UX prototyping design of HealthKit app for heart disease patients

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Summary (English)

The goal of the thesis is to explore the possibility of creating a personalised treatment for chronic heart failure patients in Denmark. The goal is to investigate how to use lean innovation in the Danish health care sector by creating a user centered solution, to avoid the current heavily over-regulated health care sector. The thesis is based on an exploratory inductive process, to create the base for future projects.

This thesis is based on five iterations, each which has sought to validate various hypotheses related to what a personalised medical treatment of chronic heart failure patients should contain. These examines how data can be collected by patients to give insights. It is investigated how these insights can motivate the patient to be involved in the treatment. The insights is a tooll for the nurses in the decision making process of treating the patients.

By utilising lean prototyping in user experience the five iterations are tested and verified by key stakeholders, representing; the medical staff, patients, universities and companies. The validation process have lead to a fast refinement of the prototypes, towards the alpha version of the solution.

The results and outcomes from the five iterations to support a personalised treatment of chronic heart failure are: collect quantified measurements related to weight and blood pressure; to contextualise these measurements with symptoms from the patient; To sort the patients accordingly to their needs based on measurements and symptoms; and to provide the patients personalised information about the medication and lifestyle changes.

The results of this thesis shows that lean UX prototyping can be highly beneficial in the context of the health care sector. And that contextualising data with subjective measurements, can provide a better treatment for heart failure patients.

Summary (Danish)

Målet for denne afhandling er at undersøge mulighedere for en personaliseret behandling for kronisk hjertesvigtspatienter i Danmark. Målet er at afsøge hvordan lean innovation igennem brugerorienterede løsninger, kan gennemføres i det danske sundhedssystem, for at undgå en overreguleringer.

Afhandlingen tager udspring i fem iterationer som igennem validering af forskellige hypoteser, at klarlægge hvad en personaliseret behandling skal indeholde. Disse undersøger hvordan data indhendtet af patienten kan give mere indsigt. Det bliver undersøgt hvordan disse "insights kan motivere patienter til at være mere involveret i deres behandlingsforløb. Det bliver også undersøgt hvordan sygeplejerskene kan bruge disse "insights"som et støtte værktøj i en medicinsk beslutningstagningsproces.

Ved at anvende lean prototyping in user experience som et redskab, bliver hypoteser verificeret og testet af centrale aktører, der repræsentere det medicinske personale, patienter, universiteter og virksomheder. Denen valideringsproces har ført til hurtig viderudvikling af prototyperne, mod en alfa version af løsningen.

Resultaterne af de fem iterationer i for hold til at personalisere den medicinske behandling for hjertesvigtspatienter er: indsamle kvantificeret målinger fra vægt og blodtryk; At kontekstualisere disse målinger med registrerede symptomer fra patienten; At kunne sortere patienterne i forhold til deres behov basered på målinger og symptomer; og at give patienten relevant information of medicin og livstilsændringer.

Preface

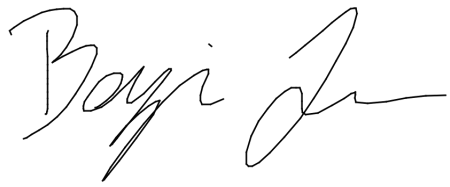
This thesis was prepared at the Cognitive Systems section of DTU Compute in fulfilment of the requirements for acquiring an M.Sc. in Engineering. The thesis have been prepared under guidance of Michael Kai Petersen and Jakob Eg Larsen in the autumn of 2015. This project accounts for a total of 30 ECTS points.

The thesis deals with the analysis and implementation of an IT solution in the Danish Health care system, specifically at the out-patient clinic, within the heart clinic, at Herlev Hospital. The thesis describes how user experience and lean tools have been used, to deploy a prototype for testing at the clinic. The focus of this thesis is: *How to personalise the treatment of chronic heart failure patients.*

The thesis consists of the following chapters:
Chapter 1: Context of study and motivation
Chapter 2: Research objectives
Chapter 3-7: Iteration 1-5 including description of relevant literature, field work (if applicable) and conclusions
Chapter 8: Future work and discussion of the outcomes
Chapter 9: Conclusion and concluding works

The data for the final prototype can be downloaded here, and should be run on a node.js server.

Lyngby, 03-January-2016



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Acknowledgements

I would like to thank my supervisors Michael Kai Petersen and Jakob Eg Larsen, who have provided guidance, support, valuable feedback and long conversations about the current and future state of the project. They have been a great support, to come up with new ideas, always ready to find solutions, and to give insights to the academia of the thesis. Special thanks goest to Michael for always being available and willing to give feedback, even at the oddest time.
I would also like to especially thank Nima Zandi from Apple Denmark. Without him it would have been challenging to get access to Herlev hospital, and the nursing staff. He have also provided hardware for usability testing, and support in regards to Apple services.
A special thanks goes to the heart clinic at Herlev hospital. As the project have been done "under the radar", Head doctor Thomas Høi-Hansen have had to tip-toe through the system, in order to provide us access and insights to the clinic. Head Nurse Vibeke and leading Nurse Marianne Steen Andersen, for participating in various interviews and usability tests.
Thank you to various students who have been involved from DTU Compute and Aalborg University Copenhagen, for assisting in the scoping, design, development and field research in the project. A note of thanks also goes to Emil Bunk, student at DTU Compute and working at Nodes, for the many talks we've had about user experience, and what relates to it. Also thanks to Emil, and Per Bækgaard, for talks regarding learning Javascript and the content of this thesis.

Contents

Chapter 1

Introduction

1.1 Purpose

> A disruptive innovation is a technologically simple innovation in the form of a product, service, or business model that takes root in a tier of the market that is unattractive to the established leaders in an industry. *Clayton Christensen*

1.2 The key issue - a personalised treatment of chronic heart failure patients

The key issue in this project is: *how to make a personalised treatment plan for the chronic heart failure patient.* There are many causes of heart failure among other: many symptoms, side effects, various types of medications, different sensitivity level to medication, an individual medical history, demographics, environment and cultural factors, which all affect the treatment of the patient.

There no treatment that can cure the chronic heart failure patients. The main purpose of the medical treatment, is to train the patients body to accept the maximum dosage of medication. The nurses spend months figuring out the best

way to medicate the patients. The process can be slowed by patient setbacks and/or neglect of the medical treatment. This can prolong the treatment for up to 8 months.

The high complexity of this relative "simple" question can be seen in the failure of similar projects, which have not managed to address this problem. The goal of this thesis is to address this problem, and design a solution (which may not be able to solve the problem). The goal is to lay a solid foundation, routed in user experience, in which this issue can further be addressed, and hopefully (for us) one day be solve.

In this thesis the solution will be based on two questions. *How do we use continuous monitoring of the patient to obtain insights and relevant information, to personalise the treatment of the patients.*
And, how do we support the obtained quantified data, with qualitative and self reported data, related to symptoms?

1.3 A brief note on scoping

The scope of this project is to look further into how digital innovation can support the current health care system in Denmark and how to personalise the treatment of chronic heart failure patients. A general visual representation of this scoping process can be seen in figure 1.1. This is also a reflection on how the real project plan went.

1.3.1 Scope, the decision to focus on up-titration

After conducting field work at Herlev hospital, it became evident that working with patients of chronic heart failure is not as simple as it first appeared. Through the use of user journey maps[1], it was possible to define the scope.

There are several phases a heart failure patient goes trough, based on the user journey map these are identified as the following:

1. **Symptoms and diagnosis**:

[1]The user journey maps, defers from user story maps as the focus is on telling the users *current* story. The user journey map in this project have been used as a communication tool. It has especially been used as a communication tool between various stakeholders. The user journey map have developed through the project, the latest version can be seen in figure 1.2.

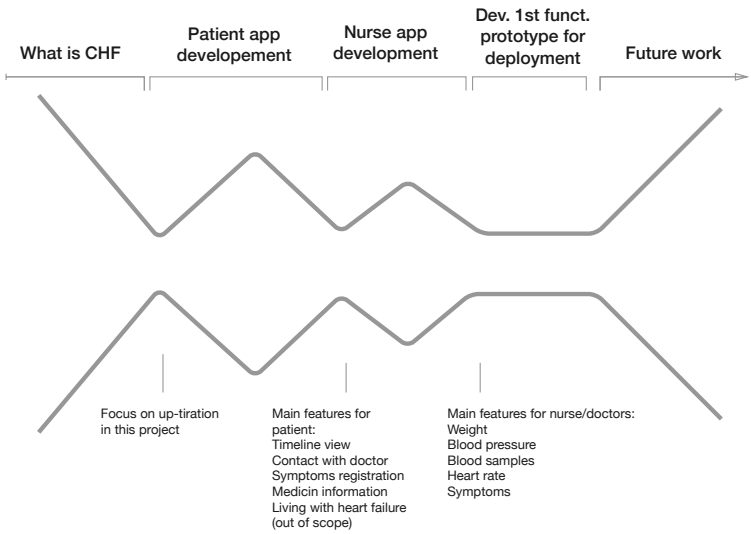


Figure 1.1: Visualisation of scoping of the project

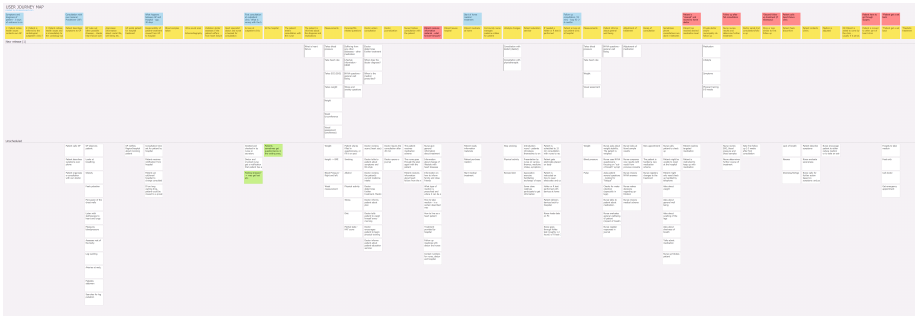


Figure 1.2: The final iteration of the user journey map - for an earlier version, see appendicies

The first contact with the disease. First indicators of something being abnormal.
Involved stakeholders: Patient & general physician

2. **From general physician to hospital**:
After getting a positive diagnosis of cardiovascular disease, the patient will be called in for a consultation at a heart clinic.

Involved stakeholders: Patient, general physician, hospital secretary, specialised nurse and doctor (booked for consultation)

3. **First consultation in hospital and diagnosis**
   The patient has a positive response to (cardiovascular disease) and is moved into treatment.
   Involved stakeholders: Cardiovascular Physician, cardiovascular disease nurse & patient

4. **Follow up consultations and medication**
   The patient starts treatment in heart-clinic, lasting up to 8 months, with regular consultations.
   Involved stakeholders: Primarily cardiovascular disease Nurse & patient

5. **End of hospital visits**
   The patient ends hospital treatment, and start on specified follow up outside of the hospital. Is cleared of hospital
   general physician & patient

6. **Possible re-admission**
   In case of fall back, the patient is re-admitted to the heart clinic
   Involved stakeholders: general physician & patient

1.4 Learning goals

- Can identify and reflect on technical scientific issues and understand the interaction between the various components that make up an issue.
- Can, on the basis of a clear academic profile, apply elements of current research at international level to develop ideas and solve problems
- Masters technical scientific methodologies, theories and tools, and has the capacity take a holistic view of and delimit a complex, open issue, see it in a broader academic and societal perspective and, on this basis, propose a variety of possible actions
- Can, via analysis and modelling, develop relevant models, systems and processes for solving technological problems
- Can communicate and mediate research-based knowledge both orally and in writing
- Is familiar with and can seek out leading international research within his/her specialist area.

- Can work independently and reflect on own learning, academic development and specialisation
- Masters technical problem solving at a high level through project work, and has the capacity to work with and manage all phases of a project – including preparation of timetables, design, solution and documentation
- Can apply and solve problems by using user experience tools
- Can utilise and develop digital prototypes in a new language
- Shows understanding across scientific knowledge domains. Including knowledge outside of the specialist area.
- Can communicate with various stakeholders, with different backgrounds.

1.5 Project Plan

The project plan looks as following:

- Literature search and related studies - August
- Framing of the problem and scoping - 01-15 of September
- Goal and research objectives - 01-15 September
- Method: Iteration 1 - UX for the patient, Build prototype September
- Method: Iteration 2 - UX for patient, Build prototype - October
- Method: Iteration 3 - UX for patient, Build prototype - November
- Method: Iteration 4 - Build prototype - Novmeber and December
- Results - December
- Future work and discussion - December

And here's how it turned out to be, also graphical illustrated in figure 1.1.

- Literature search and related studies - August
- Framing of the problem and scoping - September to medio October
- Goal and research objectives - August to December

- Method and Results: Iteration 1 - UX for the patient and visit at Herlev hospital - September
- Method and Results: Iteration 2 - UX for the patient - Late September to medio October
- Method and Results: Iteration 3 - UX for the nurse, change of focus medio October to medio November
- Method and Results: Iteration 4 - UX for nurse and patietn - Start November to medio November
- Method and Results: Iteration 5 - Building prototypes - Medio November to medio December
- Result: Medio December
- Future work and discussion - December

1.5.1 Reflections on process

Using lean user experience principles as a back bone for this thesis, turned out to be a sensible approach. In the beginning of the project most of the time was spend on exploration. Because of the inherent inductive nature of this project, following a more classic deductive project plan didn't work. The project plan underwent revision once a month, as it was hard to tell what the conclusions from each iteration would bring of insights. A majority of the project have been spend in designing and verifying hypotheses and this also altered the final project plan.

Some great learning points consist in the ability to assess and update the research goals during the project. As the project has been scoped from start to end, the end goal has not always been apparent. It has taught me that many detours eventually lead to a clearer path.

Working in a diverse team proved a greater challenge than anticipated. It also gave support and insights otherwise not obtained, and for this project have been crucial.

The challenge of going from design to prototype is also worth mentioning. As no prior knowledge of Javascript had been obtained, it was a great experience to see the design from sketches to a working prototype come to life.

Chapter 2

Context of study - why is a digital solution for heart failure patients needed?

This section gives a brief introduction to the topic at hand. The focus will be a brief introduction to what chronic heart failure is. After having been introduced to the topic to the overall KPI's that guides this thesis.

2.1 Why is chronic heart failure of interest

According to "Dansk Cardiologisk Selskab" (Danish Society of Cardiology) chronic heart failure is a very serious syndrome. This extract is from the booklet "Hjerteinsufficiens", it is here stated (translated from Danish):

> *"chronic heart failure is a complex clinical syndrome with high prevalence and bad prognosis both in chronic and acute form. In Denmark it is estimated that 60.000 patients are living with chronic heart failure and a similar number with decreased systolic function (decreased pumping function) of left ventricle without a clinical incidence of*

chronic heart failure. Yearly 11.000 Danes are hospitalized with chronic heart failure. Despite improved treatment for these patients, the 1 year mortality is around 20% after the diagnosis of chronic heart failure[1]".

An American study from 1992 shows that the mortality rate increases drastically over a 10 and 15 year period time[2], after the diagnosis.

The survival rate over 10 years are close to 60%. After 15 years the survival rate decreases to 44%.
Due to improved treatment, medication and a unique Danish health care model, the mortality in Denmark has been decreasing in the past 10 years. For all chronic heart failure patients in Denmark, the mortality rate was 25,5%[3]. It cannot be denied that chronic heart failure is a problem in a global context, as well as in a Danish context.

2.2 What is chronic heart failure?

In short, chronic heart failure is a decrease in the hearts pumping function. This means the heart cannot pump enough blood around the body. The consequence is a limited oxygen flow to muscles and organs. The heart compensate by pumping harder and/or having a higher frequency of heart rate. This leads to hypertension (high blood pressure). For a small animation that displays this, go to the American Heart Association, by following this *link* or refer to figure 2.1

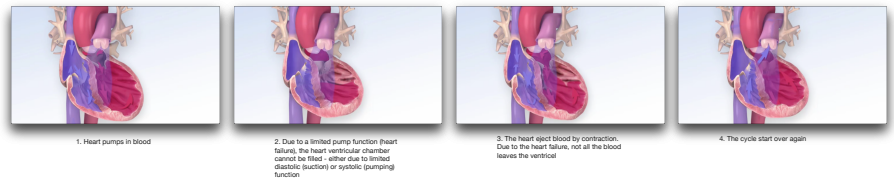


Figure 2.1: A graphical explanation of heart failure, annotated. Courtesy, the American Heart Association (AHA)

There are two common cases of heart failure - see also figure 2.2.

- **A stiff heart muscle** is called a *diastolic heart failure*. Here the heart has

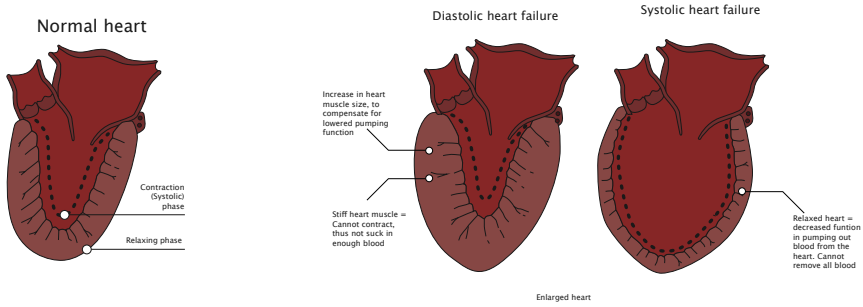


Figure 2.2: Two types of heart failure, annotated. Courtesy, Hjerteforeningen[4]

trouble filling the ventricles (larger chambers in the hear), as the muscle is not elastic enough. It can be compared to a balloon that's very stiff and difficult to blow up.

- **A weakened and lax heart muscle** is called a *systolic heart failure*. As the heart is lax it have difficulties squeezing all the blood out of the heart. It can be compared to an old balloon, where the air is slowly seeping out.

2.2.1 Symptoms of chronic heart failure

Chronic heart failure is a syndrome. This means that many different symptoms, such as oedema, breathlessness (due to water in lungs) and dyspnea are common and present in patients suffering from heart failure.

For many patients it is difficult to accept heart failure. The syndrome is not curable. The pharmacological treatment patients receive stabilizes the heart and extended the survivability. Some of the most common symptoms of heart failure can be seen in table 2.1

2.2.2 Causes of chronic heart failure

There are many causes to chronic heart failure and it is difficult for the medical personal to determine what caused it. Some causes of chronic heart failure are: *Hypertension, ventricular diseases, blood clots, infections, cardiomy-*

Common symptoms	
Symptom	Description
Hypertension	Systolic blood pressure above 140 and diastolic over 90
Dyspnea	Shortness of breath. Typically at normal activities
Orthopnoea	Dyspnea at sleep
Nocturnal dyspnea	Severe coughing attacks and shortness of breath
Oedema	Swelling in limbs, typically ankles
Fatigue & tiredness	Typically after exercise
Abnormal heart beats	Racing heart, heart skipping beats, double beats etc.

Table 2.1: Common symptoms[1, 5, 6]

opati (chronic heart diseases can come from: family diseases, diabetes, alcohol, medicine etc.), myocarditis (heart inflammation), tachyarrhythmia (high resting heart rates, above normal), strokes and atrial fibrillation (abnormal heart beats).

To determine heart failure it is recommended to use an echocardiography - an ultra sound scan of the heart. The European Society of Cardiology thus encourage that echocardiography is the first method to use when a suspicion of a patient with heart failure occurs[5].

2.2.3 Classification of chronic heart failure

The primary method to classify the severity of the chronic heart failure is the New York Heart Association (NYHA) functional classification. The official description from the New York Heart Association can be seen in table 2.2.

The NYHA classification is an indicator that will be used through out this thesis, to asses when a patient is ready for up-titration.

2.2.4 Treatment of Chronic heart failure

There exist several types of treatment. One is lifestyle changes, which all patient are encouraged to follow. This include lowering salt intake, staying active (by walking regularly) and adapt a diet that supports a weakened heart.

From figure 2.3, it can be noted that as soon as the patient move from NYHA class 1 to 2 or more severe, the suggested treatment and medication changes

Class	Description
Class I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
Class II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
Class III	Dyspnea. Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
Class IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

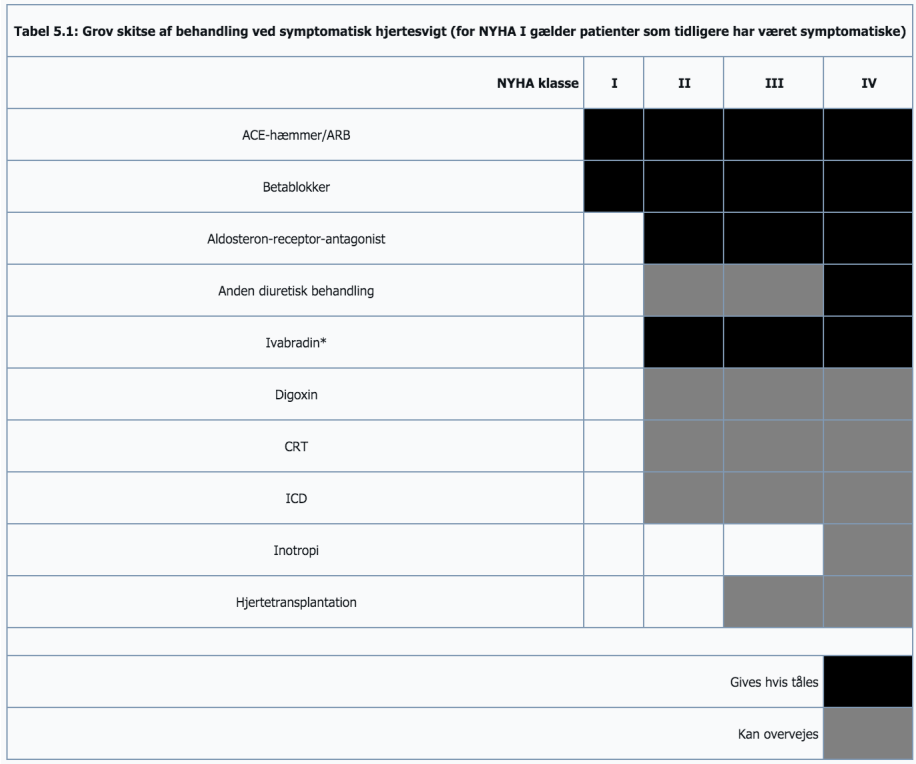
Table 2.2: Common symptoms[7]

accordingly. From the table, it should be noted that CRT (cardiac resynchronization therapy - electrical impulse therapy), ICD (Implantable cardioverter-defibrillator) both are implants that need surgery. The same is the case for an open heart surgery. These treatments will not be considered, as it is out of the scope of this project.

