

and

INT: If we play a game, where the patient had to bring something to show you.

RH1: Well, it could definitely be relevant.

(Appendix 20, p. 1)

The scepticism at the beginning of each test session is argued to be both a consequence of the Rheumatologists trying to preserve the sparse amount of time allocated for consultations, but also a result of time pressure in relation to the test session itself. The Rheumatologists hesitated through the events thereby potentially missing some information along the way.

Rapid-3 was shown to support the requirements that additional information needs to be recognisable and presented in a simple way. An example of this is shown in the following quote where a Rheumatologist agrees on the advantages of the score.

INT: That's exactly what we thought, that when it was that number. Then it as like. Then you didn't need to make a lot of decisions.

RH2: Exactly. Not think, yes
INT: Then you could focus on the number.
RH2:Yes.
INT: And then the graphs could underpin the number.
RH2: Yes. Yes, that's very sensible.
INT: That's good.
(Appendix 21, p. 2)

A hypothesis was made that Rapid-3 would act as a tool for dialogue, supporting and empowering the young people. One of the Rheumatologists strengthened this assumption by stating that she found the tool useful for the young people and that it might support communication in consultations. This hypothesis is also supported by the works of Pincus et al. (2012), who states

that assessing disease activity quickly within a consultation can prove beneficial for both the Rheumatologist and people with RA:

INT: Could you see it adding any value to a consultation? That's hard to estimate, I know.

RH2: Yes. There's a lot you, like. The young people get a lot of use out of it, and then communication with them might become a little better.

(Appendix 21, p. 2)

The Rheumatologist also commented on the Rapid-3 score after she had spent more time understanding its purpose. It was considered a useful feature to provide an overview of the young peoples condition:

RH2: It's actually. It's a good thing with that number. It provides an at-a-glance idea that, okay, it's going reasonably well. Or that, like, it's not going so well. And then you can use that as a jump-off point and say. You've had a rough week here. So you could definitely, like, in that way.

(Appendix 21, p. 2)

Both Rheumatologists raised a concern that the young people might become too aware of their disease due to the recurring focus on their disease by constant encouragement of self-monitoring via an app. They stress that it is important to avoid to imply that higher registration frequency in the app leads to more precise results, as this might eventually have an unwanted side effect; making the young people too aware of their own disease:

INT: Yes, during the week, and the more they do it, the more precise it would become.

RH2: But perhaps you shouldn't tell them that. Because then they'll just be doing it morning, noon and evening.

INT: Yes.

RH2: And that's not a good thing.

(Appendix 18, p. 1)

In addition to this point it was stressed that the young people might only use the tool when they are having outbreaks. However, this is considered positive, as it is ideal if they forget to self-monitor at times of remission. In addition, data solely derived from times of severity of the condition does not compromise the quality of the data as these periods are the most important seen from a clinical perspective. RH1: I just have some concerns about constantly monitoring yourself. I think I said the same thing last time.

INT: Yeah, that's what you said last time.

RH1: That I. Sometimes. But I think that you might also be more likely to do it if you're feeling bad, and then that's very relevant. Then you should do it. That's what the doctor needs to know. An you could say that if you're feeling fine then you don't have to do it.

INT: No.

RH1: At least not as frequently.

(Appendix 20, p. 1)

A noteworthy point is that even though the system is indicated to be useful as a tool for facilitating dialogue and for empowering the patient, it is still necessary to engage in a clarification of expectations between the Rheumatologist and the young people. This has to be done whenever a patient brings in additional information to the consultation. Especially when the young people have spent a fairly large amount of time on producing the information they might expect the whole consultation to revolve around their self-monitoring and that might not be realistic:

RH2: The more information the patient brings in, the more work there is for us to do. So we're put under a lot of pressure. And again. And when the patient, like. They've spent so much time. They care so much about it. And for them it's like, theirs, and they know themselves. And in some way they expect us to go through it in detail. So if you just say "well, that looks fine", then they might feel like they're not heard or seen.

INT: It's a balancing act.

RH2: Yes, it is actually.

(Appendix 21, p. 1)

It is also acknowledged that adopting anything new, in this case technology inevitably requires a process of implementation. If this is done adequately the system is considered a valuable tool:

RH2: It's all a process, just like anything new. It's about finding the middle ground, how much the patients expect and how much it can actually be used, but it can easily be used. (Appendix 21, p. 3)

One of the Rheumatologists added that she was not, from a clinical perspective, interested in the mood scale presented on the graph. It was argued that the value might be affected by other variables than the RA. This clearly elaborates the point that importance is highly dependent on the perspective; people living with RA might consider mood highly relevant, and Rheumatologists obviously consider it useless:

INT: Do any of the graphs not make any sense to you?