The main treatment is the pharmaceutical treatment. Depending on the severity and advancement of heart failure. The "Dansk Kardiologisk Selskab" (*Danish Society of Cardiology*), have made recommendation based on the NYHA classification of the patient, which can be seen in figure 2.3. The pharmalogical treatment stretches from 3-8 months depending on the patient. Two important standards should be noted (which will be used further on): *Start dosage (e.g. the amount of medication prescribed at the beginning of the treatment) and End dosage (the targeted dosage).* All patients have to receive ACE & Beta-blockers as this medication relieves the heart.

2.2.4.1 The effect of various medications[4, 1, 9]

The various medication is corrected by a holistic assessment, and by blood samples. The medical staff uses this to determine if a patient needs to adjust the medication. Often the medication affects the kidneys, liver and haemoglobin levels. If a patient blood samples are out of "normal", a up-titration will most likely not occur. For more details see section 7.5 on page 63.



Tabel 5.1: Grov skitse af behandling ved symptomatisk hjertesvigt (for NYHA I gælder patienter som tidligere har været symptomatiske)				
NYHA klasse	I	II	III	IV
ACE-hæmmer/ARB				
Betablokker				
Aldosteron-receptor-antagonist				
Anden diuretisk behandling				
Ivabradin*				
Digoxin				
CRT				
ICD				
Inotropi				
Hjertetransplantation				
Gives hvis tåles				
Kan overvejes				

Figure 2.3: Recommended medication given to patients depending on the NYHA classification[8]

ACE and ARB

Given to all heart failure patients. This type of medication increase the survivability rate, without any major relieve of symptoms. The primary function is to lower the systolic blood pressure.

Beta-blockers

The beta blockers lowers the hear rate (pulse) of the patient, thus relieving the heart from strain. Usually several side effects in the beginning of the treatment, while the patient are getting used to the medication. The most common symptoms are similar to the symptoms of heart failure.

Aldosteron receptor antagonist

It is recommend to all patients above NYHA class 1 to receive this treatment. These are a type of diuretics and helps the kidney's to increase the liquid removal from the body. The effect (and side effect) are an increased need for urination.

Can relieve pressure on organs and reduce water in lungs.

Diuretics
Give when a rapid increase in weight (thus water retention) is observed, usually 1-2kg in 1-2 days. Increase the need for urination. Can be given too all classes of NYHA when needed.

Digoxin
Increase the pumping function of the heart. Recommended for patients suffering from atrial fibrillation or severe symptoms. Should be used with care and only when needed. Common side effects are nausea and diarrhea.

2.3 Key performance indicators

Based on the input gathered, the key performance indicators (or motivators), which can also be described as the overall goals can be found below and can be observed in figure 2.4.

Figure 2.4: KPI's as presented in a user story map
Provide a personalised treatment of the patient

2.3.1 KPI's for the patient

Provide a personalised treatment of the patient
Chronic heart failure is a serious diagnosis with a high (one year) mortality rate. Today many patients experience feeling lost, confused, depressed and similar feelings when diagnosed with chronic heart failure. Chronic Heart failure have many causes, various side effects, different types of treatment etc. There are not a "standardized" solution that fits all patients. The key to solving this issue is to personalised the treatment for each patient, based on the needs and measurements of each patient. A KPI for this project is to investigate how to involve and engage the patients in their treatment.

It is hypothesised, that if the patient gets specific insights about their medication, they're more willing to take the medication. This can support a later KPI related to reducing the cost for the hospitals.

2.3.2 KPI's for the nurse

Increase time spend on nursing (decrease time on documentation)
The core of nursing is to provide *the best care for the patient.* However due to an *increase in documentation and bureaucracy* the time spend on patient care is now extremely limited. Up to 50 % of the nursing time, is spend on medical record-keeping.

Better medical treatment of the patient
It is common practice that a nurse follows a patient from start to end of medical treatment. The nurses perceives *each patient as a unique case.* Despite similarities among patients in demographics, symptoms and medication, each patient is treated uniquely. The nurse have a limited amount of patients. Because of this they posses *in depth knowledge of (each) patient.* This is a factor that motivates the nurses to work with the patients. However, this is this limits the flexibility (just imagine a nurse getting a long time leave).

2.3.3 KPI's for the doctors

More effective treatment
This KPI is related to the fact that if the clinic can find a recipe to successfully treat patients, it can bring major benefits along. The doctors do not perceive each patient as a unique entity. The doctors look more into *trends of the patients in treatment.* A major motivator for the clinical doctors are, if they can *optimise the treatment time* and thus treat more patients - or provide *a more effective treatment* to the patients.
If the doctors can treat 10% more patient with the same resources at hand, or decrease the medical treatment time, it could prove a major breakthrough.

Increased patient engagement
If the patient engagement can be increased, it is possible to positively affect the patients to adhere to their medical treatment. This on the other hand, could result in a more effective treatment of the patients. Patient involvement is a hot topic in the medical world, and it is important to include the patient in

their treatment. A tool to support patient engagement would be a goal of this project.

Reduction of re-admissions
The doctors consider long term treatment of patients. One of the goals of the doctors is to *reduce re-admissions*. This takes resources from the staff, that could be used elsewhere. A reduction in re-admissions is an indicator of an effective clinic. Another goal of the doctors are to extend the life time for the patients for as long as possible. The motivator is to *reduce the mortality of the patients*.

2.3.4 KPI's for the hospital (administration)

The economic cost of running a public (and free) health care system is enormous. It is estimated that the Danish society spend 102 billion Danish Kroner per year on public health care[10]. Of these, around 80% (in 2014 around 82 billion Danish Kroner) is allocated to the hospitals and around 5.5% for subsidising medicine. Around 16% of the Danish gross national product (GNP) is allocated for the health care system in 2016 [11].

Higher effectiveness and better re-location of resources
There is a constant political pressure on the health practitioners to *increase the effectiveness of the health care system*. It is well known that having patients in hospitals, are extremely costly. Looking into the cost of patients suffering from cardiovascular diseases. In average a newly admitted patient cost 57.000 kroner in admission and an additional 6.600 kroner per day. A 3 day admission quickly cost almost 80.000 kroner. A goal of this project is to investigate, and design measures that can support this KPI.

Reduce re-admissions by 20%
For re-admissions, the associated costs are even higher. In average a re-admitted patient cost 95.000 kroner and an additional 7000 kroner per day. A 3 day admission quickly cost almost 106.00 kroner[12]. Numbers are based on data from the Danish Heart society and the Danish National Institute of Public Health, published in 2008.
It can quickly be concluded that it is not desirable to have patients admitted to the hospitals, and even less desirable to have patients re-admitted.

2.3.5 KPI's for Apple (Denmark)

Increase hardware sales
Apple's stake in this project is fairly straight forward. One of the KPI's is to boost hardware sales. In recent years there have been a boost in mobile devices[13], and everything seems to be moving in this direction, thus a key KPI for Apple is to design, produce and sell tailor made solution to increase the sale of their hardware, since especially the iPad is falling behind in sales [14]

Gain a unique market position
Several sources are indicating that Apple is looking for new markets to enter. With the emergence of the open source framework ResearchKit Apple is now looking for creating a unique market position in the health care sector. As mentioned in the article about iPads[14], a new business area has been identified as the health care sector. From this project, Apple is looking for a unique value proposition, that could make them the to-go to partner of the future.

2.4 A short note on similar projects and related studies

A comparative case is done through the study of the HIT Project (HIT) (Hjerte Insufficiens behandling via Telemedicin) project [3].

The HIT project, in short, have been to move the consultation from the hospital to the patients home, and enabled the patient to do home monitoring - the consultation has been the same, it has been conducted over a phone. An example of a telemedicine solution is illustrated in figure 2.5 on 17.

A brief summary of the differences between the two projects can be seen in table 2.3

2.5 Sub-conclusion

Chronic heart failure is a special syndrome with high mortality rate. It is difficult to determine the cause of the syndrome, and to adjust the medical treatment for each patient. It has been identified that chronic heart failure is something that will not go away in the many next year, and it makes a good project case.

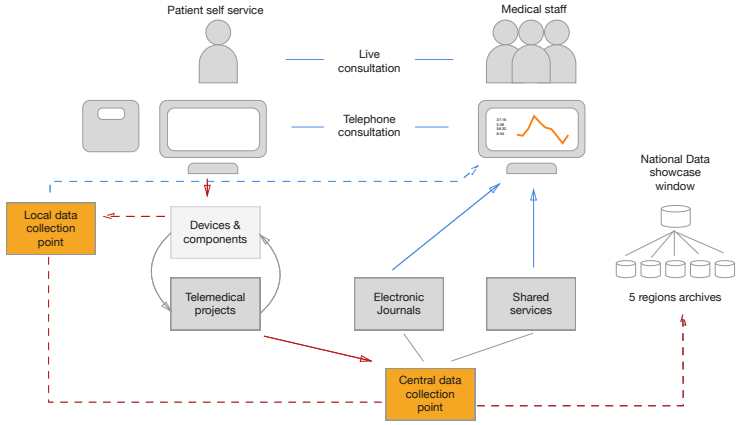


Figure 2.5: A figure of how telemedicine is currently working

Differences between classic telemedicine & this project	
HIT	HjerteVen
Rigid & static	Dynamic & Flexible
Staff centered	Patient centered
Calendar based	Based on patient current condition (need)
Insights for medical staff	Insights for patients and medical staff
Obtrusive	Unobtrusive
Information and power for the staff	Power to the patient
Well fare system owns data	Patient owns data

Table 2.3: Comparission of HIT and Heart UX projects

The main problem to solve for this thesis is *a personalised treatment of chronic heart failure patients*. As of today, no projects have been working from the patient perspective or have address how a treatment can be personalised.

In the second part of the chapter the KPI's for various stakeholders has been identified these are as follows:
For the patient: Provide a personalised treatment
For the nurse: Increase time spend on nursing; Better medical treatment of the patient and an increased trust in technology
For the doctors: More effective treatment; Increased patient engagement; and

a reduction of re-admissions.
For the Hospitals: Higher effectiveness (increased by 20%); and reduction of re-admission of 20%.

Chapter 3

Research Objectives

3.1 Problems statement

Innovating in the health care sector is challenging. Even when the focus is on a small part of it, it becomes evident, that creating change in a clinic, is no easy task. The following statement will convey the scope of this project:

How can a lean IT project generate (disruptive) innovation within the field of chronic heart failure in Denmark, by supporting a personalised medical treatment for chronic heart failure patient?

3.2 Research objective

The research objective is related to the problem formulation and is stated as the following.

How to deploy a functional prototype, corresponding to a minimum viable product, ready for "pre-clinical" testing with chronic heart failure patients in treatment. And how is the impact of such a solution estimated.

In order to measure the success of the project, there are several actions that will specified below.

3.2.1 How to innovate in the Danish Health care system

Innovation in the Danish health care system is currently close to zero. Many of the "top-notch" solutions we see today, contains aged technology. The whole system is geared towards a conservative mindset where: "Safety first" rules. This is not equal to the best provided treatment. Due to over-regulation it is close to impossible to innovate.
This research project will see if it's possible to innovate by bypassing the strict regulation. The goal is to see what happens when the patient have full "ownership" of devices and data, that can help the medical staff to better treat the patients. By giving "full" ownership to the patients, the hypothesis is that the current regulations can be "avoided".
Another point to note is that this is a highly monopolised market, with great potential for developing, and opening up. This could provide great financial benefits to involved stakeholders.

3.2.2 How can a user experience (UX) perspective empower the patient? Which factors and mechanisms in the solution will empower the users?

One of the purposes of this thesis is how to solve problems applying user experience methodology. This is a multifaceted field, and the goal is to provide a good user experience both for the patient as well as the medical staff. The purpose of having a heavy focus on user experience, is to investigate if a focus within user experience, will allow for higher adaptation. One of the motivators for this project is that it ends a project implemented in a clinic.

3.2.3 How can patient involvement be increased through insights

This is also related to the user experience, however there's some differences. One of the greatest challenges today with the increase of wearables, is to make sense of all the quantified data. How can data sets, with "meaningless" data be converged into something useful for both the patients and the medical staff?

Related to this, a sub-research objective is also to investigate how to turn data into meaningful insights.

3.2.4 Increase the hospital treatment efficiency

The hypothesis is, that if a compelling solution is presented, that both increases the patient engagement, and at the same time bring valuable input to the medical staff, the overall efficiency in the hospital can be improved.

A goal of this project is to investigate whether it's possible to make a dynamic up-titration treatment for patients, to treat them when needed, rather than when the nurse have time. The objective is to investigate which factors affect the up-titration, and to include these in the final product.

3.2.5 How to improve the communication between medical staff and patients

The goals is to determine how a digital solution can support both the patient and the medical staff in the on-going treatment. Many other projects have placed the power of the IT solution with the medical staff, and thus not changed how the communication is - this is described more in the section about similar projects. In this project a goal is to investigate what is needed in order to facilitate better communication between the patients and the medical staff.

Chapter 4

Iteration 1: From the patient point of view

In this section a description of the patient point of view will be presented. Learning points from the field studies and from the literature will be investigated further, to create a solution that supports the patient. The first part relates to the motivators the patient have, how these motivators are translated into a user journey map. In the end of this chapter a small conclusion will be presented.

4.1 Hypothesis

The hypothesis to be verified in this chapter are:

- Is it enough to measure weight every morning?
- Measuring blood pressure once a day is enough
- Continuous heart rate provides insights about the heart condition
- Weight measurements happens once a day, in the morning before intake of food or liquid.

4.2 Methods

The user story map, which will keep re-occurring and develop due to the scoping will be presented in its first form.
A brief introduction to the measurements chosen, and a brief study of the usability of the hardware planned to use (piggyback) for a quick deployment of a test.
And finally how an interviewed have been used to verify the user story map.

4.2.1 Lean user experience and prototyping

The main concept of her approach is *early validation*. This translates into validating often, frequent and to learn from the mistakes and insights given through direct and indirect feedback. There are three elements in the model utilised: Idea, Design and Product. Where a validation should happen after each part. A visual model from *Lean for UX startups* can be seen in figure 4.1.

Figure 4.1: The importance of early validation, by L. Klein[15]

The lean UX approach is a pragmatic approach. And the main points, and utilities from the literature are:

Validate: Early validation of an idea is very important. Rather fail at the idea stages, than keep an idea that will fail. It is encouraged to make some simple landing pages to test the idea with potential "customers/users". If no pain or motivators can be found, then there will not be any market potential.
Early user testing is crucial. This is incorporated in this thesis, where simple prototype on paper is tested, even though they are far from resembling a finished product, this gives insights and forces the designer to focus on what matters. A final note on validation is to include A/B testing where applicable.

Design: It is more important to sketch something out, than making the perfect design. The goal is rather to figure out what the minimum passable design is, and then go for that. A good idea is here to use user story and user journey maps to help guide the design.
It is critical to understand the usage of the product, that's how design come

in handy. Consistency is key, which will be covered a bit more in micro-interactions. Fidelity is the last thing, a proper balance should be found between high and low fidelity. Too much detail and the user feedback colour schemes, too little, and they can't make sense of it.
A primary goal of this process is to create a minimum viable product (MVP). It should be functional to work, but doesn't need to have full functionality. It's like making a layer cake, you can get by making a layer or two, and it would still be a good cake, where you can get feedback. Then over time the full cake will appear. This is the approach used in this thesis.

Product: The product comes alive. This is detail testing, the devil rest in the detail!
Here key parameters to measure for success are; Retention, Revenue, Net Promoter Score (recommendation to friends), Engagement, Registration (like sign-upp for beta testing).
Last key point, do it fast! Ideate, design and test over and over, even small iterations are good, and the aim is to learn, and to build lasting layers of the layer cake, instead of the whole cake at once. This has heavily been emphasized through out this thesis.

4.2.2 User Story Maps

User story mapping is a tool to understand the various users in the system, and to be able to see the system as a whole. The process of user story mapping can be split in 3;
Part 1 mapping user stories, e.g. figuring out the user and their "flow" within the system. What actually gives them a good user experience.
Part 2; Plan incremental and valuable releases. One of the main goals of a user story map is not being able to launch an full scale IT system. Rather it looks into how all/most of the values can be implemented, incrementally. This process is called slicing.
The 3rd part is more about how to actually start working with this, and to implement the user story map iteratively, to ensure it's not becoming a wall artifact.

In this project, the user story map have been used mainly for the first part, as the whole project have been exploratory. However, part 2 and part 3 have not been neglected, and the outcomes can be seen through out the thesis, this is especially true for the chapter concerning deployment. A user story map con

4.3 Biomedical background to support the user story map

4.3.1 Blood pressure

Blood pressure is one of the indicators of a malfunctioning heart. This is one of the first measurements done at the patient general physician. Why is the blood pressure important to look into? It is one of the first factors that affect the heart, when a cardiovascular disease occurs. An symptom that may indicate that the heart have a decreased or abnormal pumping function. There are two main factors that affects blood pressure.

Blood pressure contains two measurements, the systolic blood pressure and the diastolic blood pressure. The systolic blood pressure determines the blood pressure when the heart beats and pushes the blood around the body. While the diastolic blood pressure is measured between beats when your heart rests. Having too high or too low blood pressure is not desirable - for a graphic presentation, refer to figure 4.2 from the UK Blood Pressure Association. A normal blood pressure would for example be 120/85.

Hypertension (abnormally high blood pressure)

There are rarely any symptoms related to hypertension, and is usually only discovered at a doctors consultation. Patients with a hypertension has an increased risk of cardiovascular diseases. Hypertension is of high interest for this project, as it is an indicator for a abnormally functioning heart[16, 17].

Furthermore, hypertension can also cause abnormal kidney function, which is also looked further into when a treatment plan is ruled out. According to sundhed.dk, hypertension is defined as a systolic blood pressure above 140 and diastolic above 90, measured in an out-patient clinic [17]. This can be seen in figure 4.2 It is proved that the prevalence, conducted in a research study at Fyn, that around 20% of the adult population (20-89 years of age) suffer from hypertension. The prevalence increases to 40% for the adult population between 60-69 years of age[18]. To see how hypertension is an increasing issue with age, see figure 4.3

It is recommended that the patient is also monitored at home, however the values are 135 systolic blood pressure over 85 diastolic blood pressure, a bit lower than in the clinic. The reason for this is the so called "lab-coat effect". In short, several studies have raised the issue that patients blood pressure is higher in an out patient clinic, or at the general physician, compared to similar

Category	Systolic		Diastolic
Optimal	<120	and	<80
Normal	120–129	and/or	80–84
High normal	130–139	and/or	85–89
Grade 1 hypertension	140–159	and/or	90–99
Grade 2 hypertension	160–179	and/or	100–109
Grade 3 hypertension	≥180	and/or	≥110
Isolated systolic hypertension	≥140	and	<90

Figure 4.2: A table of blood pressure related to hypertenstion [9]

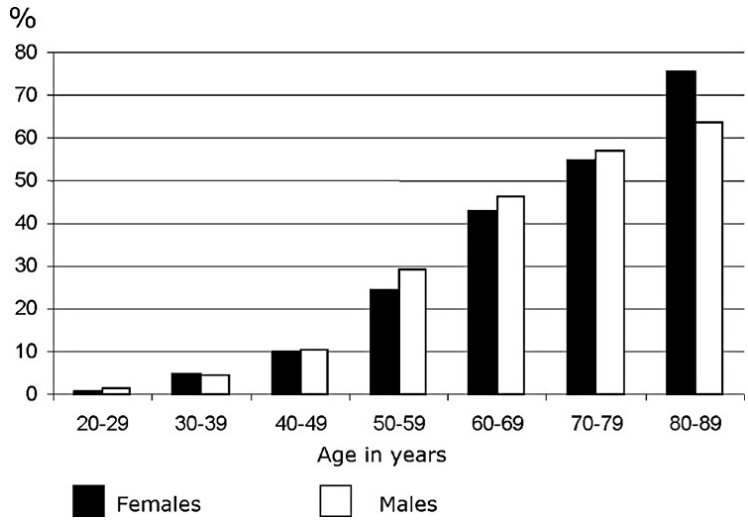


Figure 4.3: Crude prevalence of hypertension by Kronborg, Hallas & Jacobsen[18]

measurements at home[19]. This conclude that doing home monitoring of blood pressure may be beneficial for this project and future studies.
On a side note it can be mentioned, that the prevelance of chronic heart failure with age, is also increasing.

Hypotension (abnormally low blood pressure) An abnormal fall of blood pressure can occur due to several causes. One of them is an acute drop in

pressure caused by a trauma. This usually happens in case of heavy bleeding or other trauma to vital organs [20]. It is not in the scope of this thesis.