RH2: Mood

INT: Mood doesn't.

RH2: I don't need it for anything.

INT: No, you don't need it for anything. It's good that you say that, because for the young people it was important to say that they were in a bad mood and so on.

RH2: We're living in a world where we need to, like, one, two, three, four, five, and mood can affect all kinds of other things. It might be all kinds of different factors that affect mood.

[...]

RH2: [...] So here's an opportunity to get rid of your frustrations by hitting bad mood. (Appendix 21, p. 3)

Another point that was mentioned was that the prototype has potential besides being a tool for dialogue. The self-monitoring can help to determine regulation of intervals and doses of medicine because the graph can show in detail how the young people are affected when they take their medicine:

INT: Now, if there is this correlation between Dash-28 and Rapid-3, would that give you anything that you could look at on a weekly basis over a certain period?

RH1: Yes, well, it would be very relevant if someone got. Well, you could say treatment at regular intervals. But that doesn't hold up. Like, they might need it more frequently, or need a higher dosage. That might be a good thing if you could. Some of the medications that are given every eight weeks, and you can see that right around the point where they're due for one, they feel bad.

INT: Then you might decrease the interval.

RH1: Yes, decrease the interval or increase the dosage, depending on. So in that way I could definitely see that it could be relevant.

(Appendix 20, p. 1)

9.3 SUMMARY

The test session at this stage showed some minor changes that needed to be done in relation to the user interface. This was mainly improvements in relation to how different parts of the app were explained, making the information more accurate. The last part of the session showed that after the Rheumatologists had comprehended the purpose and premise of the prototype, especially the Rapid-3 score, and that they found that the prototype would be relevant to include in consultations. This was caused by the fact that the Rheumatologists acknowledged the premise of letting the young people bring in additional information to the consultation. They argued that the prototype would successfully function as a tool for dialogue. It presented them with a simple, recognisable visualisation that created useful, temporal insight into the young peoples' disease activity. Additionally the prototype has, due to its detailed insights over time, the ability to provide the Rheumatologists with new information. It can help them to regulate medicine more appropriately, to ensure the best treatment. Combining the different statements from the Rheumatologists gives an impression, that they acknowledge the usage of apps in consultations. Not only as a means of empowering the patients, but also from the perspective of the Rheumatologists themselves.

Stage 7

Discussion, Contribution, Future Work

This stage serves the purpose of discussing the research that has been done in this study. The methods as well as the role of the researcher will be discussed:

- The research has shown to provide additional knowledge to the research field by adding knowledge about how to include target group and health professionals in the process of developing apps in health care, how to overcome challenges of efficacy of systems and quality of data and finally the importance of combining qualitative and quantitative data.
- The findings might be transferrable to other contexts.
- Finally the section provides information about how future research can add knowledge to research field.

10 STAGE 7: DISCUSSION

By raising the abstraction level from reflections upon the research to reflections upon the reflections themselves, this stage will contribute to this master's thesis by providing methodological, case-specific, and theoretical discussions of the work carried out. Combined these discussions will provide a basis for an assessmement of the trustworthiness of this master's thesis.

As this study is relying solely on qualitative data, a specific position must be chosen as the basis for assessing the quality of it. Relying directly upon the quantitative quality measures *reliability* and *validity* is deemed inadequate in this case. Due the qualitative and social constructivist approach to this master's thesis, quantitative measures cannot adequately provide an assessment of the quality of this master's thesis. An example from this master's thesis will explain why the positivist measures cannot be applied: The system being designed in this master's thesis relies on Rheumatologists and young people living with RA to accept it and acknowledge it, in order for it to work. Both Rheumatologists and young people living with RA must consider it valuable, which they did in this research. The consequence of this approach is that this might not be a reproducable finding in similar research with other participants.

Therefore, the quality assessment of this master's thesis will rely on another set of concepts more specifically devoted to qualitative studies. The evaluation framework is developed by Lincoln and Guba (1985). They acknowledge the importance of quality assessment of all types of scientific research. However, they do not apply to the concept of measurable quality assessments. They have developed four principles: *Credibility, transferability, dependability* and *confirmability* which will provide the basis for the quality assessment of the work carried out in this master's thesis. (Lincoln & Guba, 1985).