4.3.2 Electrocardiography (ECG)

electrocardiography is usually only measured in the initial diagnosis of a cardiovascular disease. The ECG is in short, a tracing of the electrical activity of the heart. It's based on the electrical impulses that makes the heart beat, and thus, it does not have a direct comparison with the heart rate. It does have a direct comparison with heart rate variability, which will be detailed later in the chapter. Graphic representation of the electrical rhythm of the heart. The ECG consist of two parameters, electrical impuls in micro volt (mV) and time in milliseconds (ms). In the hospitals a 10 electrode ECG is usually used.

Interesting parameters are as follows: *P-wave* the P-waves are interesting as this is the starting electrical impulse for the heart. The P-waves indicate when a sinus-rhythm starts. First a P-wave and then a QRS complex will appear, this indicate a full sinus rhythm.

Description	Measurement
Suspicion	If $P_{volt} > 2.5mV$ If $P_{time} > 0,08s$
Atrial fibrillation	Abnormal rapid heart rate (tachycardia) Rhythm irregularly irregular No distinct P-wave (noise)

Table 4.1: Suspicious P-wave patterns and their effect

Irregular rhythm is detected between the height of different R-waves. If the height is varying across, it indicates something is wrong with the heart rhythm. As long as the ECG diagram looks normal, e.g. no peaks, no extreme delays/short time of the different waves and intervals, no spikes or drops in electricity, no noisy or irregular wave-forms, everything from an ECG point of view seems normal. For examples of abnormal heart beats, see figure 4.4

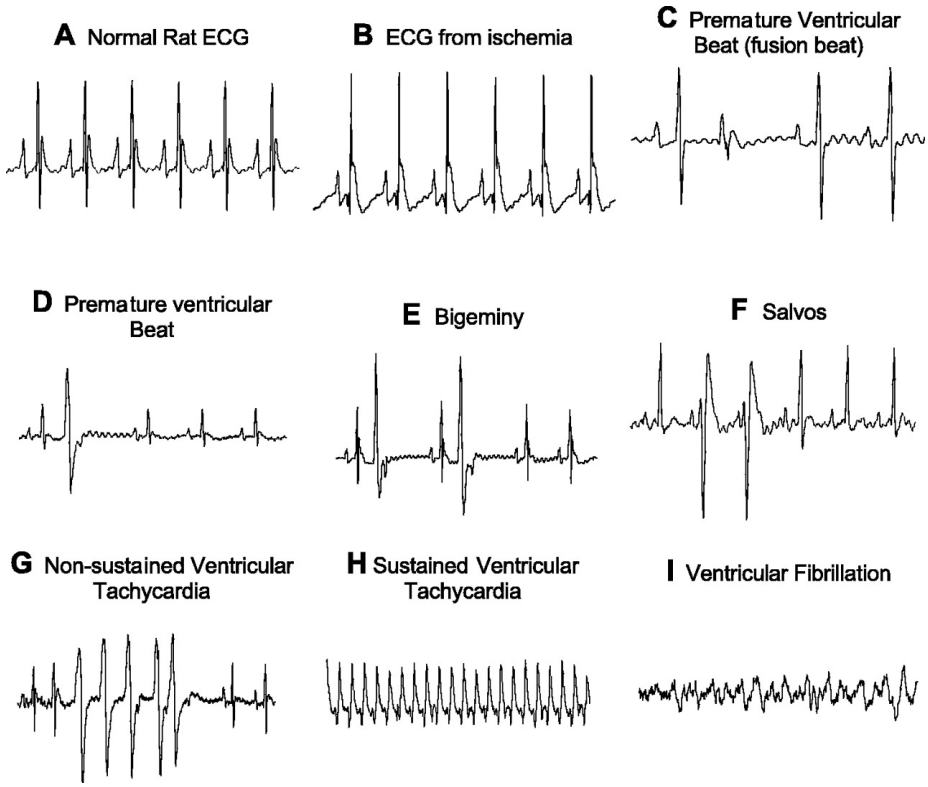


Figure 4.4: Comparison of normal and abnormal ECG[21]

4.3.3 Heart Rate Variability

No clear indicator have been found between heart rate and chronic heart failure. However, there are indicators that the medicine given for treatment aims both at lowering the blood pressure, as well as lowering the heart rate. For the case of decreasing heart rate, it is usually beta-blockers prescribed for the patient[4].

Heart rate variability is measured in an R-R interval, e.g. the peak of a QRS wave from the ECG. ECG is still considered superior for this measurement, since it is clear when the R peaks occur [22].

Several studies have shown that the heart rate variability does tell something, or indicates if something is unhealthy. An optimal level of HRV within an organism reflects healthy function and an inherent self-regulatory capacity, adaptability, or resilience[23].

4.3.4 Pulse Rate Variability

In this project one of the research objectives is to see how we can incorporate wearables and off-the shelves devices, to track and measure various body measurements. One of the most available measurements is pulse rate. Then how can pulse rate be used and what does it say about things? Despite pulse rate being more inaccurate than heart rate variability, in several studies, the to have been found to correlate in subjects at rest, e.g not during exercises[24, 25]. For example Wong et al.[24] finds a correlation between the two, but, it deviates a bit and thus are not the same. However, for this study and for the future, it may be accurate enough. They also prove that for the ultra low frequency measurements, usually used over 24 hour periods, the results seems to have a higher degree of correlation.

4.3.5 Weight changes for chronic heart failure patients

Through field research it has become evident that weight changes is something used frequently in the heart failure clinics. A rapid weight change, here noting +/- 1kg in 24 hours, is an indicator of water retention. This is of serious concern for CHF patients, as it indicates a lowered pump function of the heart. A typical symptom of this is breathing difficulties, and in severe cases the liquid retention can build up around the lungs, limiting the breathing capabilities of the patients. The effect of the weight change can cause many difficulties for the affected patient, including sleep difficulties.

It is easy to remedy the quick weight gain by using prescribed diuretics, usually the symptoms can be cured. However, it may take some time for health cares to notice this, as it requires the patient to contact the hospital. A typical symptom related to the weight change is swelling in limbs, such as ankles and legs.

4.3.6 Activity measurement

In order to see if the patient is moving around, or just laying in bed or being sedentary most of the day, activity measurements are also included. An idea is that it's healthy for chronic heart failure patients to move around during the day. Also, this is a low hanging fruit as most, if not all smart phones today have a built in pedometer, in the form of an accelerometer.

4.4 Verifying the first user story map

The focus of the first user story map, see figure 4.5 was on the measurements (which is not as high level goals in the expected form). The user story map was created before the first visit at Herlev Hospital, which is also evident, since, there was not a clear scope in mind just yet.

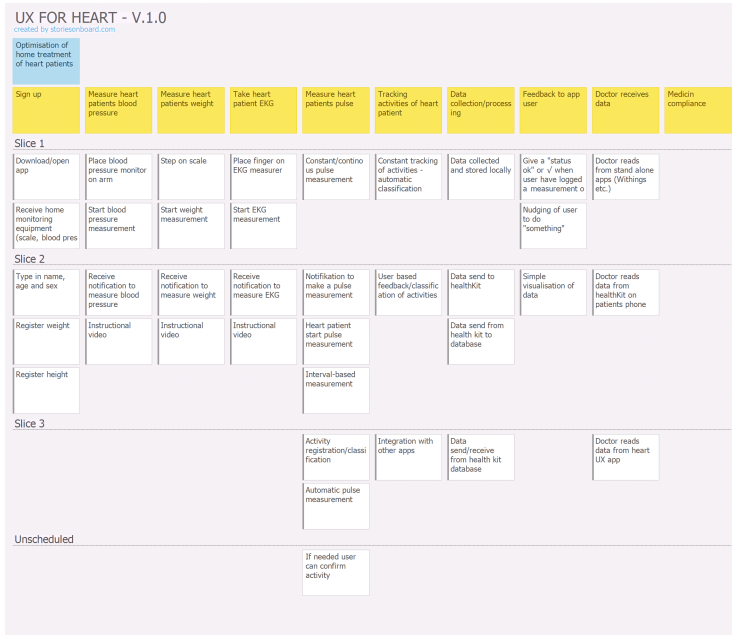


Figure 4.5: The first user story map, used in the scoping

To validate the user story map an interview with two nurses was conducted. It became evident, that measurements are only a small part of what is used to diagnose and evaluate a patient today. The nurses are working with a holistic picture in mind. The learning points related to this user story map, and to the treatment of chronic heart failure patients are:
The evaluation of a patient, is holistic, this means that the nurses pays more attention to how a patient is feeling in general, how they do in their everyday life, and when and/if they have trouble with everyday chores (this, is related to breathlessness). They also usually do a visual inspection of the patients to determine whether they look pale, have oedema s or in other ways look impaired.

Blood pressure is only measured once at every consultation. According to the nurse this is enough. Even once a day is considered to be too frequent for

this measurement - It could cause too much focus on the disease. However, a measurement at home, would save time at the clinic. The blood pressure measurement should be correlated with symptoms if possible. It would be a benefit for the patient to know if their blood pressure are in normal, however as it's heart failure patients, the blood pressure in normal range varies.

Heart rate, only used to estimate if the pulse is *high or low*. To be totally sure about the heart rate, an EKG is used. *At the end of the up-titration, the ideal rest pulse should be between 70-75 beats per minute (BPM).*

EKG Is not considered as an important measurement, only used in severe cases where abnormal heart rate, atrial fibrillation or other abnormal heart symptoms are showing. Currently only used on patients where there's doubt about the heart condition. It would be helpful for patients with atrial fibrillation, if the assessment could be done easily for the nurses.

Weight was one thing the nurses would like to frequently monitor. The weight is an indicator of liquid retention. The nurses can ask the patient to take diuretics to relieve pressure on organs. The weight should be logged every day. The weight is important to monitor as it can cause water in the lunges, which basically is drowning and need hospitalization.

NYHA classification, to evaluate if the patient is in the same NYHA class or have changed in condition. This is based on a holistic evaluation of for example, the patient is sitting up sleeping, or lying down. Also breathlessness in normal activities, such as walking, walking up stairs or a hill.

Blood samples are an important factor for the nurses. It is taken every 3-4 weeks, in a relative short period (only during up-titration). The measurements are; Kidney function, Haemoglobin percentage, Potassium, Sodium, Creatinine and GFR (Glomerular Filtration Rate). The blood samples are used to evaluate the kidney function, as the medication affects the kidney.

4.4.1 Overlooked aspects; The importance of NYHA in the overall evaluation and the medication

The user story map revealed that one important aspect had been overlooked, a telephone consultation, what later will be referred to as **remote up-titration**. Which at times occur only based on stable symptoms and weight.

Secondly, a qualitative assessment by the nurses. The nurses uses a standardized questionnaire to ask questions related to; *Shortness of breath; Ability to climb*

stairs. How many stairs?; Are you able to walk up a hill? With wind in the face?; Fatigue. Patients feel extremely tired. (Typical symptom that most patients experience. Not caused by the medication but by the syndrome). Based on this the patient is then classified according to the NYHA classification, depending on the severity of the symptoms present.

Some of the key points related to medical treatment are; *How to support the patient to distinguish between up to 5 different medical drugs; The drug dose changes over time (it's gradually increased); The drugs does not cure, they suppress symptoms; the medication is taken 1-2 times daily.*

The dose is personal, and the speed and amount of drugs taken depends on the NYHA classification and the general state of the patients health. Especially in the beginning the medicine can cause symptoms that are similar to the symptoms of chronic heart failure.

There are many issues related to taking medication, what the nurses would like to see in the next iteration would be: *If the patient takes the medicine or not; information about the function and side effect of the medication; reminders could be helpful for forgetful patients*

4.5 Sub-conclusion

The first user story map was used to verify the validity of focusing on using quantified measurements at various times a day to design the first prototype of an app with. The user story map proved to be a good tool , from which discussions could start, and combined with a user journey map, gave good insights in the current work flow. As a scoping tool it is difficult to master, based on the input from this chapter, the next version of the user story map, will be updated accordingly.

Several hypothesis's was stated in the beginning of the chapter, some was verified others was not. A brief summary of the learning points from the chapter are:

- Weight measurements on a daily basis is a must
- It would be a big plus if either the nurses can contact the patient via the app based on some parameters, or if the patient can contact the nurse with added relevant information
- The NYHA classification is not measurable, in the current work flow. It is one of the more important tools in the holistic assessment of the patient,

which is the main decision parameter that support the nurses in decision making regarding up-titration.

- Medication monitoring and information is something that usually is difficult for the nurses to convey. A solution that could both help monitor the medication intake, as well as provide information about the medications function and side-effects could help in motivating the patients for a regular medicine intake.
- Blood samples are important, if available, for when a patient should be regulated about their medication (both up-titration or pausing)
- Blood pressure gives insights, but it is more important to see it as a trend over time. It is not necessary to monitor it on a daily basis (according to the nurses)
- Heart rate (pulse) is important to monitor if it drastically increase or falls. The target is a resting heart rate at 70-75 BPM. It is now taken at blood pressure only - however this project could look into continuous heart rate monitoring.
- EKG is mainly relevant for determining heart rate and heart rate variability. It can also be used in case there are heart (beat and/or rate) abnormalities.
- Piggy backing on 3rd party hardware is possible, and the hypothesised time intervals from a usability point of view is also valid.

The list above will be the basis of the next chapter, which will look into the further scoping by using the user story map framework combined with a prototype on paper.

Chapter 5

Second iteration: Going deeper into the patient view

The confirmed hypothesizes will build the basis of a second version of a user story map, where the insights from the previous chapter will be translated to higher level goal, with accordingly activities. The prototype on paper will be tested at Herlev hospital, with a nurse, and the learning from this, will later be used as a basis for developing the patient app for the first prototype to be tested in a future pilot in the real world.

5.1 Hypotheses for this chapter

The desired outcomes of the prototype was to test the following hypotheses, to support a personalised treatment are:

- An analytic page representing insights for the nurse. This should assist the nurse as a tool during the consultation. The key insights to be tested and verified are; *Weight changes over time; Medicine intake and following the medical treatment (regime); And blood pressure and symptoms correlated*

- Adding symptoms from the patients supports the nurse in making a holistic conclusion of the patient current state.

- Weight registration. The patient can manually register their weight. The hypothesis is to confirm that the patient can enter the weight manually.

- Contextualized feedback, when the patient registers a new weight measurement, a contextual feedback is given, such as "you're stable". The hypothesis is that this motivates the patient to keep registering the weight, compared to a numeric feedback.

- Medication and information. The hypothesis is that information about the medication's function and side effects, and only the medication relevant for the patient, will make the patient feel more comfortable taking the medication, and following a treatment plan.

- Medication reminders. The hypothesis is that friendly reminders help the patient to take the medication, without them feeling forced to so.

- One app, that the patient have full ownership over, is enough to improve the consultation.

5.2 Methods

5.2.1 A small usability test of some hardware devices

As the final product should be useful and easy to interact with, the usability of the hardware solutions employed in this project, should be; *Easy to set up/install, easy to use and somewhat reliable.*
From the user story map in figure 4.5 the following measurements are highlighted: blood pressure, heart rate, weight, ECG and activity measurement should be carried out. For more information about the specific measurement devices.

In order to figure out whether devices would fit in a user context or not, and what usability issues they may possibly invoke, a lean user ability test was conducted on Benjamin Johansen in a period of 10 days. This is based on the validation stage of Lean UX, see figure 5.1

Figure 5.1: The importance of validating ideas by L. Klein [15]

5.2.1.1 Measurement tools

The devices have been selected according to a) measurements needed, b) availability (for this thesis, and in general), c) testability/usability.
What has been *disregarded* is parameters such as: accuracy (as this thesis is focused on lean prototyping in UX), cost (as it is assumed key-stakeholders will cover the cost) and if it's been clinical approve since the goal is to see if devices that haven't been clinical tested can be used.

Weight measurement
A *Withing's Smart Body Analyzer: WS-50* scale is used for conducting the weight collection. The scale collects the patients weight, send it to the Withings server, and is then send to the Apple HealthKit. The scale is used in this project due to relative simple installation. Being fairly user friendly. It needs the Withings app to connect with the scale and a WiFi or 3/4g modem to connect and communicate with the Withings servers. Additionally it have some added functionality such as body fat measurements and heart rate measurement.

Heart rate measurement
An *iHealth Wireless Pulse Oximeter: PO3* heart rate and pulse oximeter is used. This heart rate monitor is simple to setup and get started with. It's similar to a heart rate monitor found in hospitals, and uses a clip-on finger tip method and a pulse oximetry method, using two LED's (red and infrared) to shine light through the finger. The reflection change is registered, which give the heart rate reading. Additionally this devise also have the option to measure the oxygen level in the blood.

Blood pressure measurement
A *Withing's Wireless Blood Pressure Monitor*. Connects via Bluetooth to the Withing's app. Easy to install by placing the device cuff on the arm, and then starting it from the phone. Measures systolic and diastolic blood pressure, as well as heart rate. This device has additionally been approved for clinical usage.

ECG
A *AliveCor Mobile ECG* clinical - quality electrocardiogram (ECG) recorder. The usability and setup is good and easy, and only requires a cover that fits the patients phone. The recorder comes with two "electrodes", where a normal ECG recorder comes with either 9 or 12 electrodes. For this project, and many

health physicians, it's been evaluated that the AliveCor mobile ECG is accurate enough to use in treatment. This ECG recorder is FDA approved, and thus approved for clinical measurements.

Activity measurement
For the activity measurement the idea is to use the patients smartphone. As one of the partners in this project is Apple Denmark, the idea is to use an iPhone 5s or newer model with iOS 7 or newer. This setup uses the accelerometer in the Apple M7 Motion sensor, and HealthKit is build in, in iOS7 or newer versions of iOS. There may also be a possibility to include an Apple Watch later in the project, as this can both track activities and heart rate.

5.2.1.2 The usability test and conclusions

The test involved three elements to be tested, these are:

- Usability of 3 devices. The iHealth Wireless Pulse Oximeter, the Withings Wireless Blood Pressure Monitor and a normal scale. How difficult are they to use on a daily basis, what causes frustrations.
- How intrusive is it to use the devices over one week
- How difficult is it to log the measurement (semi)-manually

Conclusions

- The more automatic a device is, the less intrusive it is.
- With the current blood pressure technology, measuring blood pressure will always be a bit uncomfortable due to the pressure exerted on the arm.
- As soon as the app's have been installed, caring out the measurements are very easy. A limitation for the blood pressure is that the patient needs to start the device through the app.
- In order for the blood pressure measurement to be more accurate, the user should take three measurements. This can be enabled in the app, but is hidden away in a menu.
- The main usability issue is installation and first time setup.
- The pulse oximeter was the most hassle free as it's very similar to the type of measurement done at the hospital.

The sub-conclusion is:
With the currently available devices, even weaker patients should be able to operate these, as long as the app is installed for them and they get a thorough instruction on how to operate the devices. On a side note, it can be concluded, that even small usability tests can be crucial to groom out poor usability of 3rd party products and/or services, before deployment for test.

5.2.2 Prototype on Paper - POP

One of the tools used for quick iteration and prototyping is by applying PoPs. Through out the project different fidelities will be demonstrated through PoPs. A PoP is basically just an interactive prototype that can be designed from low fidelity, such as hand sketches, or to high fidelity using graphical software. The power of PoP is that it's easy to collect qualitative feedback from the users, using very simple sketches. It allows for fast iterations, and to fail faster, thus optimising the design.
The only point to be aware of by using PoPs, or other interactive prototypes, is to have a given user scenario ready before hand, and not a random test. A user test could in theory be to check how well the welcome screen works. In general PoPs give very fast insight into what works, and what doesn't.

5.3 Updating the user story map

The previous version of the user story map was focused mainly on measurements. After evaluating the high level goals at Herlev hospital, the map was slightly changed to better accommodate the goal of personalised treatment. The second version of the user story map can be seen in figure 5.2.

The high level goals now changed to the following:

- **More accurate medication**
  The goal here is to have a better insight into the patients medication patterns, in order for the nurses to better monitor and adjust accordingly and timely.
- **Increase awareness of patient well being through insights**
  The nurses conduct a holistic evaluation of the patient. In order to support this holistic evaluation, on of the higher level goals are to give the nurses better insights into how the patient are faring in their everyday.

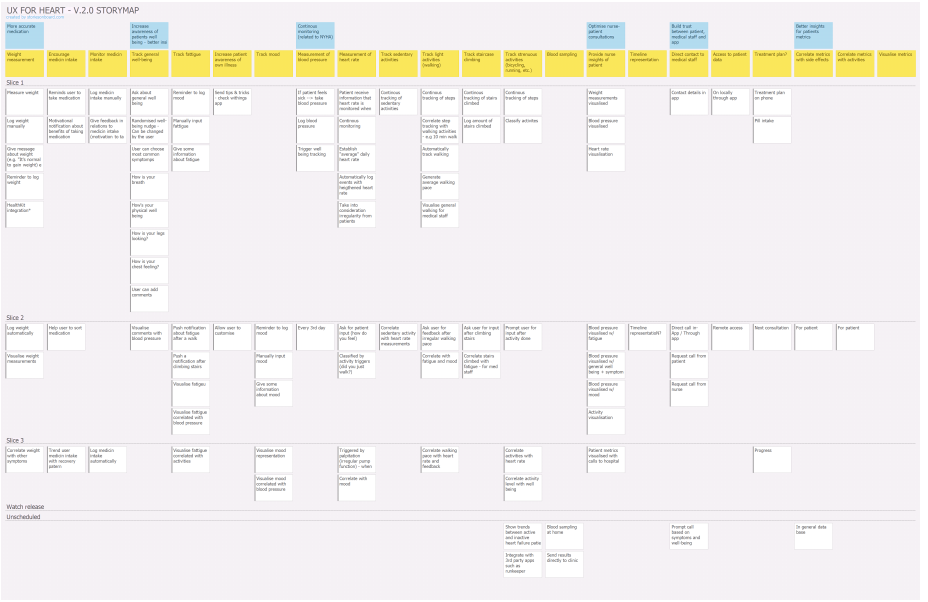


Figure 5.2: The second version of the user story map for the patient

- **Continuous monitoring for NYHA classification**
  NYHA classification is used by nurses to adjust medication, and thus the importance of the classification was discovered. To support this classification, some build in measurements is supposed to assist the nurses, while engaging the patient at the same time.