Credibility is the term positioning itself closest to *validity*, as it refers to the degree to which the study can be deemed true. As mentioned earlier, social constructivists do not acknowledge truth as a definite term. Therefore, credibility in this master's thesis will be understood as an argumentation supporting that the usage of several sources of data and a diverse set of research methodologies provides sufficient basis to claim that the findings are credible.

Transferability is also to some extent linked to *validity* as it is sought to be the qualitative equivalent to *external validity*. The purpose of this term is to determine if the findings from this master's thesis can be applied in similar contexts. Relevant discussions about why it might be transferable will be addressed under this point.

Dependability is related to *reliability*, as the purpose of this concept is to assess whether or not the findings can be trusted. The aim of qualitative research is not to conduct research which is

reproducible, instead the important factor when ensuring dependability is to provide an extensive elaboration of the work carried out in order to make other researchers able to *repeat*, not *reproduce*, the research. In this master's thesis, supporting this factor is done by carrying out an extensive discussion of various topics related to the master's thesis. This is done in order to apply openness towards the research design.

Confirmability is the last assessment term. Confirmability strives to make sure that the findings presented in this master's thesis actually derive from the field of research, and not from the bias of the researcher. This cannot be measured, however an elaboration of the relation between the researcher and the field of research will support the claim that the findings are *confirmable*.

Below, a section devoted to each of the four principles derived from Lincoln and Guba (1985) will unfold the necessary discussions of each of the principles. These discussions will be followed by a discussion of how the findings from this master's thesis has provided new knowledge into the research field of developing mobile health applications. Finally the the stage will present a discussion of future work.

10.1 Credibility

In qualitative research, *triangulation* is a well-known term for strenghtening the arguments of research by using different research methods as well as multiple sources (Lincoln & Guba, 1985). Although the social contructivist approach deems triangulation as controversial, it is argued in this master's thesis that it provides the most sufficient assessment method for reflecting on the quality of the study. This master's thesis has actively emphasised triangulation by using a variety of different qualitative research methods: Focus group interviews, contextual inquiry, observations, semi-structured interviews, collaborative workshops, and cooperative evaluations. In addition to the diversity of these research methods, both Rheumatologists and young people living with RA have been used as sources of generating data. Hence, the research design of this master's thesis acknowledges the importance of triangulation in qualitative research. The results supports the importance of this research design because valuable points regarding user requirements of the system were revealed due to the diversity of the research design. Below is a more elaborate discussion of how the methodological framework impacted the findings.

10.1.1 SOFT SYSTEMS METHODOLOGY AND PARTICIPATORY DESIGN

SSM has been designed to support decision-making in organizations, when implementing a new system. The definition, a new system, is used as a broad term, also covering non-technical inventions (Dix, 2003b). Although SSM applies a broad approach to systems design, it is still considered adequate in this master's thesis. The methodology has been chosen due to its strengths of emphasising a systematic inquiry into the design situation and yet it still works as a guide and

not a strict model that has to be fully applied. An additional advantage is the iterative approach to the design process that SSM supports.

The SSM structure has been combined with PD. The combined design framework enhances the focus on user participation in the design process. The participants contributed throughout the design stages, and they also developed a close connection and ownership towards the system. The empirical data showed that the participants' reactions to the system, created on the basis of their own design proposals and inputs, had a positive impact. As this is one of the major points of PD, it can be argued that the sample size was small when conducting the workshop, as well as when the user testing was carried out. However the actual participation of the individuals is rated higher than the sample size due to the social constructivist approach as utterances and considerations of individuals are equally important. It is presumed that the ownership feeling towards this system might trickle down through the organization FNUG; thereby creating a solid base for the system to be adopted by other young people living with RA.

SSM and PD did have a synergetic effect. SSM as the organizational methodology used for developing systems within an organization, and PD as the approach emphasising as much user involvement as possible. Bringing these two methodologies together has provided not only a framework for systems design, but as well a framework capable of managing academic research at the same time.