- **Optimize nurse-patient consultation**
  One of the thing that motivates the nurses are the patient care. Due to the increase of documentation, which was noted in the interview with two nurses, only half of the consultation time is used for actual patient care, where as the other is used for updating the medical records. From the remaining time, around 1/3 of the time is used on various measurements. The goal is to allow for more time for the actual patient care during the consultation. It also gives the nurses a tool to fast focus on what needs attention.

- **Build trust between patient, medical staff and app**
  As the current system relies heavily on *"do as your told to do"*, the level of trust between patient and nurses are varying. Many patient go home and look up information on the Internet, which is interpreted as a sign of mistrust. Thus this goal is to create the necessary trust between the patient, the nurse and the app, to give the best treatment.

- **Better insight for patient metric**
  This goal is general and seeks to correlate how various metrics, and their correlations affect the patient or a patient group. This is also a longer term goal, which seeks to give more insight to the doctors and researcher about trends in heart failure patients and the treatment they're undergoing.

The user story map looks different from the last version. This is due to the added insights, which shows that *understanding the user and the context* is of very high importance when designing a user story map.

5.4 Designing the first prototype on paper

To verify the user story map a user test was scheduled at Herlev hospital with a nurse. The user story map has been the base for testing the hypotheses at the hospital. The design process used is fairly simple: first, draw up the hypothesis's wished to be tested, then determine the high level goals, make/update the user story map, design a prototype on paper, test the prototype and receive feedback, the process then restarts.

The very first prototype was designed by hand and sketched out, it can be seen *here*. To make it look a bit more a like a real product, a design was drawn up digitally and implemented, this prototype can be found **here**. A story board can be seen in figure 5.3. The story board give an overview of the navigation through the app.

5.5 Verifying the prototype at Herlev Hospital

A test of the first prototype was setup at Herlev Hospital with the head nurse Vibeke. She is one of the gate keepers among the stakeholders and have both great insight and understanding of the patients and the disease, from many active years of service. This can also influence her opinion about the solutions presented through out the project.
The user test and verification at Herlev hospital did confirm that PoP's should be the right fidelity to reach the desired conclusions.

The feedback received through the user testing is:
Include more information for the nurse (this is what she/he needs): After reviewing the app one of the main feedback points was the analytic page.

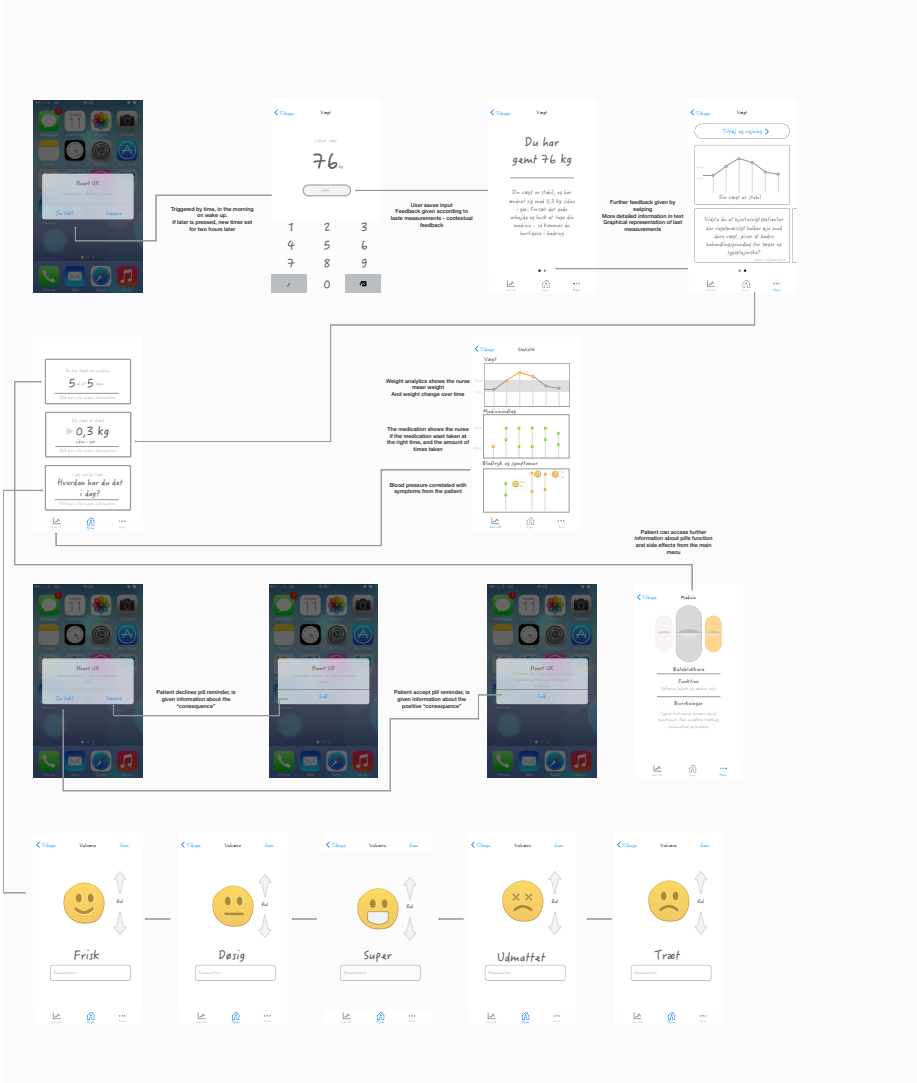


Figure 5.3: A storymap displaying how the app is connected

The layout and visualization was fine, more interesting findings were a) some information missing, and b) the confusion about context (correlation of blood pressure and mood).
On the lack of information it was mentioned that the nurse spend a lot of time looking for information related to the patient. From this Vibeke highlighted the following as items the nurse have difficulties finding, and which is important for them:

- Visual overlook of the graphs, e.g. graphical representation is preferred.
- Patients medical history - This is relating to the medical record, which is now in a centralized system.
- Cause of heart failure, a note on this, as the patient sometimes are unsure, and the nurse cannot remember the cause for all of the patients.
- Heart rhythm information. This is related to whether the patient have a *Normal heart rhythm, or have atrial fibrillation*
- Access to Previous ECGs, the nurse uses this for comparing current ECG (if any) with previous to check for any change or abnormalities
- Weight information and history
- Blood pressure (history) and supplementing information. E.g. it would be valuable to know if the patient has a tendency to low blood pressure
- Information about medication, which medication the patient is on.
- Does the patient have a community nurse (who may be in charge of medication)
- Does the patient require transportation? (It is the job of the clinic to arrange for this). Patients who need transportation cannot be scheduled for the afternoon because of the long waiting. They might not have been picked up when the clinic closes.
- Information about need for interpretation - What language?

Include a function to keep track of appointments. Many of the patients forget when they have an appointment, and skip it. It can take several days or weeks, before the appointment can be rescheduled. This is an issue that requires a lot of the nurse time, and could easily be optimized.

The solution should shorten the consultation time. It has been mentioned that it would be beneficial if the consultation time could be shortened.

The HIT project have proved that remote consultation could support this.
A main reason for the slow up-titration is that the same patient is booked with the same nurse for every consultation. This means that the nurses are limited in when they can see patients.

Issues with medication. It is good that the patient receive more information about the medication that they currently receive. This functionality should be kept, and even build more extensively. When the patients do not take the medication, the up-titration period is prolonged.

Correlating blood pressure with mood. The nurse did not understand this feature. She liked the feature about tracking well being, and the blood pressure also was good to keep track of - however, not more than once every 2-3rd day. The learning point is to contextualize the right information.

5.6 Sub-conclusion

The nurses spend a lot (too much perhaps) time on looking for information about the patient. To make up for this, the nurses usually follow the same patient through the up-titration. The consequence of this is that the system becomes more rigid, as the patient can only see the same nurse, when the nurse have consultation time - in some cases the nurse only consult patients once a week. The solution in this project **have to address this issue. The high degree of rigidity slows the up-titration process**. There may not be a solution, in the scope of this project, for solving the data stream from the current systems. In the future it should be thought about how the systems integrate, and how this can improve the information availability for the medical staff.

Second learning point is that the nurse wants access to a wide variety of information, where much of it is out of the scope of this project. Based on the input from the nurses, see the previous section, the functionality to build upon will be; *Various measurements and their history (blood pressure, heart rate, weight, ECG and possibly blood samples.*

Any solution that makes time spend more efficient, would benefit the system as a whole. For the nurses it would be beneficial if they could spend the time on nursing, rather than documentation and measurements. While for the patients it would be beneficial (and desirable) to shorten the up-titration time, as this is a difficult period.

Medication is a major issue, both for the nurse, and especially for the patient. More relevant information both for the nurse and the patient should be available.

Symptom tracking should still be considered. The nurse liked the emoji style of representing symptoms, and this should be worked further upon in the next iterations.

By testing this prototype it also became evident, that adding the nurse functionality and wishes to a patient app, may be adding too much to an app. As this project deals with user experience, one of the key points are to avoid "we can do it all" solutions, and focus on "we can do what is important" solution. Having this in mind, the next iteration will shift focus slightly, and work on developing the nurse app. It will build on the learning points previously mentioned.

Chapter 6

Iteration 3: A slight change of perspective, towards the nurses

In this chapter the focus is slightly changed from mainly focusing on the patient, to also include and adopt the view and the needs of the nurses, since they are the ones in immediate contact with the patients. From the last iteration it became evident that the nurses have many wishes for functionality of the app. The nurses are the ones who can support in personalising the treatment to the patient. In this iteration the focus is on finding out which key parameters the nurses needs, to optimise and personalise the treatment to each patient. The given hypothesis's will be tested with another prototype test on Herlev, this time using a physical card based design as a tool for discussion.

6.1 Hypotheses

The hypotheses in this chapter are focused on getting the "buy in" and commitment from the nurses. This reflects, that the usability now are focusing more towards how, and in which way the solution can support the nurses in their treatment. The nurses have been identified as a key gate keeper. If the nurses

don't buy in, the system will never work, as they're the ones (along with the patients), that will have most direct engagement with the solution. The following hypothesis's will be verified in this chapter:

- A timeline representation of events occurring during the day of a patient, can used as a supporting tool during the consultation. The main purpose is to give the patient a tool to relate to the data collected, as well as giving the nurse a tool for quick insights.
- Weight changes should be presented in a graphical layout. It is assumed that it is important to quickly identify the changes of weight, especially in cases where the weight is reaching "out of bound" or out of normal levels. The weight should be registered once a day.
- The symptoms the patient is suffering from. It is hypothesized that the most relevant symptoms in this regard are: *fatigue, tiredness, lack of breath/breathlessness, weight changes, sleep and abnormal heart rhythm.* Symptoms should be registered once a day (morning) or when appropriate.
- A summary view which highlights the days of interested. To give the nurse a very quick overview if something abnormal have occurred.
- Blood samples. When these are available, once a month.
- Blood pressure in a graphical representation. The last 7 days and month is hypothesized to be of relevance. Once every day, in the morning.
- Heart rate in a graphical representation. The last 7 days and month is hypothesized to be of relevance. Once every day, in the morning.
- The two above in one view, as it was requested by the nurse in the first interview.
- A medicine tracker to give a fast overview if the patient is following the medical treatment. Several times a day. Should be coordinated to fit with morning and evening medication, and accommodate afternoon medication. Should be tracked at specified times.
- The order of importance are thought of being: Weight, Interesting days, symptoms, medication, blood pressure, Heart rate & blood pressure and ECG.
- One app, residing on the patients phone is enough to enable better communication between the nurse and the patient. One app is enough to make this project a success.

6.2 Updating a user story map relevant for the nurse

As previous mentioned, the nurses have different goals than the patient. Due to this, a user story map specifically targeted at the nurses was created. The user story map can be seen in figure 6.1. The high level goals of the nurses differs from those of the patients, and are as follow:

- **Quick interventions (reduce patients feeling ill)**
  In the current system the patient can call the nurses, at specified time slots, if they're feeling ill or not well. In some cases the patient don't call, and thus the symptoms progress in a negative way, which can have severe consequences. In other cases, patients call when there is not an acute need for help. The goal is to give the nurses a tool, that can assist them in a remote or local decision making to do an intervention, if needed.

- **Increase efficiency of consultations**
  One of the improvement points mentioned in the previous chapter, was to increase the efficiency during the consultation. This is a complicated topic, that involves many parameters. In order to address this issue, insights related to the metrics collected by the patient is to be visualised. This combined with a time line tool, should support the nurse and patient in the consultation, to allow for more time spend on the patient care, and less on making measurements (and discussing these). It also gives the nurse a tool to show the patient, that indeed change, or no change have happened, over the last period.

- **Determine if patient is ready for up-titration**
  This build on the last high level goal, as many of the metrics needed from the measurements also relates to whether the patient is ready for being up-titrated or not. The measurements visualised in the previous points, are measured in this high level goal, and displayed to the nurse. Based on measurements and symptoms, the nurse should have a better decision making foundation. This would also support a faster treatment plan of the patients.

- **NYHA classification**
  As this is still the "to-go" method, along with symptoms, of making a holistic evaluation, that are the basis of the up-titration, it is included as a high level goal. Due to the lack of coherent materials and objective measures of NYHA classification, it is planned for a later release when more insights on this topic have been gained.

- **Build trust between patient and nurse**
  The last high level goal for the nurse is to build trust between the nurse, the patient and the technical solution. This includes an easy way to contact the patient, and also the patient knowing they can easily be contacted. For a future release more detailed information about the patient should also be accessible in the solution, this could be similar to how medical information is stored in the Apple HealthKit framework.

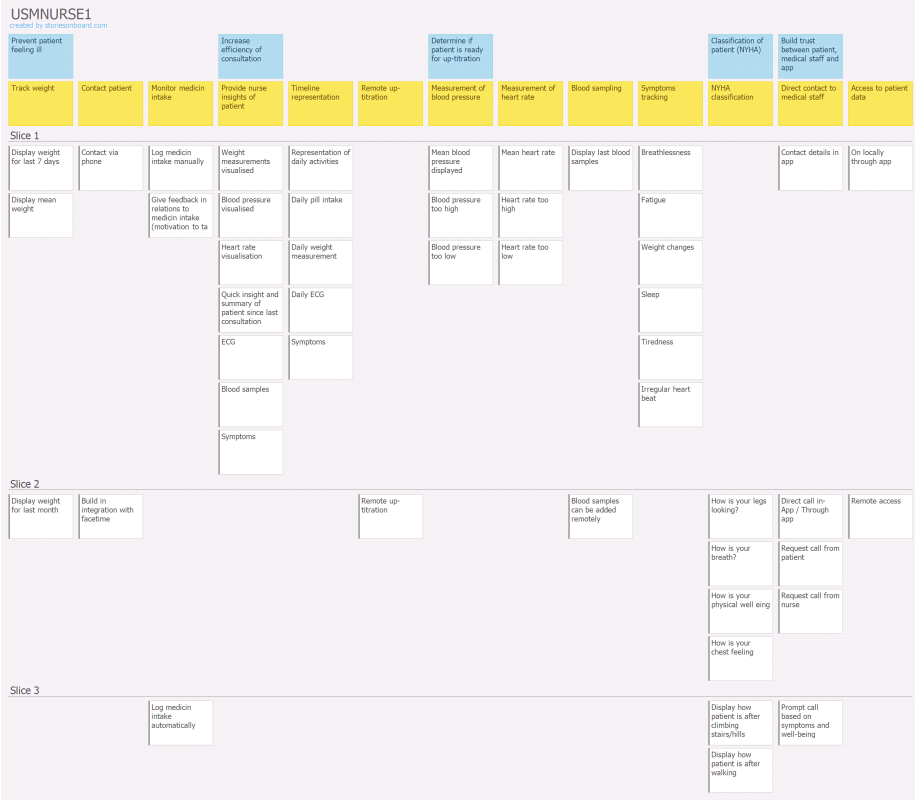


Figure 6.1: A user story map customized to the nurse's

6.3 Testing and verification at Herlev hospital

As in the previous iteration, a story board was made to show, how the prototype would interact in between different screens. This storyboard can be seen in figure 6.2. It displays the key functionality to be validated by the nurse, in order to be

able to design the nurse solution. The design has also changed slightly, based on the feedback from the first user test. For this user test a prototype on paper

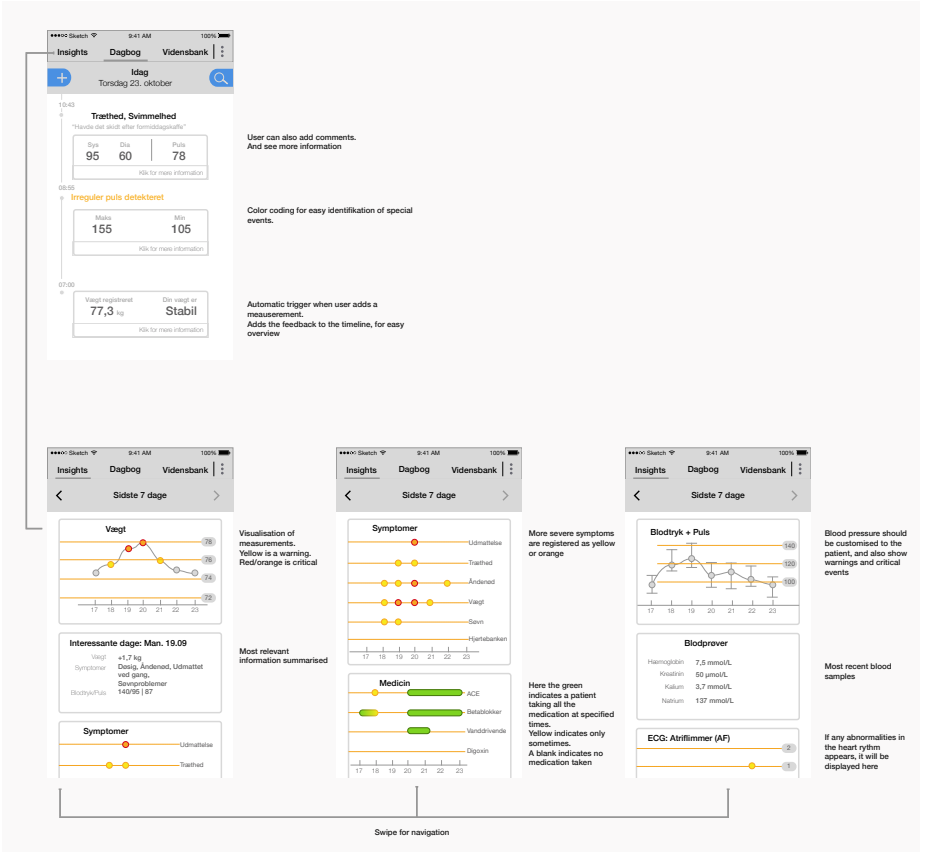


Figure 6.2: A storyboard customized to the nurse's

was not brought along, instead a deck of cards was brought along for testing at Herlev Hospital. These can be seen in figure 6.3. The physical cards was used for an A/B test.

Using the cards it was much easier for the nurse to focus on the content. The cards allowed the nurse to come more freely with suggestions. One of the hypothesis are related to the importance of different measurements. By having physical cards, it was easy for the nurse to move them around in the order she thought was of most value.
A crucial insight was obtained here. That when the designer/developer brings physical objects to be tested, it can provide insights otherwise not attainable.

Figure 6.3: The setup with physical cards

Empty cards was also brought along which the nurse and the developer both freely could add notes to. This learning is important, and should be noted for future work.

The main outcomes from this user test, which creates the bases for the next chapters are:

- **Weight** is the most important measurements for the nurses. They use the weight to intervene if the patient is unstable. The weight typically indicates that the medication is not working as it should, or that the patient is not taking the medication. The intervention can be done with diuretics, and works within hours. It should be noted that some patients don't like to take the diuretics, as a more frequent cycle of urination will occur. The weight should be measured once in the morning, preferably after urinating.
- **Symptoms** are very important for the nurse. In the current form, they are not understandable. Also not all of the symptoms tested are relevant the nurse pointed out that the most relevant symptoms for a holistic diagnosis

are: *No symptoms (if everything is ok), Tiredness, Nausea (as this is a common side effect of the medication), Dizziness (also common side effect), Fatigue and Lack of breath.*

- **Blood pressure and heart rate**. Not currently used. It would be beneficial if the nurse can quickly see if a sudden rise or drop occurs. This indicates that something is not as it should be, and is usually related to the medication. The blood pressure should not be taken more than every 2-3 day as it could make the patient feel more ill - this could be an indication that the patient do not understand what is measured and why.
- **ECG**, the nurse still don't use it. If it can give insights or warnings, when something is not as it should be, the function could be useful. The reason for the hesitation is most likely related to the current working methods, were ECG is worked through manually, and not automated.
- **Medication** It would be very beneficial for the nurse if he/she could follow up on the patients medicine intake. A major problem today, is that the patients don't take the medication. It can be very hard to track the medication intake, and no good solution exists (yet).
- **Other**, it was confirmed that weight and symptoms are the most important indicators for the nurse. If the presentation could be visualized according to a context it would be good.
- **Measurements at home**, if the patient could conduct some or all measurements elsewhere than in the consultation, this would save the nurse some time. Also the overview would give her/him a better decision making platform

6.4 subconclusion

From this iteration it became evident that the nurses and the patient have (very) different needs, in rder to reach the goal of a personalised treatment. The nurse are looking more into insights as a tool to review the patient current state of health. The patient on the other hand, have difficulties understanding what these insights means for them. This indicate that the motivational factors for these stakeholders are very different.