10.2 TRANSFERABILITY

Transferability refers to how knowledge can be transferred into a different context. The design process and the methods applied in this master's thesis have served to provide a sufficient knowledge base for designing an app that creates value for both Rheumatologists and young people living with RA. Due to the social contructivistic approach, understanding findings of specific studies will always be tied to a specific context. This does, however, not imply that the app will only be able to support the exact young people represented in the study. Arguments drawn from the literature presented previously, as well as the findings from the thesis itself, supports the claim that the app will be valuable to other young people living with RA. This study might be transferable to target groups of a different age. It can be argued, however, that the use of smartphones decreases the older the target group is (Gauthier et al., 2012). Moreover, because consultations with RA patients do not differ significantly from other Arthritis patients, the findings of this study might be transferable to these contexts. Whether the knowledge from this study is transferable into the context of people living with other chronic diseases is too difficult to determine. However, the framework and the methods applied have proven to be able to produce a solid basis for developing apps in close relation to both the target group and health care professionals. This might serve as an indication for how a study with the aim of developing an app for other patient groups might benefit from reusing the framework and the research design.

10.3 Dependability

Relevant discussions about central elements of this master's thesis are discussed below to extend other researcher's ability to verify this work.

10.3.1 DESIGNING A SMARTPHONE APP

As mentioned throughout the master's thesis, designing a smartphone app has been the goal of the design process. Within this design space lies a variety of opportunities, which is one major reason it was considered necessary to make the delimitation that the outcome of the design process should be a smartphone app.

All participants in the PD team responded that they all use their smartphones on a daily basis. Though, relying on a technology, which is pervasive like smartphones, can have some unforeseen consequences. One of the Rheumatologists that was exposed to Rheumabuddy, and later on the prototype made in this design process, expressed a concern regarding the usage of smartphones as a self-assessment tool for people living with RA; they might be too aware of their disease, if they were to be reminded about their disease on a daily basis (section 9.2)

This concern must be taken into account. However, a part of being empowered as a patient revolves around the theme of more self-control as well as more self-awareness (Feste & Anderson, 1995). Therefore, an argument could be made that people with chronic diseases are willing to change their own conditions, either by learning more about their condition or simply by being more self-aware. This is contradicting the concern of the Rheumatologist. Though exposing patients in remission or near remission to daily notifications from a RA-app might not be considered appropriate.

10.3.2 PATIENT EMPOWERMENT

A consideration towards the Rapid-3 score as part of the system must be made. The research has considered using the clinically acceptable Rapid-3 score as an acceptable tradeoff in letting the young people bring in additional information into the consultations. It is argued that the Rapid-3 score makes it possible for the patient to add additional information about their condition when

relating it to a score that is recognisable to the Rheumatologists. This would ideally strengthen the patient empowerment. However, there might be a risk that the Rheumatologists will be the ones dictating which elements of the additional information they need, instead of letting the young people be the ones to decide.

Another risk is that the Rheumatologists might end up only being interested in the Rapid-3 score. This might create an unbalanced relation when it comes to the reconciliation of expectations.

In order to visualise the discussion in this section, the model from section 3.3 is presented, whth the prototype of this master's thesis added (figure 36).



Figure 36 - Empowerment-Compliance Scale 2

The model shows how the system developed in this Master's Thesis is placed in relation to compliance vs. empowerment. The reason that the system is placed closer to empowerment than compliance is due to the fact that the tradeoff just mentioned is considered to support the young people by empowering them when attending consultations. If the opposite turns out to be the case, the system will end up acting as a compliance tool for the Rheumatologist. This consideration can only be fully enlightened by further research. However, the issue is considered of a minor character as the Rheumatologists paid attention to this issue, and therefore there is a chance that it might be a non-issue.

10.3.3 THE SAMPLING

There are some aspects in relation to the sampling of participants made for this research that need to be discussed. There are four implications that will be subject to reflection. Three implications related to the young people living with RA and one implication about the two Rheumatologists.

The first implication is the sampling of the participatory design team. It consisted of six young people living with RA for the initial focus group interview. Including existing research literature to support the findings strengthened the findings from this focus group interview. The sample size, however, decreased as only three participants showed up for the workshop. As the workshop was based on the findings from the initial activities of the qualitative research design, the basis for the conceptualisation was considered valuable. However the fact that three participants did not show up might have left out some insight and ideas when working on turning challenges into concepts for supporting them.

Secondly the origin of the young people living with RA will be discussed. The participants were recruited through FNUG. This might influence the findings, because people in patient organisations have acknowledged their condition, and thus might have a different approach to dealing with the disease than people that have not yet acknowledged themselves as chronically ill. As people in patient organisations might have an extended knowledge base about their disease due to their membership, they might be more explicit about requirements able to enhance their quality of life.

Third, the participants might not represent the patient group with the highest disease severity. Two of the patients were in remission during the research and the others talked about other FNUG members that would not be able to even make it to events outside their house. The participants also stressed how simple tasks requiring a minimum of functional capability were made considerably complicated for people with severe RA outbreaks. Although certain tasks are complicated due to disease outbreaks, the group of people with the most severe outbreaks might as well benefit from the self-monitoring in this app.

Finally, interviewing two Rheumatologists might have provided diverging results compared to a broader study i.e. studies including Rheumatologists from different hospitals or Rheumatologists of a different gender. However, the benefits of including Rheumatologist at all are considered to strengthen the research design. Overcoming this hypothetical bias has been pursued by including the Rheumatologists twice during the research process. By including the Rheumatologist into the design process the system has been qualified, at least to some degree, in terms of adding value to consultations.

10.4 Confirmability

In qualitative studies, the researcher will inevitably become a part of the research design. Especially in a master's thesis like this, which revolves around systems design using participatory design. This combination provides plenty of reasons to remain precise in the distinction between two roles.

Being a designer and a co-creator at the same time requires respectful manners. Being part of the design team is time consuming for the users as well as expectatious. The designer has to remain persistent in the pursuit of user input, thus building expectations for the user, and thus maintaining the necessary amount of critical thinking when designing can be difficult. On the one hand, the design must meet certain criteria prescribed within the field of systems design. On the other hand, designing a solution too far away from the users' input can disrupt expectations.

In this master's thesis the extensive involvement of the users provided some challenges. From the beginning it was decided that their requirements should be determined through several cocreation activities, making it possible to work on how to support them. Therefore, as a designer, reflection both *in* and *on* action is required to conduct thorough research (Argyris & Schön, 1978). Stage 4 in the design process was separated into two distinct activities. The first activity was the workshop, in which reflection *in* action was performed, as the design was developed collaborating with the participants. The second activity, systems design, was carried out as reflection *on* action as the requirements of all stakeholders were transformed into a prototype supporting as many of said requirements as possible.

These considerations during the design process have made it possible to maintain a balanced relation between being both designer and researcher.

10.5 CONTRIBUTION

Literature of the field of research has shown that there is a need for research regarding: Development of smartphone applications for Rheumatoid Disease (1)(Azevedo et al., 2014), efficacy of systems use and quality of data (2)(Sunyaev & Chornyi, 2012), and knowledge on how to combine qualitative and quantitative data in self-monitoring smartphone applications in health care (3)(Faisal et al., 2013).

This study contributes with:

1. A design of a smartphone application for Rheumatoid Disease involving health professionals and target group.

2. Knowledge on how to overcome the challenge of *efficacy of systems use* and *quality of data*

3. Knowledge about the importance of combining qualitative and quantitative data in smartphone application design for consultations

1. "There is a need for the development of more smartphone applications in RD (Rheumatoid Disease red.) aimed at disease-related symptoms; treatment; physical, and psychosocial consequences of disease; and lifestyle changes" (Azevedo et al., 2014, p. 6). It is stressed that it is important to "[...] certify that there is sufficient health professional and target users involved in applications design [...]" (Azevedo et al., 2014, p. 6)

This study shows that developing a smartphone application for self-monitoring by involving young people with RA as co-creators in a collaborative design process can empower young people living with RA, because they are the ones in control of the information that is brought into their consultations. The application provides them with the opportunity to monitor and assess data about disease-related symptoms, treatment, as well as physical and psychosocial consequences of disease. Including Rheumatologists in the design process ensures that the information brought to the consultations is accepted, and is recognisable and valuable to them.

As a result, this study contributes to the field because it demonstrates the benefits of including a target group of patients, as well as health care professionals, in the research field of RD. Involving the target group as co-creators in a collaborative design process that also involves health care professionals has helped to ensure that the system can both empower the patient and create value for health care professionals. Hence, the likelihood of the system being used is enhanced.

2. This study also provides knowledge about how the contradictory entities (Sunyaev & Chornyi, 2012), *efficacy of systems use* and *quality of data* can be handled. This point is stressed because of a lack of research in relation to overcoming this challenge. However, this study contributes to this

issue. By co-creating with the participants, it was found that users of a self-monitoring system are willing to provide quality data to a system, as long as the effort of each entry is minimal. Additionally, their willingness to self-monitor is argued to be caused by the participants' feeling of ownership towards the system that has been designed.