A re-occurring theme is that both the patient and the nurse would benefit from *contextualised information*. For the nurse it is especially relevant if they can see a measurement (or several) contextualised with self-reported symptoms from the patient. For the nurse the symptoms plays an important role and should also do this for the next iterations.

Chapter 7

Iteration 4: Combining the patient and the nurse solution in one

In this chapter an update to the patient user story map, which involves motivation of using the app. The chapter will feature a storyboard with the updates and a brief motivation of why.

In the second part of the chapter, after reviewing the changes for the nurse app and the patient app, the two will be combined in one story map. This story map will be verified by a doctor, who will give hints towards the next steps of implementation

7.1 Hypotheses

The hypotheses for this chapter are as follows:

- When the patient is more involved, through insights and relevant information, they will engage more in partaking and using the solution provided for them.

- Remote up-titration is beneficial for both the nurse and the patient.
- Symptoms logging and easy accessibility, are key factors for success.
- The nurses can benefit from quickly assessing which patients are in (critical) need of assistance, for example when a fast weight gain is experienced, or a sudden drop of blood pressure.
- The system can benefit if the nurses can remotely up-titrate based *on the need of the patient, e.g. if they're ready for up-titration*, rather than when the nurse have time.
- A general sorting system can bring more flexibility to the nursing staff, as not one, but all the nurses would have access to key data about the patients.
- The most relevant data from the patient, e.g. when treatment started and type on medicine currently taking, can support the nurses to be more flexible in the treatment of the patients.

7.2 Methods

7.2.1 Micro Interactions

In broad terms, based on Dan Saffer's literature[26], microinteractions can be split in four parts: Triggers, Rules, Feedback and Loops & Modes. In short:

Trigger: initiates anything, an action, an input, automated. Either user generated or system generated. A manual trigger should be easy recognisable by the user, and it must be coherent, e.g. perform the same action every time it's engaged. Also, the more a trigger is used, the more visible it should be. If a micro interaction can display something of what's going on inside when triggered, awesome, check the mail/SMS notification on iPhones, it's just a simple number that tells a lot.

Rules: determines how things are functioning. What happens after a trigger? The rule determines this. Rules dictates what is allowed and disallowed, and in which sequence events should occur. The fewer options the better, this makes designing rules easier. A good rule of thumb is to use rules to decrease human errors.
The rule determines how the microinteraction reacts after the trigger, control sequences, sequences of executable actions, what feedback is delivered and when,

how to interact with data (both visible and invisible) and what action should happen when the microinteracion is over. Sometimes a logic diagram can help in designing rules (and microinteractions in general).
Rules are many times part of, or make parts of an algorithm.

Feedback: This is the output generated by the rules. What should be shown to the user? And/or what should go back to the system?
In short feedback is aimed at humans, some of the most common traits are: Something has happened or is happening now. You did something. User is not allowed to do that. Using the right amount of "human-touch" such as humour, without it being intrusive, can support the feedback in a positive way
Common elements of feedback are visual, use of animations, audio (for emphasizing something, or create more salient alerts), Haptics (vibrations for example). The most important thing for feedback is to make it relevant (otherwise it turns into distractions), and to use the right feedback for the right context - you don't want to press through several menu's while changing something on your car GPS system.

Loops & modes: This is the meta rules of the system. May be running all the time in the background.
Modes are actions that are performed rarely, for example changing settings. A one off mode could be when an iPhone is charging, and the user calls "Hey, Siri" to wake it up. Spring loaded modes are engaged for a short time, and then jump back to initial state, for example holding down the shift key to capitalises while typing.
Loops are similar to a loop in computer science, it keeps occurring until a certain parameter is reached. An example of a loop is fading an icon/song, or when buffering a video. It could also be setting an alarm for weekdays only, and excluding weekends. Loops extend the life of a microinteraction

The microinteractions are used in the storyboard that can be seen later in this chapter.

7.3 Revising the user story map for the patient

Based on the feedback from the last "prototype"/mock-up, the story board have been revised. The user story map can be seen in figure 7.1.

The goals to support the main goal of a personalised treatment are:

- **Increase patient involvement**. This is the number one goal for the

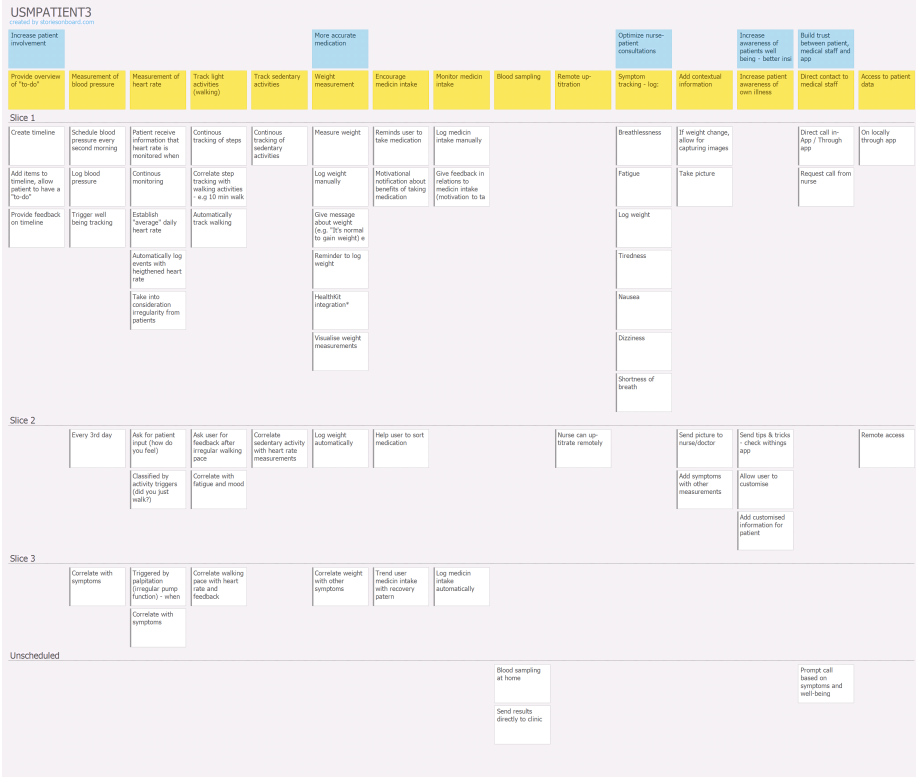


Figure 7.1: A storyboard displaying how the app is working for the patient

patient solution, to support the main goal. If the patient do not feel engaged, the patient will not use the solution. In order to facilitate this, user experience comes into the picture. It is expected that the user interact with the solution on a regular basis, the solution must motivate the user to this.

- **More accurate medication**. Blood sampling and remote up-titration have been added. These are not present in this project, due to the technical- and non-technical challenges. Which could be a project in itself.
- **Optimise nurse-patient consultation**. Changed from providing insights and timeline representation, to symptom tracking and contextual information. This is based on the input from last user test, that it gives better insight and understanding for the nurse, and possibly also for the patient, when the patient log certain symptoms. This would add contextualized information to the symptoms. It could be further optimised with written comment, audio notes or pictures to the symptoms.
- **Increase awareness of patients illness**. This is not considered in this iteration. The idea is to give the patient more relevant information about their illness. The goal is also to increase the patient engagement and involvement by providing more personalized information.
- **Build trust between patient, medical staff and solution**. This is the same as in previous iteration.

One thing to notice is the (drastic) change to the welcome screen. It is now featuring a dynamic timeline. In the morning looks as a to do list for the patient, and during the day, it evolves when the user completes tasks. The reason behind this design is to give the patient an overview of their day, and thus motivating them as a reminder, to finish the to do list. When the patient check the app on a regular basis, they will be able to track their progress, and to see what has happened for them over the course of the day. The timeline is thought to support the nurse/patient consultation. It can act as a reminder for the patient what has happened since the last consultation.

Another evident change is the addition of symptoms tracking. As the symptoms plays an important role for the nurses, this functionality have been added to support them. Symptoms will automatically be added to the timeline, and to the overview for the nurses, making it easy to find exact times, when the patient felt at unease. This could help building the trust and relationship between the patient, the nurse and the app.
It should be noted that only a limited amount of predefined symptoms have been added. This is based on input from the nurses, as well as to avoid an overload for the patients.

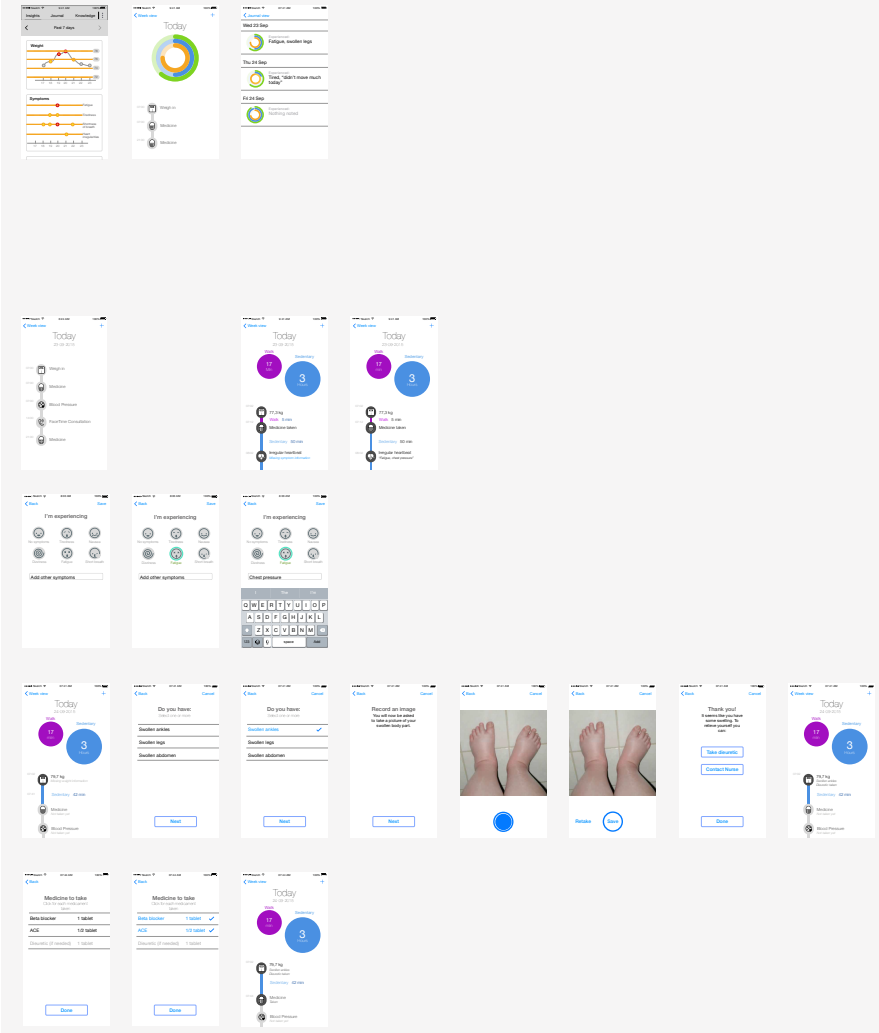


Figure 7.2: A storyboard displaying how the app is working for the patient

To support the high level goal of contextualizing symptoms with a measurement, the weight measurement have been used as an example, as this is a typical case described by the nurse. If the patient have a sudden increase in weight, they're asked if any swelling is occurring in their extremities. After they're asked to provide a picture for the nurse and the doctor to assess. This gives a better treatment foundation, and the medication can be corrected accordingly. Also, in the case of symptoms and measurements having a correlation, an option to contact the nurse have been listed. This is to build trust between the patient and the nurse.

7.4 Updating the nurse solution

Based on the input from the previous iterations, combined with interviews, and literature studies, the nurse side of the app has also been updated to support the goal of a personalised treatment. The updated user story map can be seen in figure 7.3

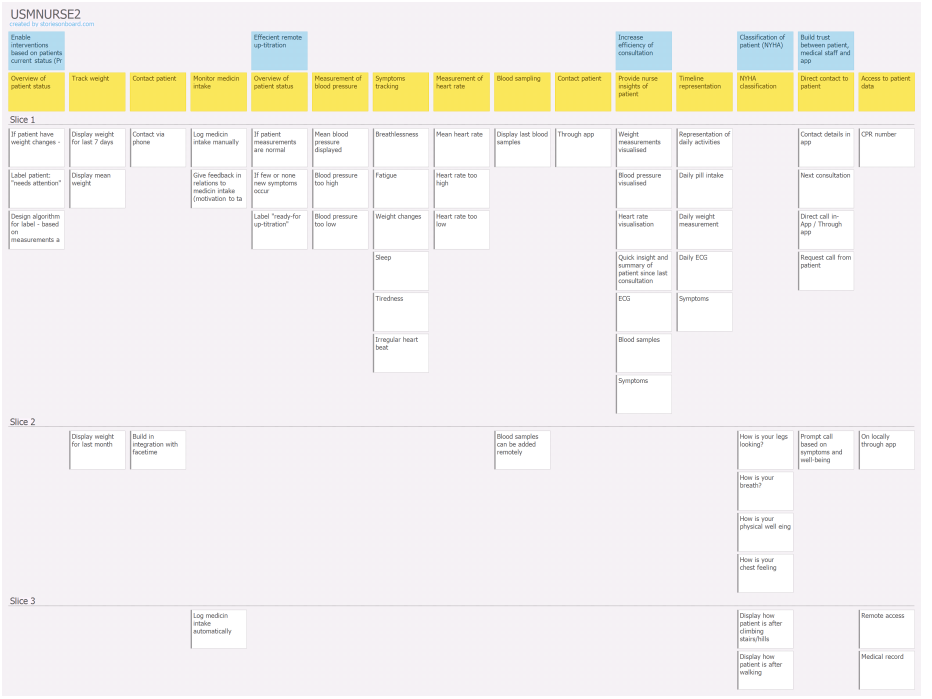


Figure 7.3: An updated user story map for the nurses

The high level goals are:

- **Enable interventions based on the patients current status**. This goal has been combined with the high level goal *Prevent patient feeling ill*. The goal is now including a sorting algorithm, which should help the nurse in quickly over-viewing which patients needs help, now or soon. This should assist in a more efficient intervention for the patient, which could be helping to reduce the amount of re-admissions to the hospital. It should also build trust for the patient, as they can see the nurses are keeping an eye on them, and making sure they don't get critically sick. This is one of the key goals to achieve.
- **Efficient remote up-titration**. This is a new high level goal with high importance. It is merged with the previous goal of *Determine if the patient is ready for up-titration*. This is in the family of the previous goal with sorting. The goal is to provide the nursing staff the right information they need, in order for them to remotely up-titrate the patient. This should make the up-titration treatment more efficient, which in consequence would mean more up-titrated patient in shorter time, and that patients possibly could be up-titrated much more rapid than today. It is related to moving towards a more dynamic treatment work flow for both patients and nurses.
- **Increase efficiency at consultations**. Same as in previous iteration. However, it should be noted, that this also covers remote consultations now.
- **Classification of patient (NYHA)**. Same as previous. It is still considered important, and there are no clear scientific evidence, in which way it can be quantified, besides a 5 minutes walking test (can the patient walk more or less than last time, when treatment started).
- **Build trust between patient, medical staff and app**. Same as previous. Some more activities have been moved up in this iteration, mainly concerning personal details on the patient.

As the user story map has been updated, so have the nurse solution. The latest solution, as a storyboard can be seen in figure 7.4. Two different scenarios are present. One scenario is a patient that needs attention. From the second screen details about why this patient needs attention is displayed. Ditto, is a screen for a patient that are ready for up-titration.

It can be immediately noticed is the change from the insights and analytics screen, to a patient overview screen. Since the focus for the nurse have been

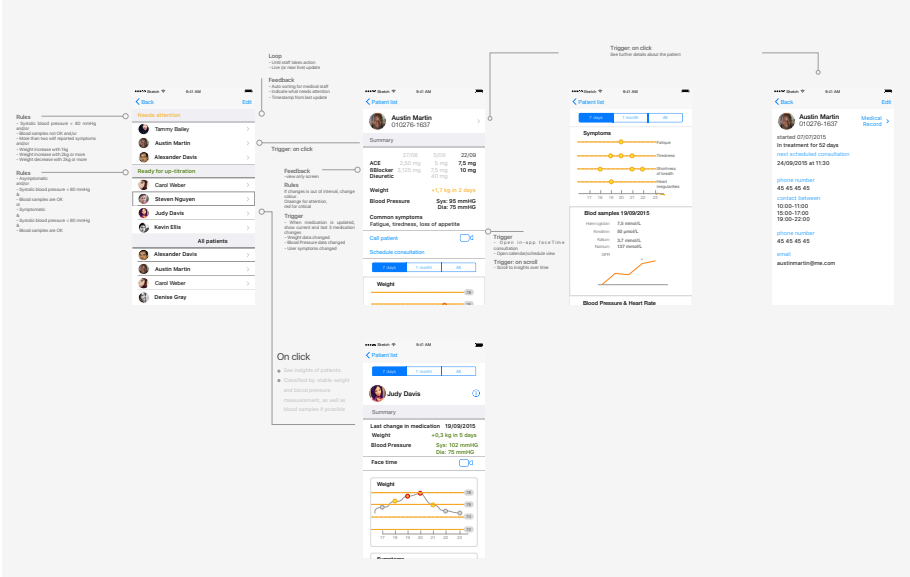


Figure 7.4: An updated design for the nurses

specified more, they now have access to more patients and more data. From the screen it is easy to determine, which patients are in need for an intervention to prevent them from becoming more ill, or to ease the symptoms they have, as well as a "ready for up-titration" filter.

7.5 Algorithm for remote up-titration

The symptoms in the need of attention, is summarised in table 7.1. These are based on the interviews and user testing with the nurses, as well as literature from the Danish Society of Cardiology, the New York Heart Association and the American Heart Association.

The second important feature is the possibility to classify which patients are ready for up-titration. As already mentioned, this is a key feature to move towards a dynamic treatment of the patients. Based on the article by [27], the algorithm have been adopted, can be seen in figure 7.5. For a bigger size see appendix A.3 on page 119. In table 7.2, a summary of what should be used for up-titration[27, 28]. The summary is based on two articles focusing on remote up-titration and looking into quantified measurements.

Description	Parameter
Change in weight	+/- 1-2kg in 1-3 days
Blood pressure	15% drop or increase since last measurement should be 140 > BP > 85 (systolic)
Symptoms	Recording 2 or more symptoms Systolic blood pressure < 95 mmHG + Symptoms
Heart Rate	Asymptomatic compared to mean passive heart rate

Table 7.1: Parameteres for classifying the patient in "Needs Attention"

Description	Parameter
Minor/no change in weight	Weigh change < 1kg in 1-3 days
Blood pressure	130 mmHg > Systolic > 80 mmHg and no symptoms
Heart rate	Heart rate > 70 BPM
Blood Samples (if available)	If labs look normal

Table 7.2: Parameters for classifying the patient in "Ready for up-titration"

7.6 Combining two, into one storyboard

As the solution is now being sketched out and coming together, it is time to combine the solution into one storyboard. When doing so, the solution comes one step closer to a finished result, and is now ready to be verified with an end user, in this case a doctor. The purpose of this storyboard is to figure out how the two apps communicate together, by using various scenarios. It is also a tool used to base discussions upon, and to determine the next steps with the project.

The detail level is higher in this storyboard, with four defined scenarios, these being: *Patient registers weight, Patient registers blood pressure; Patient add symptoms; Nurse and patient have remote consultation.*

7.7 Verification

As no further usability testing had been scheduled at Herlev hospital, there was not a direct testing of the prototype. A PoP was made per request, as a health conference organized by Apple Denmark was scheduled for the beginning of November. *The PoP can be found **here**.* The prototype was demoed and the

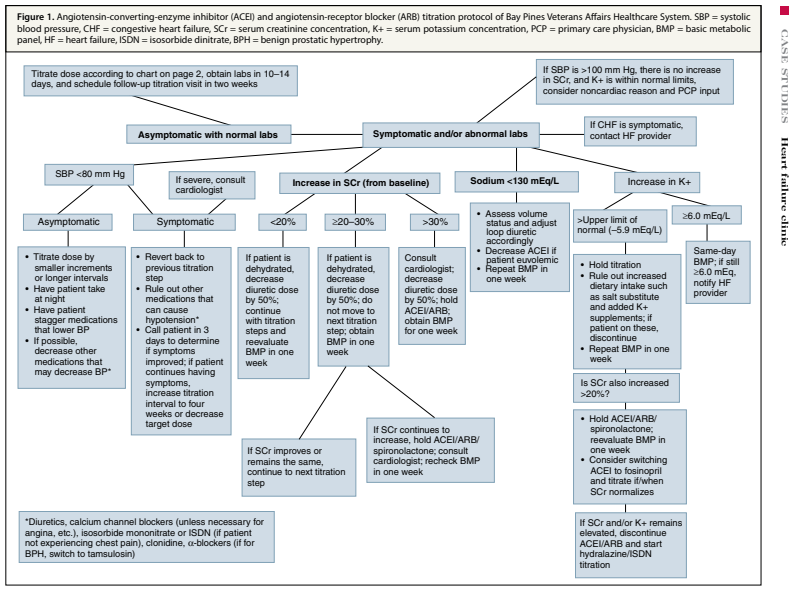


Figure 7.5: Algorithm based on finding in a pharmacist managed heart failure clinic

project presented, where it received positive feedback. The PoP is focused on exploring the possibilities of the patient solution.