3. Finally, this study shows that it is important to combine both qualitative and quantitative data in order to assist users in making sense of personal health. According to (Faisal et al., 2013), there is a lack of knowledge about how to successfully achieve this: "Additional research is needed on how to design visualization tools that assists users in making sense of personal health" (Faisal et al., 2013, p. 211). Additionally, this study shows that adding qualitative data to visual representations of quantitative data is considered useful for health care professionals as well. The most important notion, though, is that the users need to be able to make a selection of which segments of the qualitative data that they choose to bring into consultations with their Rheumatologist.

The data presented to Rheumatologists has to be visualised simply and rely on recognisable measures in order to be included seriously in consultations.

11 CONCLUSION

It can be concluded that an application for smartphones can enhance patient empowerment and thereby support the young people living with Rheumatoid Arthritis in Denmark when attending consultations with Rheumatologists. An app has to be designed in close relation to the target group by acknowledging them as part of the design team. Furthermore an app has to be developed in close relation to health professionals as well, as the adaption of the app into the consultations are dependent on the premise of the Rheumatologists.

It is concluded that in order to design an application supporting people with a chronic disease, it is crucial to develop a detailed understanding of the problem situation from various perspectives, involving all the stakeholders, even the tertiary stakeholders. Understanding the situation fully requires the researcher to gather knowledge by interviewing the relevant stakeholders, and to get first-hand experience of the context that the app has to be adapted into. By conducting contextual inquiry it was possible to discover how the actual consultation progressed. This made it possible to discover that an app had a chance of getting accepted in the consultations, because the already existing practice is centered on a computer screen. Thus an app will not change the existing practice significantly in terms of technological interruption. Moreover, the Rheumatologists rely on rather sparse and compressed knowledge about the young peoples' condition. Bringing additional information about the young people into the consultation has to take into account that the information has to be represented in an easily interpretable manner, and must be recognisable to the Rheumatologists. The Rapid-3 score correlates to scores that the Rheumatologists rely on. Thus, using the Rapid-3 score as the basis for providing additional information into the consultation is concluded to be successful, based on the positive feedback from both the young people living with Rheumatoid Arthritis and the Rheumatologists.

The self-monitoring, on which the additional information is reliant, needs to follow a simple and linear process in order to keep the user's attention and to ensure the quality of the data. Data that relies on measures dating back in time are considered valuable, both from the perspective of the young people and the Rheumatologists. It is important that the quantitative data, represented by graphs, supports a functionality to provide qualitative information like notes. Furthermore, the young people have to be in control in terms of the information that is presented to the Rheumatologist. This requirement was met by letting them select the information prior to the consultations, thus supporting the empowerment, by emphasising the young people as the owners of data.

12 FUTURE WORK

This section serves two purposes. The first is to describe how the research carried out in this Master's Thesis should proceed in order to develop a fully functional application. The second section elaborates a more general suggestion for future research to be done in order to extend the knowledge within the research field.

Due to the limited timespan of this research, the system that was designed still has to be coded in order to be fully operational. The app should be given to several young people living with RA in Denmark, to let them use it regularly over a longer period of time. The app then has to be tested in the real setting of a consultation. This process will further determine the full potential of the exact contribution in supporting the young people living with RA in their consultations. This future research will help to uncover the issue mentioned in section 9.1 on whether or not the Rapid-3 score will create an unbalanced relation in terms of reconciliation of expectations between the young people and the Rheumatologists.

This research has shown, but not elaborated on, on the nurses' role in relation to consultations. Future research into this matter might provide additional knowledge to the research area. Throughout the research of this master's thesis, the nurses were mentioned as being the ones having conversations with the young people about personal and private matters. They were also the ones to provide the young people with additional information with regard to side effects, practicalities and more. Researching the nurses' role in more detail might provide valuable insight into how the young people living with RA could be supported when attending consultation. A lot of the young peoples' challengess arose from the frustration of the limited time allocated for each consultation, and that they do not feel acknowledged by their Rheumatologist. Principles for supporting these challenges have been provided by this master's thesis but the investigation into if and how the nurses could enforce this support would be an interesting perspective relevant for the research field.

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+ fra + pilot + til + f%C3%A6lles + l%C3%B8sning

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