The storyboard was used in a discussion with Thomas Høi-Hansen about how to proceed with the project. Positive feedback was given in relation to using an algorithm for remote up-titration, and to determine when a patient is in the need of help. The wish from Thomas was to see a system life, that can show the data, and evidently, handle the information collected from several devices.

7.8 Sub-conclusion

The positive feedback on the mock up did lead to a later scheduled meeting, which the next iteration will be about. For this the first pre-prototype is the goal. As a result a prototype ready to be demoed for Thomas Høi-Larsen, one of the head doctors at the heart clinic of Herlev Hospital. The goals of this will

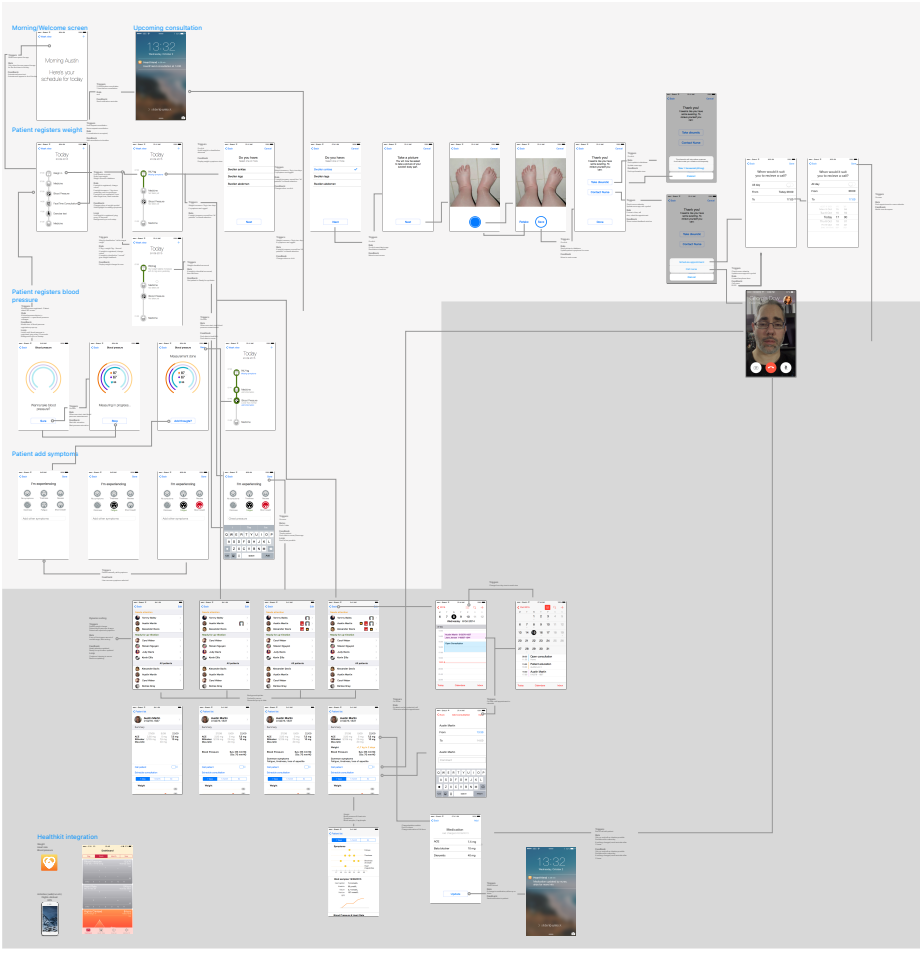


Figure 7.6: Upper part is the patient solution, and the lower part, the medical staff solution

be presented in the next chapter, in short, it is to make sure there's buy in that can be used to facilitate a later meeting with the hospital board of directors.

Based on the input from the doctor the next step are now to work on a working prototype. The key is to update a user story map that can act as a mediating agent, to build the prototype, which main point is to gain "buy-in"/commitment from the hospital side. This also means that only the key measurements, will be implemented in this very first "real-life" prototype. The goal is to have a minimum viable product ready, that can be used to verify and assist the nurses.

The measurements are *Weight measurement, blood pressure, heart rate, activity level, patient information.* The algorithm for sorting the patients will be further detailed in the next chapter.

Chapter 8

Iteration 5: HeartFriend a prototype ready for test

In this chapter the implementation phase is started. The goal of this chapter is to introduce the thoughts about what to implemented and why. It also reflects on why the implementation only includes the core features. The chapter explores how a personalised treatment plan can be shaped into a minimum viable product The chapter includes several iterations, that displays the progress of developing the prototype, and the stages it goes through in it's development.
Again there will be no patient or nurse usability test in this chapter. The prototype is to be tested and showcased at a meeting with several key stakeholders at Herlev hospital. The chapter will conclude with some reflects on how to carry on the work, and how to deploy the prototype.

8.1 Hypotheses

- **A webbased platform is the most sensible solution**
- **The sorting algorithm used is appropriate for implementation**
- **Data from 5 test persons are enough for selling the solution**

8.2 Development frameworks

This section briefly covers the used frameworks. It gives a short introduction to each framework, and describes why this framework was used. As the thesis has been carried out in collaboration with Apple Denmark, the preferred frameworks, have been provided by Apple.

8.2.1 Apple HealthKit

The Apple HealthKit was introduced in 2014 with the launch of iOS8. The purpose of HealthKit is to collect, what apps have been doing beforehand [29]. This includes:

- Statistical Analysis (Graphs, Trends) *This include data visualisation, and other representation of data collected from various sensors, devices and wearables*
- Enter Information *A place to collect and store data that previously have been entered manually, or scripted through various apps*
- Applications From Health Providers *Applications that sends, stores, and retrieve health data between patients and doctors. These applications does occur in the Apple Store. One would be the AliveCor app*

The HealthKit is a framework that's easy to work with, within the ecosystem of Apple. The framework in itself is very simple and provide the following features:

- It receives/ask for data. *Either from a sensor, such as the accelrometer (could be step counting), a heart rate sensor, or input from a scale*
- It saves data. *The so called **HKStore** is basically a server service, either on the local device or in the cloud.*
- It creates data. *It can do simple (mathematical) manipulations of the collected data. The HealthKit allows for simple mathematical calculations such as sum, difference, average and multiplication*
- It have a strong focus on privacy. *One of the key features of the HealthKit is the fine masked filtering of privacy and sharing settings, between the devices and the user*

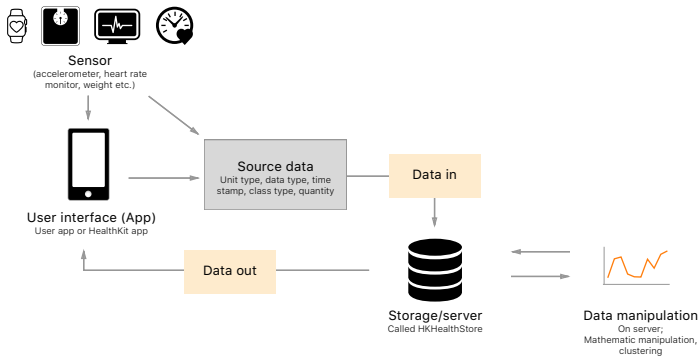
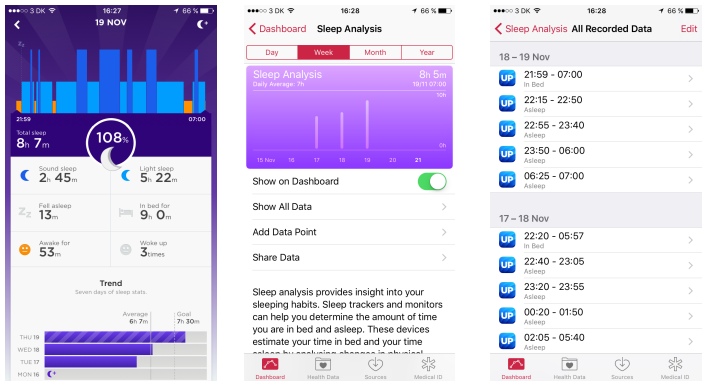


Figure 8.1: Apple HealthKit abstracted, for more information see appendecies

This functionality is built into the framework. By using global parameters, such as common units, and predefined classes, such as steps, any app can send, store or pull data from the HealthKit framework. This allow for high flexibility and manipulation of data. An abstract representation of the HealthKit framework can be seen on figure 8.1 on page 71.

Furthermore, when an app, or a cloud service retrieve data from the HealthKit, a local data manipulation can be done. This allows for special classifications, which may not be supported by the HealthKit framework. An example is the UP by Jawbone app, where a more detailed view of sleep can be accessed within the Jawbone app, while the HealthKit only receives the total amount of sleep. An example can be seen in figure 8.2, where the UP app push the data, and the Health app shows a culminate view of the sleep.



UP by Jawbone | Cullitimate view Health App | Data type in Health App

Figure 8.2: Comparison of data management in Apple HealthKit

HealthKit integrates across devices, it can be connected with many different types of hardware. Apple also continously updates and maintain the HealthKit, for example by adding new data types[30] This gives flexibility and allows for future implementation of different types of hardware. It also allows for customisation of data types for different clinics, both within cardiovascular diseases, and within other treatments that could benefit from this framework.

8.2.2 Apple ResearchKit

Apple ResearchKit is a new open source framework that is supposed to help health care professionals conducting research, without having to develop a solution from scratch. The framework have many build in libraries that makes data gathering, asking for consent, getting feedback, etc. easier. ResearchKit is fully functional and works in tandem with Apple HealthKit. ReserachKit can collect data from all the sensors on the iPhone. The access is granted by the user, and the app will not look into private data, unless access have been granted by the user (patient).

One of the goals of the researchKit is to give bigger sample sizes to researcher, and giving better insights. To compare, clinical research now a days consist of 50-100 patients, and big scale trials involves a couple of thousand of patients. Another point to note is that a goal is to give researcher bigger data sets to measure on, as well as real life data (contra controlled lab tests). This potentially can give research better insights on how diseases and illnesses effect patients in

their everyday life.

ResearchKit consist of 3 major parts. Surveys, which collect data manually in a predefined format. Consent, which ensures all data can be used for research. And Active tasks, which are tasks that can be predefined to collect certain types of data.

The ResearchKit is used to build the framework of the app, and the three elements will be considered in the development phases and for the future.

8.3 The first iteration of the prototype

The focus of this iteration is to lay the foundation for the future iteration and implementation. The back-end mainly focuses on gathering, sorting and sending data. The back-end have mainly been developed by Henrik Holm in python and node.js.

The author of this thesis have mainly focused on the frontend development of the solution. Both frontend and backend have been working with implementing the user story map, primarily for the hospital side. The user story map have been proved to be an invaluable tool to communicating between the different developers on the project. Now, all in the team knows why the weight is so important, and needs to be one of the first things implemented.

The goal of this iteration are as follows:

- To develop a frontend webbased platform that can read and translate data provided from the backend services.
- To have a backend service that can handle patient information in a sensitive way.
- To be able to collect relevant patient measurements, send these to the backend service, and present them on the frontend service.
- To have a prototype that is operating on real data (even in small quantities)
- To present the first prove of concept

The user story map for the nurse was updated, to focus on the minimum viable product, which became the top most slice. At a closer look, it can be noticed,

that only very few functions are included. This is because developing the system is resource heavy. And as this thesis focus on the user experience and lean prototyping, the focus is on implementing the most necessary functionality for key stakeholders to buy in. It is like building a classic Danish layer cake. The whole cake won't be build before asked feedback. It will be build in layers that build on top of each other. The update user story map for the nurse can be seen in figure 8.3

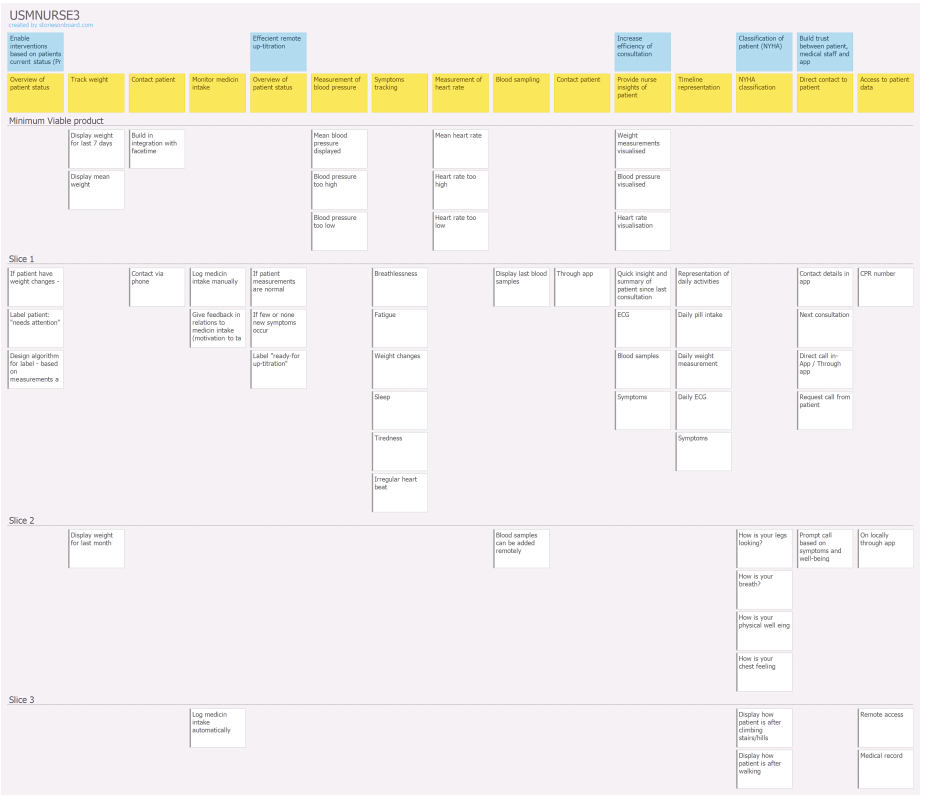


Figure 8.3: User story map for nurses, updated for minimum viable product

Many of the previously defined tasks are still incorporated, and are resting below the minimum viable product. This simply means that they will be implemented as soon as the minimum viable product has been approved (or "bought") by the relevant stakeholders, in this case the hospital staff.

A few additional features have been implemented on the side. One is sign-up and patient data storage. A server at DTU compute is hosting the website, and all the patient data. The reason for this is to emulate how a server solution

would work. In the end, it is hoped for a national deployment, and this would be on a secure server, probably provided by Sundhed.dk
On a side note, patient data security is an extremely sensitive topic, and will be further discussed in the section regarding further work.

8.3.1 Representing data on the frontend

A key in the usability and the user experience of this project, is how to present key information for the nurse. As the focus in this iteration have been on quickly (and lean) to have a working prototype, a webbased solution has been developed. The reason for this, is that the data handling is much easier, since it will be working in the same environment - and don't need to send data back to Apple HealthKit. Learning and using Javascript is fairly simple, which meant that the author relatively quickly could design an interface. Another reason for choosing a webbased solution is that there are many frameworks, like Twitters bootstrap, that makes it easy to design a webplatform, to maintain it and to update it according to the needs of the users. In figure 8.4 it can be observed how "mock" data have been used to build the very first layout of the web platform.

From the figure it is easy to see how data is represented. And in case it's needed, it is as well very simple to change the design, and remove data fields.

When looking at figure 8.4 there are many data fields represented. The reason for this, is to verify what is needed for the nurses. It is also used to showcase the wide variety of data types that can be collected and displayed. The datatypes are directly related to the user story map. In the first iteration, Henrik Holm and I, disregarded the collection of patient data, and focused on working with the backend server and the frontend website. The data provided was simply provided by compiling a small javascript script that randomise numbers

8.3.2 Collecting patient data - designing the patient app

The concept relies on data provided by the patient, one part of the prototype development has been dealing with collecting patient data.

In order to collect data the Apple HealthKit framework was used. Henrik Holm developed an app that could integrate with the Apple Healthkit. Whenever the user registers a new relevant datatype, they get a notification, that the new data has been added. As the "mini-app" integrates with Apple HealthKit, it allows data from third party apps to be accessed. This is smart, while building and

Figure 8.4: The first prototype webbased platform, designed in HTML/CSS, Javascript and various .js frameworks

testing the prototype, as the user can use other apps to feed the HeartFriend app. In it's very first form, the user will simply add data, e.g. a measurement in the Apple HealthKit. Furthermore, by using the power of the Apple HealthKit and the third party app integration, it is not necessary to work on how to interact with hardware/medical devices, yet, as it can be done elsewhere.

8.3.3 Building the first prototype

The prototype works by the user registering data, that through Apple HealthKit is send to the server. The local version of the prototype can be downloaded **here** The frontend then fetches data from the server, and present it visually for the authorized personal. 3 scenarios have been sketched out in figure 8.5. These are:

- **Registration of weight**. A scenario in which the patient uses a third party app or Apple HealthKit to store a weight measurement. This can also be done automatically with compatible devices, this can be seen for the blood pressure measurement.
- **Registration of blood pressure**. In this scenario the users uses a third party app and device to log the blood pressure. Data is automatically send and retrieved from Apple HealthKit.
- **Accessing information about patient**. In this scenario the patient can see what information is stored about them within the app. On the nurse side, access to a web platform is required. From here the nurse can see the most relevant information about weight and blood pressure, as well as other measurements.

8.3.4 Verification

This very first prototype was verified by Nima Zandi, Jakob Eg Larsen and Michael Kai Petersen, none of them health care professionals. The feedback was positive. One important thing that came out was that Nima Zandi, representing Apple Denmark, was not satisfied with the webbased solution. A request for developing a native iPad app was put forward, which would be part of the next iteration. In the mean time it was agreed that when the patient app was more mature, within a very short time, a small usability test would be conducted by 5 people. The outcomes and description and reflection of this usability test, will be presented in the next section.

8.4 Second iteration of HeartFriend

The main goal of this iteration was to demo and verify the prototype with key stakeholders within Herlev hospital. This is to provide the momentum needed

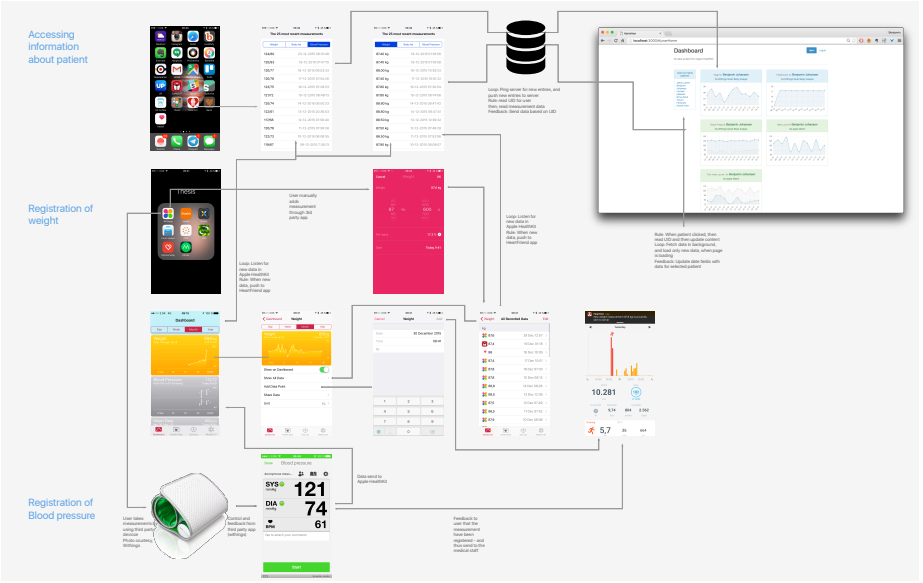


Figure 8.5: An overview of how the nurse and patient interact with the web platform

for deploying the prototype, or a pre-prototype for testing with patients and health care professionals at Herlev hospital.

The goal of this iteration are as follows:

- To collect data from at least 5 test persons, and to represent it on the frontend service
- To develop a native iOS app that runs as the frontend platform
- To further develop the patient app to handle the following measurements *weight, body fat and blood pressure.*
- To test the comparability and data collection from various hardware devices. These include a heart rate monitor, a blood pressure monitor and a smart scale.

With the help of Geekiyanage Trevone Roshant Fernando student at DTU Compute, Nima Zandi and Henrik Holm, a native iPad app was developed using the Apple ResearchKit framework. It can bee seen in figure 8.6. The app is a translation of the web interface, and have the same functionality. It has been of

high importance to develop the iPad app, since it was requested by Apple. Key functions are the build in visualization tools provided by Apple, as well as auto layout, which ensures the app can be used across various iOS devices.

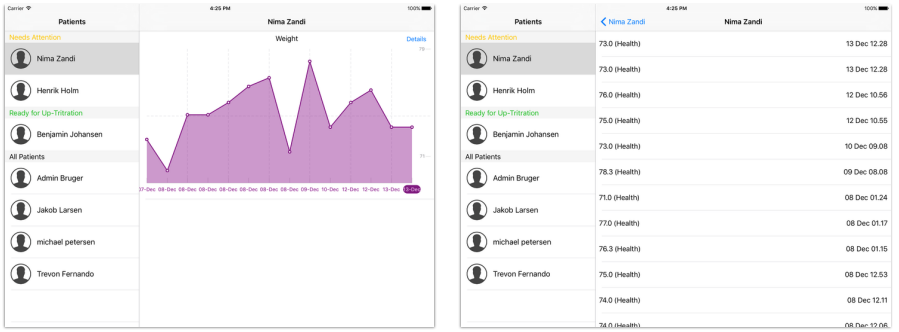


Figure 8.6: HeartFriend app as a native iOS app. Displayed on an iPad. Notice the up-titration and need attention listing

The iOS app for patient was further developed by Henrik Holm, and ready for test. For an overview of how the patient app looks like, see figure 8.5. It now contains the last 25 measurements of weight, body fat and blood pressure. The reason for including these measures in the minimum viable product is that the devices, a smart scale and a blood measurement cuff is at hand, have been tested on already, and covers some of the key measurements according to the medical staff.

Data to feed the app was collected from 5 test persons. 4 of the test persons entered weight data manually, where as the last person used a Withings smart scale to log both weight and fat percentage. All data was fed to the server, and fetched by the web platform and the iOS app for the medical staff. There was found some minor issues with the API, these were fixed and the system is now running live.
Furthermore, blood pressure was manually logged by 4 of the test persons. The last test person used a Withings Blood Pressure monitor, and logged data automatically. As with the weight, no major issues was found.

8.4.1 Verification and reception

The main purpose of this iteration was to prepare a working prototype, with the purpose of receive "buy-in" from relevant stakeholders. A meeting between

several key stakeholders at Herlev Hospital on the 18th of December would prove the viability of the prototype. The outcomes and reception has mainly been positive. The research division at the Heart clinic at Herlev hospital, led by Morten Schou, is very positive. Some key features that should be considered for the future development (which will be detailed more in the next chapter are): *A unique baseline in the measurements for each patient. In relation to weight, a 1-2kg weight deviation should trigger an alarm; Contextualization with the use of Emoji's would be essential for the nurses and patient. This would give insights not previously gained. Combined with measurements it would give the nursing staff a much better foundation to base their decisions on; An automated sorting system should be further developed. IN this regard is should also be considered who contacts who, e.g if the hospital contacts the patient or vice versa; Lastly some data quality measures should be considered, e.g. what happens if someone else steps on the users scale? or how is data kept private.* When these features are in place, it has been claimed "that a national roll out should happen, today". This support the weight of this project and the support.
Sundhed.dk was also present at the meeting. They would be able to provide the server infrastructure and the data management on the backend. Some concerns was raised with relations to privacy and patient data management. As this is out of the scope of this project it will not be considered further, however it should be taken into account for the further work.

8.5 Subconclusion

In this chapter the first life prototype was presented. The goal of this prototype is to be ready for life testing with patient and nursing staff. At the time of launch, it was tested by 5 test person. The feedback has been used to prepare the first minimum viable product, ready for test at Herlev hospital. The minimum viable product has yet to be tested at the heart clinic.

Utilizing the combined work of several developers have shown the importance of understanding and using a user story map as tool. By having the same goals, various kinds of development can happen in parallel and in tandem. It also shows, that lean and agile development is of high value, when working on getting commitment from key stakeholders. Using the improvement points from key stakeholders as a reference point, it becomes evident that what is needed, is to add features, and as the system is build in a light weight framework, it is easy to implement such suggestions.

The minimum viable product was verified at a meeting in mid-December with key stakeholders. The outcomes of this meeting was some modifications which

would enable the project for the first testing phase. The terms of this testing have yet to be defined. In the next section the future of the project will be discussed, where the roll out of the project as well as what should be rolled out will be presented.

Chapter 9

Future work

The first prototype is ready for launch and testing, so what's next may be the question. This chapter will briefly cover what aspects should be covered in the near future and in the not so near future, to carry on this project. Recommendations will be provided based on the user story map, and what possible steps should be carried out.

Much of the focus have been put towards launching a prototype of the nurse app. The reason for this is related to which stakeholders have the weight to carry this project into a real life project - and not another shelf project. In this sense, most of the emphasis have been put into converting ideas into selling points for the medical staff. The patient app is still in it's very early stages. It is ready to launch for a prototype testing, however, it may not reach the desired KPI. What is working now may prove to fulfill the goal of a personalised treatment plan.

Run a real life test with the prototype and beyond
The first suggestion for the further work, is to run a life test with patients and nurses, in the heart failure clinic. Currently only small scale testing, with the developers have been conducted. In order to receive relevant feedback, it is highly suggested that a usability test, or even a clinical trial, is run in the near future. This would provide insight into how the app can support the staff, as well what features to build next. Based on the learning's from this, an updated

user story map should be utilized.
It is recommended that a small scale test is run for a short time, a month or two, to draw these conclusions. The conclusions should be used to design the beta version of the app(s) and the entire system.

Later it would be desirable to conduct clinical trials with a beta or version 1 of the solution. This would be one step closer to implementation. It would provide insights in relations to the effect of using a digital solution in the context of a heart failure clinic - and how well this solution work, when it is build around a patient centered approach, rather than a classic "let's make the consultation digital" approach.

Develop and implement sorting algorithm
The first immediate step would be to develop and implement the sorting algorithm for "needs attention" and "ready for up-titration". The algorithm parameters have already been presented in 7.5 on page 63. It is crucial for the future of this project to implement the algorithm. When the algorithm is implemented, the KPI's related to higher efficiency in the treatment good be tested and evaluated. It would also allow evaluation of whether the nurse believe the solution brings value or not. It may support the trust between patient and nurse, as it will be a tool for the nurses to contact the patient when there's a need. The final and most important consideration is that this algorithm will be a tool, which can support the overall goal of a personalised treatment. When implemented, this allows for the nurses to *remotely up-titrate when needed and provide a fast intervention in case the patients situation is worsening.*

Including symptom tracking
A key element to meeting and solving the main problem, individualized patient treatment, would be to include symptom tracking. Any kind of subjective feedback would give the medical staff a better basis of decision making - this was mentioned by research doctor Morten Schou, to be a key parameter for a successful project. Implementing the symptom tracking and combining it with quantitative measurements, would give the nurses a more specific tool to the treatment of patients, and would lead one step closer to a personalised treatment.

The blueprints for this is already ready, and implementing the design of it would cause minor trouble. Combining this subjective input with quantified data, could give the medical staff insights, in greater and more accurate quantities, than what is currently used at the clinic. This would also be a support for the algorithm to do automatic sorting.

Progress and trend analysis for the patient To increase the patient engagement and involvement of the treatment, a progress and trend analysis should be

included in the patient app. The idea is for the patient to see how far they are in their treatment since they started, and what is the projected end time. The low fidelity possibility is to base this calculation in the difference between the start dosage, and the goal dosage. This could be updated from the nurse app, and would be highly supportive of a goal of a personalised treatment plan.

Increasing the patient engagement through trend analysis and comparison could be another tool to implement. By providing insights abouth how the patients treatment is progressing in comparison with other patients that share's the same *NYHA class, demographics, sex, age, medication type, etc.*, it could motivate the patient to follow the treatment.

Include relevant information about the medication
The patient have stated that there should be more information the medication. This includes the function & effect of the medication, and possible side effects. The nurses have mentioned that a major problem is that the patients don't take their medication. It is thus advisable to continue the work on designing the right information about the right medicine. In the first iteration there are already design blue prints, that received positive feedback from the nurse, that can be used.
The nurses have mentioned that many patient are hesitant to take the medication, as they do not know if it makes them feel better or not, since a common side effect of the medication is a worsening of symptoms.

Start partnership with other key stakeholders
Today this project have mainly been conducted "under the radar" at Herlev hospital, in the out-patient clinic at the heart clinic. There have been shown great interest in further developing the project, even for a national roll out. This means that there should be included more partners, to ensure this roll out happen. New partnerships should be build with Sundhed.dk whom have in depth knowledge about health care data management.
A partnership with a medicine school would also be beneficial, as medical and pharmaceutical insights could be provided here.
Involvement of specialist and developers of the "Sundhedsplatform" which is the new IT system for the health care sector in region Hovedstaden and Sjælland. Specialists that can work with developers on implementing the solution as a plug-in for the EPIC system (the backbone IT system).

Look into what other elements of heart failure would be interesting - The life after up-titration In chapter 3 it can be noted that there are 6 parts of being treated for chronic heart failure. The part that would be recommend to develop as the next step of this thesis would be in relation to living with heart failure. This is also known as "hear rehabilitation - phase 3"[31]. Here topics such as lifestyle changes and further information about living and managing a

chronic disease could be developed.

Build the "lifestyle" side or knowledge bank about living with heart failure

This is related to the previous topic on the life after up-titration. It could be interesting to further investigate what effect it would have, on re-admissions or set backs, if the lifestyle changes and rehabilitation program was already started, through the app, while the patient is still in the process of up-titration. Many lifestyle app's already features this, and most treatment related app's don't (they usually only contain a knowledge bank).

Chapter 10

Conclusion

This study have consisted of five iterations on a solution that could meet the KPI's stated in chapter. Each iteration have been exploring aspects related to how to implement a digital solution at the out-patient clinic, within the heart clinic at Herlev Hospital. The main focus have been to investigate and explore how to personalise the medical treatment of heart failure patients. A solution that can assist the patient and the medical staff in improving the treatment, as well as fulfilling the needs for increased sale for Apple and a cost saving procedure for society, and the Danish health care system.

The first chapters are about the motivation of the study. In these chapters the complexity of chronic heart failure is outlined. Backed by research from the European Heart Society, The American Heart Association, the New York Heart Association and the Danish Society of Cardiology, it became evident that chronic heart failure is complex syndrome with high mortality rate. It became evident that there are many causes of treating heart failure, as well as many different pharmaceutical treatments.

Based on this knowledge the main goal of this thesis was described as: "A personalised treatment of chronic heart failure patients". Many patients feel uncomfortable when being diagnosed and treated for chronic heart failure. A treatment that may last up to 8 months. Today, there are no personalised treatment that could shorten this period, or make it more comfortable.

Several Key Performance Indicators (KPI's) was listed for the main stakeholders, the patients, the nurses, the doctors, the hospital and for Apple Denmark. Each pulling the project in various directions. For this project the focus have been to investigate which KPI's could be reached, and which could not (mainly long term or grand scale KPI's)

The main focus of the first iteration was investigating how to engage and motivate the patient through lean user experience. In this iteration there was a focus on collecting data from various wearables, and what kind of insights it would provide for the nurses. The data concerned was backed up by several research papers, shedding light on how measurements can support in a medical treatment. The various measurements and hypotheses regarding which would be important, was tested at Herlev hospital. The insights was: The nurses uses a holistic evaluation to determine the state of the patients, they use NYHA classification for this. And that the main work in the out clinic is adjusting the patients to the medication. The measurements could be a support, the most important for the nurses being weight and blood samples (currently).

The second iteration focused on building a mock up of a user story map based on previous insights, to support the personal treatment plan. The app would contain several elements to motivate the patient to engage themselves in their treatment. This included how to represent analytics, trends and insights to patients and nurses. To register measurements, in this iteration weight. How to add symptoms (called mood) and to contextualise these symptoms with measurements. And relevant information (and reminders) related to the medication the patient was taking.
In parallel a small usability test of various devices was conducted by Benjamin Johansen, to see if it would be possible for a patient within normal range, would be able to use the devices, and what insights could be found from collecting data over a period of 10 days. It was concluded that most patients would be able to conduct the measurements. The user story map was translated into a prototype on paper, which was tested at Herlev hospital. The outcomes was that symptoms tracking is important. That the weight measurement also was needed. And that the correlation between blood pressure and symptoms didn't work. It was confirmed that including cause and effect information of the medication, would be relevant for the patient.
It became evident that the nurses and the patients have slightly different points of view, and needs access to different types of information to support a personalised treatment.

In the third iteration the focus was on how the nurse can be supported to personalise the treatment of the patient, and how the patient actively can be involved in this process. This iteration build on the insights related to displaying metrics to the nurse, which incorporates graphical visualisation. In this iteration it was

considered how to better include the patient self reported symptoms, in order for the nurse to adjust the treatment accordingly. A new feature was a timeline representation for the patient, that dynamically would adjust to the patient - another step towards personalising the treatment.
In order to support the nurse the focal point was on providing quick interventions based on the patient input. This combined with insights into whether a patient is ready for up-titration, supported by a NYHA classification for a holistic evaluation was tested with the nurses.
The outcomes from a usability test at Herlev hospital provided insights into what the nurses to adjust the medication of the patient, this includes primarily weight and symptoms. It would also be nice to have blood samples and blood pressure at hand. It was concluded that both the patient and the nurse benefits from contextualised information, such as symptoms and weight changes.

Iteration fourth had a focus on expanding the solution to include both the patient and the nurse side of the solution, this is a more systematic view on how the solution should be designed. The focus of this iteration moved towards a remote up-titration, contra the current "in clinic" up-titration practice. A sorting system based on the patients measurements and evaluation was included, to cater for the overall goal of this thesis.
A main outcome from this iteration is the sorting algorithm that supports the nurses in when a patient needs attention or is ready for up-titration. The sorting parameters are based on the work of Martinez, Kropf, the Danish Society of Cardiology, the New York Heart Association and the American Heart Association [28, 27, 9, 8]. The algorithm parameters can be seen on page 63. This algorithm is important for the future implementation, at it could address the KPI's related to effectiveness. It would also accommodate a personalised treatment, as it would allow the nurses to intervene if the patient seems ill, or to up-titrate when the patient seems well. This could drastically improve the medical treatment time.

The fifth and last iteration was focused on implementing the design from the previous four iterations. As the focus was on a functional prototype, some of the functionality was removed, in order to produce the prototype within a short time frame. The most important features to demo in the prototype was the combination of life data collection and visualisation from the patients, in order for the nurse to act on the data, and use it as a decision making tool. This is the minimum need to support the overall goal of a personalised treatment.
In the first iteration the focus was on building a web-based platform to represent patient insights. This webplatform is hosted at a DTU server, and have a authorisation key. In parallel an iOS app was designed to collect data from HealthKit. Both items proved successful in demoing the possibility of collecting live data.
In the second iteration an iOS app for the nurses was created. This is a trans-

lation of the web based platform. The purpose of this is to satisfy the KPI's from Apple Denmark in increasing sales.
The verification of this app has been received positively. The next steps is to include symptom tracking and implementing the sorting algorithm to have a working beta version of the outcomes of this thesis.

The first four iteration was mainly focusing on designing and scoping the app, showcased in the 5th iteration. From this it can be concluded that in an exploratory project like this a willingness to fail, often, is of high importance, to find out what is the exact needs (there are many out there). It has also proved the power and effectiveness of applying lean user experience to gather insights and data. It shows the importance of building the layer cake, layer by layer, before jumping into building a full layer cake from the start. This is an important learning point, which indicates why many big IT projects (in Denmark) fails. Hadn't it been for the access to medical staff at Herlev hospital, this project could very well have ended on the shelves.

The fifth iteration proves that with well tested design, a prototype can be build, that creates interest. It also shows the importance of moving from design to deployment to get a project airborne.

A lot of ground work have been done in this thesis. And one question remains, did a personalised treatment plan chronic heart failure emerge? All the parts of what such a solution should include have been presented, and needs to be implemented. This means that the initial goal set was not reached. Is this a failure of the project? Most likely not, it just shows that a very exciting future awaits for this project. A future where the KPI's will be materialised and fulfilled in the real world - and where you and I, hopefully can worry a little less about being a (chronic heartfailure) patient.

List of Figures

List of Tables

Appendix A

Appendix

A.1 Figures

All figures can be downlaoded here

A.2 Actual timeline of the project

- 13/08/2015 Thesis kick-off meeting with Michael Kai Petersen. Input for user journey map and initial scoping.
- 29/08/2015 First user journey map
- 27/08/2015 Thesis meeting kick-off with Jakob Eg Larsen, Michael Kai Petersen and Henrik Holm
- 01/09/2015 first meeting with Nima Zandi (Apple Denmark), Helene Klausen, Mroten Feldborg. Kick off meeting for thesis. Feedback on user journey and user story maps. Establishment of communications methods.
- 08/09/2015 First user story map

- 15/09/2015 second thesis meetings with supervisors. Feedback on user story map. From here onwards, working on implementing a first functional prototype on paper.
- 23/09/2015 - 01/10/2015 Self testing on Benjamin Johansen, weight loggin, HR logging and BP logging
- 24-29/09/2015 initial field studies done by anthropologists.
- **First interview at Herlev hospital - 01/10/2015** with Benjamin Johansen - MSc Design & Innovation DTU, Henrik Holm - MSc Digital Media Engineering DTU, Helen Clausen - MSc Tehcno-Anthropology AAU & Morten T. Feldborg - MSc Tehcno-Anthropology, Marianne Steen Andersen - charge nurse Herlev hospital &, Vibeke - head nurse at Herlev hospital.
- 10/10 updating user journey map based on input from interview
- 12/10/2015 first user test with Vibeke - next iteration!
- 26/10/2015 Second user test with Vibeke
- 02/11/2015 Apple Health Conference Copenhagen
- 13/11/2015 Meeting and follow up at Herlev hospital with Thomas Høi-Larsen, Nima Zandi, Michael Kai Petersen and Jakob Eg Larsen - presentation of "prototype" and PoP
- 30/11/2015 First prototype presented and feedback
- 07/11/2015 Request for native app prototype
- 18/12/2015 Meeting at Herlev hospital with doctors, DTU compute representative, Apple Denmark representatives and vice-director of the hospital

A.3 First meeting at Herlev Hospital 01/10/2015

Summary writen by AAU students Morten Flendsted and Helene Clausen. Second page contains questions provided by Henrik Holm, Benjamin Johansen, Morten Flendsted and Helene Clausen

Introductory Meeting at Herlev Cardiology Outpatient Clinic

Present:
Marianne Steen Andersen - Charge Nurse
Vibeke – Head Nurse
Henrik Holm - MSc Digital Media Engineering, DTU
Benjamin Johansen - MSc Design & Innovation, DTU
Morten T. Feldborg – MSc Techno-Anthropology, AAU
Helene Clausen – MSc Techno-Anthropology, AAU

The Care Trajectory for Patients with Heart Failure

Patients are often referred from the primary physician.
Patients can also be referred from the Cardiology Ward or other Wards within the hospital

For patients referred by the primary physician treatment is defined by the 'Hjertepakke'

https://www.sundhed.dk/sundhedsfaglig/praksisinformation/almen-praksis/sjaelland/patientforloeb/hjertepakker/hjertesvigt/

Initially and ultrasound scan of the patient's heart is made in order to detect the cause of his/her heart failure/symptoms.
- Often caused by reduced ejection fraction (the pumping ability of the heart)
    - For these patients this is often under 40%. Normal is about 60%

http://www.heart.org/HEARTORG/Conditions/HeartFailure/SymptomsDiagnosisofHeartFailure/Ejection-Fraction-Heart-Failure-Measurement_UCM_306339_Article.jsp

The majority of patients; 2/3 are ischemic patients 2/3. Have suffered blood cloth or treated with bypass or angioplasty

The Clinic
- The clinic is managed by nurses, but it is the responsibility of the doctor to adjust the treatment
- The clinic is run in accordance with guidelines from 'the Danish Society of Cardiology'
- The nurses are authorized to prescribe most heart medication but cannot write prescriptions

The course of treatment is very individualized:

- At the first consultation the patient most often see a doctor and nurse evaluate how far along the patient is in the up-titration, how fit he/she is and how fast the treatment might proceed
- Example of trajectory:
  A telephone consultation is scheduled one week ahead, and 2 weeks ahead
- A consultation is scheduled 3 week ahead
- Then e.g. 2 telephone consultations followed by a consultation
- In total the up-titration may take 2 months
- The treatment is concluded with an ultrasound scan of the heart in order to detect progress and a consultation with the doctor. Some patients require further diagnosing
- Usually the doctor does not see the patient again before he/she has been up-titrated unless a worsening or medical issue develop or if there is no progress in treatment due to pedagogical issues

The First Consultation

The patient visits a nurse and a doctor.
Measurements: Height, weight, BMI, EKG, blood pressure (left and right), waist measurement. The patient is required to have a blood test done prior to the consultation.
Info: The patient receives information about the cause of their referral to the clinic.
- Patients react differently to this (e.g. acceptance, anxiety)

The patient is told that heart failure requires medical treatment.

The nurse make use of a **list** for the first consultation. They describe it as a preprinted journal or macro.
- Why does the patient suffer from heart failure?
- Is the patient diagnosed with any other diseases?
- Social aspects
- Does the patient manage his/her own medication?
- KRAM factors (diet, smoking, alcohol, physical activity)
- Other drugs (non medical)
- The different measurements
- Evaluate the patients physical condition
- NYHA classification
- Chest pain
- Blood pressure
- VAS score (Visual Analogue Scale); anxiety and depression
  - The clinic cannot do anything about this except from referring to the main physician or talk to the patient. No psychological offers at the clinic

Follow up consultations (adjusting medication)

The treatment trajectory is individually adapted taking into consideration the needs of the individual patients.
Important factors are general condition and age.
The patient is offered follow up consultations with a duration of 15 min. During these the nurse assesses different parameters

- Water retention in the body. Measured by weight and physical appearance.
    - Should not exceed 4 liters
    - Indicator of the need for diuretic drugs
- Classifying the patient according to the NYHA Questionnaire (Patients' Self-Assessed Functional Status in Heart Failure)
    - The patient is asked about breathlessness during physical activity

Measurements

Ultrasound Scan
An ultrasound scan of the heart is made as the first step of treatment before the patient visits the clinic for the first consultation.
A second scan is made concluding the up-titration of medication before the patient meets the doctor for the second time.

EKG
Before starting treatment an EKG measurement is conducted
The clinic needs a baseline EKG to determine:

- Heart rhythm
- Pulse
    - Irregularities will affect blood pressure measurement which become unreliable

The measurement of heart rhythm is very important, in order to 'know it', but there is no need for continuous monitoring. This only becomes relevant in the event of symptoms occurring.

Holter and R-test are not primarily used for patients with heart failure. Could be used for these patients if they experience:

- Atrial fibrillation. Once this is diagnosed there is no need to conduct further recordings
- Extra beats. In order to measure the percentage of extra beats. If the percentage is high, it could be the cause of the patient's heart problems. Can be treated and lead to normal pump function (as one of the only heart failure conditions to be cured)

The EKG is considered a better option for e.g. patients suffering from anoxia (lack of oxygen) as it shows 12 different angles and by that assist in detecting the problematic areas.
(Further information about the different monitoring devices is given in the 1. Observation field notes)

Weight (water retention)
Measured at follow up consultation. The patient is also instructed to measure his/her weight at home. The patient is instructed to weigh him/herself every morning without clothing. A sudden weight gain of 2 kgs is an indicator of water retention and should guide the patient to take diuretic drugs. Should the patient overdose on diuretic drugs the symptoms are;
Increased urination and dizziness

- Weighing is ideally done every day
- Most important measurement as the water could infiltrate the lungs and be cause of 'drowning'.
    - Causes emergency hospitalization
- By taking the right precautions (taking diuretic drugs) hospitalization can be avoided
- The weight might be increased by 2-3 kgs over a few days. Should not exceed 4 liters
- In case of any emergency the patient should contact 1813

From a previous telemedicine project the clinic has experienced that it was applicable to get a visualization of the patient's weight over time. Provide insights to what should be focused on during the consultation

Blood pressure measurements
Advantages:

- The 'picture' would be more realistic if measurements were done several times before the hospital consultation
- Could be done more often. Compared to every 2. or 3. week at the clinic
- Would save time at the actual consultation
- *Main focus should be on symptoms*
- Value in terms of blood pressure measurements could be illustrated by a situation were the patient feels dizzy after taking his/her medication and blood pressure measurements are taken in order to determine whether the dizziness is caused by low blood pressure. In this case the medication might need to be adjusted.
    - Otherwise there is *no need for measurements several times a day*
- It may be valuable to the patient, if an app solution could provide assurance that his/her blood pressure is at a normal level.
    - This presupposes that the app is customized to accommodate the individual health data of the patient (what is 'normal' levels of blood pressure for this particular patient?)

Precautions:

- Should not be taken too often. This could cause too much focus on the disease
    - Patients often focus a lot on their blood pressure. Some buy their own devices

24 hour blood pressure

- Arm cuff and small device
- Measures blood pressure every ½ hour in the daytime and every 1 hour at night
- Provides insights about blood pressure during daily activities at home and during the night
- Used for patients suffering from dizziness where low blood pressure cannot be documented at the clinic

Pulse

- Measured with blood pressure device
- Estimate high or low pulse
- If the heart rhythm is irregular, you cannot always trust the device, which might only register 2/3 of the heartbeats. In this case the pulsation must be counted by hand. Often an EKG must be recorded in order to detect the heart rhythm
- Physical exercise: preliminary bicycle test. In this case it is relevant to measure the pulse to look at how much the pulse raises during physical effort.
- It is important information to the healthcare professionals, if the patient's pulse doesn't rise. Could be caused by too much medication.
- When medication is finally adjusted, the pulse should preferably be stable at 70-75 bpm at rest. Otherwise the patient must be given further secondary medication aimed at lowering the pulse

Circadian rhythm pulse

- Information about how well the atrial fibrillation is regulated
- How can the atrial fibrillation be monitored in a satisfying way? This would save a lot of recordings needed to be assessed at the clinic

Blood Samples

- Drawn every 3-4 week when medication is up-titrated
- Only needed for a short period of time; 2-3 moths while medication is up-titrated
- Results regarding:
    - Kidney function
    - Haemoglobin percentage
    - Potassium
    - Sodium
    - Creatinine
    - GFR (Glomerular Filtration Rate)
- Most often taken at the hospital
- Could be taken at primary physician but because of economic regulations they are only allowed to draw a limited amount of blood samples. Hence resources are prioritized

Patient's Own Records

- Symptoms. Chest pain; how often? Do they take Nitroglycerin?
- Weight

It could be relevant to obtain data about the patient's blood pressure and pulse in combination with personal recordings of symptoms

Telephone Consultation

- If patients are in doubt about their condition or medication they are able to contact the clinic during telephone hours (one hour every morning)
- They are also able to leave a message with the secretary. Patients often make use this possibility
- Patients often feel insecure about their drug intake and want to consult with the nurses before making any adjustments
- Most of patients who call in are those who have an understanding of their disease and their measurements. This entails that they have often carried out measurements beforehand e.g. weighing and call because they feel insecure about how to act and need reassurance before adjusting medication

The telephone consultation is also used during **the treatment trajectory in order to follow up and adjust medication** according to the patient's condition

- For telephone consultations the nurse does not focus on blood pressure but more on the general condition of the patient
- The nurse will ask questions such as:
    - Weight
    - Overall experience of wellbeing
    - Water retention in the legs
    - Breathlessness & dizziness (related to NYHA).
    - E.g. If the patient feels dizzy, how fare is he/she able to walk uphill or how many stairs the patient is able to climb
    - Is the patient prevented from doing any activities of a daily living that they are used to do (e.g. because of shortness of breath)?

Some patients might call in regarding sudden weight gain and shortness of breath (water retention). In such cases the nurse might instruct the patient to take diuretic drugs and call again after 3 days should the symptoms not have decreased.

The Medical Treatment

- Patients receive up to 5 different kinds of medication
- The drug dose must be gradually increased in order limit the adverse effects of the drugs
- It is not possible to cure the condition, as this is a chronic possibly life threatening illness. In this regard the medical treatment addresses the symptoms and prevents hospitalizations
- The medical treatment is lifelong
- Medication is taken 1-2 x daily

For a person with a normally functioning heart, drugs that e.g. lower the blood pressure is tolerated much better than is the case for an elderly with a heart condition

- This affects how fast the medication can be increased to achieve the full effect
- The dose is adjusted according to symptoms and measurements
- By gradually increasing the dose, more patients are able to reach the maximum dose without experiencing to many adverse effects. Not all patients get the maximum dose
- The medication could affect the kidneys

Barriers in Medical Treatment

Most patients want to take as little medication as possible. The nurses often experience barriers in connection to increased drug intake. Patients seem to relate increased drug doses to being sicker, which actually is not the case. Also many patients think that symptoms such as dizziness and nausea are due to adverse effects of the medical treatment, when actually these are caused by their heart condition itself.

The healthcare professionals at the clinic are aware that some patients do not take their medication as prescribed, which definitely is a problem

- It is considered as valuable information to the staff, whether or not the patient has taken the medication
- The interviewees suggest that the pillbox register if pills have been removed

Patients not taking their medications as prescribed has several causes;

- Some patients forget to take their medication (e.g. patients suffering from dementia)
- Some mentally well-functioning patients do not acknowledge their disease and/or understand the need for medical treatment
- Could also be caused by communication difficulties. Do the nurses succeed in explaining the situation?
- Some medication result in a period where the patient feels worse

- Common skepticism regarding drugs (poison)
- Look at the adverse effects described in the patient information leaflet
- Stories about other patients “mishandling”
- Some patients think they are part of an experiment because the dose is gradually increased

(Solution: Look at: Possible Features)

- As a general trend the approach to treatment should be discussed amongst the doctor and patient. This however is not of particular relevance to this group of patients as they follow the ‘Hjertepakke’ which is a standardized care trajectory
- It is the case though that the healthcare professionals and the patient must arrive at a common understanding. The patient must be made aware that the medication is essential to their treatment and progress

Personal Assessment of Physical Exertion/The NYHA Questionnaire

A need to adjust treatment or how well the patient tolerates the treatment does not necessarily show in their measured health data.
Adjustment of treatment should be assisted by the patient’s subjective experience of his/her condition.

- In relation to this the nurse makes use of the NYHA Questionnaire
- The questionnaire is used at every consultation

For the patients to assess their experience of exertion through an app solution, they could make use of the ‘Borg Scale’. A the moment the clinic only use the Borg Scale for the bicycle test.

Questions asked:

- Shortness of breath
- Ability to climb stairs. How many stairs?
- Are you able to walk up a hill? With wind in the face?
- Fatigue. Patients feel extremely tires (fatigue/trætbarhed). (Typical symptom that most patients experience. Not caused by the medication but by the disease)

Following the patient is categorized in NYHA 1-4

Monitoring Physical Activity. Motivation

- The interviewees do not offhand identify a need to record physiological parameters (Pulse, heart rhythm) during the patient's daily physical activities
- Knowledge about physical performance could have a motivational effect. The patients benefit from physical activities and some patients like to keep track of their efforts
- Improved physical capacity does not effect the need for medication
- Effects of physical activity include: better pump function of the heart which results in decreased breathlessness during physical exertion
- Asking the patient from time to time about their physical wellbeing in relation to physical activities measured by the device could provide valuable insights (Also see previous Telemedicine Projects)
- Could be attractive to visualize the development in physical capacity over time

Effect of the Psychological Aspect

First consultation
- VAS score (visual analogue scale); anxiety and depression
  - The clinic cannot do anything about this except from referring to the main physician or talk to the patient. No psychological offers at the clinic
- The psychological aspect reduces 'compliance'
- Greater risk that the patient doesn't take medication
- Higher mortality (may be caused by not taking medication)

'Heart Education': how to tackle life with chronic illness

Two categories of patients:
- Positive outlook despite being very ill
- Nervous very fearful of what might come
  - Pattern of reaction is not caused as much by the illness as by disposition
    - Antonowsky: Sense of Coherence (often referred to within healthcare)

- The healthcare professionals try not to ask too many questions about the patient's psychological condition as the situation might develop and cannot be handled due to current resources and the timeframe of the consultation
- For shorter consultations the healthcare professionals try to address the kinds of information they need in order to treat the patient's medical condition. The interviewees reflect that this might be wrong, as all aspects of the bio-psychological-social situation of the patient ideally should be taken into consideration

Possible Features

Some patients might become reassured about their physical state by receiving feedback from the technological solution about their state of health in situations where they experience symptoms or feel insecure about the medication.

- E.g. Immediate consultation based on measurements made by the devices
- The interviewees estimate that this would require personal contact. A need identified with both staff and patients. E.g. video function
- The interviewees identify that new events of symptoms would cause the patient to insist on personal contact

- The app might supply generic information about e.g. beta-blockers, however a lot of other factors are at play.

It could be **valuable with a function that mediates the contact between patient and clinic.**

- At the moment the clinic receives a lot of calls from patients requesting to be contacted by the clinic regarding symptoms or adverse effects. The secretary handles this information.
- The interviewees envisions that this communication could be handled easier through a new technological solution

Patients registering physical discomfort might also result in the clinic contacting the patient.

- A possible function of the technology could be: A patient registering discomfort. Staff is notified. Staff checks measured current health data. Staff e.g. clarifies the situation as OK by pressing a green button. Patient is notified that everything is OK. *Alternative*: the patient is contacted due to irregularities
- This solution would require the patient to perform the relevant measurements in advance

It is important that a solution doesn't add to the amount of time spend registering. Some patients would ideally prefer to get daily feedback, however this does not appear to be a likely solution due to restricted resources.

Blood samples drawn at the patient's home

It is a nuisance to a lot patients that blood samples must be drawn prior to consultation

- This means that the patient must go to the hospital twice in a short time
- Expensive if patients need to be picked up
- At the moment blood samples are sometimes drawn after consultation in order to avoid double visits. In this case the medication is adjusted and further adjustments must be made after the results of the blood sample are in.
- At the moment blood samples drawn at home are very expensive as the community nurse must do this

Previous Telemedicine Projects at the Clinic

- The patient used computer and weight at home
- The patient made notes about his/her physical condition in order to keep track of progress
- Data from blood samples was translated into a curve to be used for the consultation
- The patient provided data about weight, which was translated directly into a graphic curve for the nurse to view before the consultation. This provided insights to what should be focused on during the consultation
- Used tele-consultations
- A lot of the patients were happy about this
- Resulted in the patients receiving almost better treatment because of the attention they were given. They were in closer contact with the clinic
- The staff had no difficulties up-titrating the dose. This could be done every week or every 14 days in contrary to patients who had to wait 5 week before a consultation was available in the physical clinic. In this case the patients became well treated faster
- Required more resources from the clinic because of the current systems, which required 3-5 systems to be active during a tele-consultation
    - Consequently this type of consultations requires that the technical solution work satisfactory. The systems must be connected
- The configuration of the project required the nurses to make records in both the project system and the journal and other systems
- The devices used could only be installed at the patient's home. Especially younger people who go to work could have benefited from a technological solution. But this was not possible in this case

An App has been developed at the ward to be used by community nurses

Advantages of a Technological Solution

If everything worked at the same time (was integrated) the interviewees estimate that the clinic could complete 4 consultations rather than 2 per hour

- The clinic would save time on measuring weight and blood pressure and accompanying the patient from and to the consultation room
- The talk may become more focused
- More resources could be addressed at talking about the wellbeing of the patient if measurements were done beforehand and the clinic was provided with information about whether or not the patient had taken his/her medication

Medication

If it would be possible to weigh or measure whether or not the patient had taken his/her medication. Knowledge about this kind of inspection of medication could function as:

- A motivational factor
- The patient to be more open about the subject. Whether or not medication was taken

The ability to monitor drug intake is perceived as a very interesting possible aspect of a future solution.

- Possible ethical aspects. Considerations about how this monitoring is presented to the patient are important, as surveillance is a controversial subject. Information about studies showing the importance of monitoring drug intake could be presented to the patient
- According to the interviewees the patients must accept this as a natural part of the treatment
- In this regard medical treatment is an option and no one is treated against their own will

A mobile solution would accommodate younger people going to work

- It is perceived as problematic to take time off in order to visit the clinic. (People employed within the public sector are almost unable to follow the course of treatment)

A possible user group could be very ill patients. The data in this case would be obtained by the home care provider or community nurse.

Blood samples drawn at home
The ability to drawn blood samples at home at a low cost would save money and patients' double visits to the clinic

Challenges Regarding Technological Solutions

Patients who experience difficulties with measuring physical parameters might be:

- Post apoplexy
- Blind

For people who are deaf or people with foreign backgrounds that do not speak Danish. Some kind of translation must be provided.

It is not as easy to observe the patient
Patients are observed when walking from the waiting area:

- Shortness of breath
- Facial coloration
- Dizziness

Would require adaptation to do this in different ways through the technology

Patient Requests for Technology

- No direct requests
- 2 groups of people:

- Some want to meet at the clinic as often as possible
- Some feel more sick from meeting at the hospital and want to be as independent as possible

- There is no particular pattern in terms of age or gender

E-mail

- A lot of patients ask about the possibility of using e-mail
- The staff does not have personal e-mail accounts

The Possibility to Access own Data through the Website

- Most patients probably do not make use of this possibility
- The interviewee has not been informing the patients about the possibility

Spørgsmål til intro på Herlev Kardiologisk Ambulatorium SA53S1

IMPORTANT practical questions:
1. Can we get access to patients?

2. When is it possible to do the test? With medical staff and if possible with patients

Spørgsmål til Herlev fra Henrik og Benjamin (DTU)

- Forventningsafstemning
    - Hvad forventer i at vores løsning/app kan/vil bidrage med?
        - Goals? → hvor vil I gerne se projektet ende?
- User Journey Map
    - Afklaring af nuværende user journey map
        - Kigger vi både på Hjertesvigtsklinikken og Hjerterehabilitering?
        - Henvist lægen (3 veje ind)
            - Hvilke målinger er det præcis i måler ved:
        - 1 konsultation
        - Efterfølgende konsultationer (hvor mange?)
        - Afhænger af person til person?
- Konsultationer generelt
    - Hvad måler i på?
        - Hvad basere i det videre forhandlingsforløb på baggrund af?
            - Hvilke data/information vil i gerne have opsamlet?
            - Hvilke data/information er mest vigtige at opsamle?
            - Hvad kigger i på i data'en? (Hvad er interessant?)
                - Blodtryksmålinger (Udsving, afstand mellem systo- og diastoliske?)
                - Puls
                - Vægt (Væskeophobning?)
                - EKG?
                - Ekko?
                - Medicinindtag
                - Måske sammenhængen af alt ovenstående?
    - Hvad er det for nogle helbredsproblemer patienterne kommer tilbage efter den opfølgende konsultation/endt forløb?
        - Hvilke hjemme devices kunne hjælpe med dette?
    - Hvilke information kunne være interessant at opsamle?

        - Devices
        - Medicinindtag
        - Bivirkninger
        - New York Heart Association
            - Hvornår bliver denne klassificering lavet?
            - Og hvordan måler i den?
                - Spørgeskema?
    - Hvilke ting er vigtigst i forhold til hele patientforløbet for jer/patienten?
        - At der bliver doneret den rette medicin hurtigst muligt?
        - At der kontinuerligt bliver opsamlet data fra patienten?
            - Hurtigere kunne reagere ved væskeophobning - så de ikke skal indlægges igen i mange dage?
        - At man ved om patienten har taget sin medicin
            - Rette mængde og på rette tidspunkt
        - Noget helt tredje, fjerde eller n'te?
    - Hvor tit skal data opsamles?
        - Blodtryk - 2 gange om dagen?
            - 2 timer efter patient har taget medicin?
                - Afhænger af medicin?
        - Puls?
            - Hver 10 minut? En gang i timen?
            - Mere når patient er aktiv?
            - Korreleret med når patienten er aktive (for eksempel efter gang eller cykling)
        - Vægt - 1 gang om dagen?
            - Morgenen efter at have urineret? Eller om aftenen?
            - Væskeophobning
                - Kan de godt have hjertesvigt selvom de ikke har væskeophobning i kroppen?
        - Iltindhold i blodet?
            - Er det vigtigt at måle for hjertepatienter?
    - Skal medicin tages i forhold til devices målinger?
        - Hvad er mest optimalt?
- Medicinering
    - Lad os antage at patienten tager medicin 4 gange om dagen på bestemt tidspunkter
            - Ville det hjælpe hvis i kunne se om patienten har taget sin medicin?
        - Patienten kan give tegn på hvordan han har det
            - Er det værdifuldt for jer at vide det?

                - Hvilken slags indsigter kan det give jer, når dette selv-rapporteret humør og biometri, såsom hjertefrekvens og blodtryk er kombineret
            - Hvordan vil patienten reagere til disse ekstra målinger?
                - Kan vi motivere dem til at lave de ekstra målinger?
            - Ville det give mening at spørger patienten hvordan de har det efter:
                - Gået op af trapper
                - Rask gåtur
                - normal gåtur
                    - Både Indendørs og Udendørs
                - Cykling
                - Stillesiddende / stationær
                - Andre anstrengende aktiviteter (såsom løb)
            - Ved i om patienten tager medicinen i har givet dem?
                - På det rigtige tidspunkt og i rette mængder?
                - Hvis nej, kunne dette så være interessant at vide?
                    - Mht. justering af medicin for at finde den rette dosis og evt. anden medicin der er bedre?
                        - Kan tage op til 6 måneder at finde optimal medicinering
    - Rehabiliteringsforløb
        - Kunne data også her give jer indsigt i hvordan det går med patienten og om han rent faktisk følger det program i har givet personen?
- Kunne man forestille at indsamlet data via. devices, bivirkninger etc. kunne hjælpe med at justere/dosere den rette medicin/mængde medicin?
    - Og derved minimere det gennemsnitlige forløb for en patient?
- Baseret på field test af Helene og Morten
    - I laver manuelt analyse af R-test (15 min) og Holter monitor (1,5 time) nu
        - Kan det ikke automatiseres?
    - Data
        - Skrammel data
        - I er bange for at der kan blive generet for meget data
            - Tager længere tid at analyse og måske ikke brugbart

Svar fra spørgsmål (Henrik og Benjamin)

- 1 samtale (1 time)
    - blodtryk
        - højre venstre arm
    - EKG
    - Vægt
    - Højde
    - BMI
    - tajle mål

- Blodprøver taget på forhånd
- Behandles meidcins
  - 2-3 præpater
  - nogle gange 5 præpater
  - Længere forløb 6 måneder
  - Langtsomt optrapning
  - Ikke kurere, men hjælpe så de lever længere
  - Livsvarende medicin
  - Medicins trappes op hver uge/naden uge
    - Andre 6-8 uger
  - Kontrol:
    - Puls
    - Blodtryk
    - Vægt
    - Kan patitenen ligge ned
    - Strammer bukser (væsken i kroppen)
  - De fleste patitener kan godt selv tage vægten derhjemme
    - Forsigtig med at tage medicin mod væskeophobning (Vanddrivende)
  - Medicin
    - gradvist optrapning
      - patitenter skal vente sig til
    - medicin baseret på symptoner og målinger
      - subjectivt for patienten
    - 3 gange dagligt
      - morgen og aften
  - NYHA
    - journal / spørgerskema
    - Klassificeres ved hvert besøg
    - iskæmiske patientier
      - ⅔ af hjertesvigts patienter
  - angst/dpression patient
    - nedsætter medicin compliance
  - Patienter meget forskellige
  - Selvmåle blodtryk derhjemme
    - mere realistik blodtryk
  - Vægten hverdag
    - væskeophobning

            - 2-3 kg
                - vanddrivende medicin
        - Telefon konsultationer
            - vægt
            - hvordan de har det
                - svimmel
                - forpuste
                    - hvordan kan du gå
                    - etager gå op
                - Bliver du begrænset i hverdagen?
        - Hjerterytmer
            - Vigtig
        - Aktivitet
            - Skal øge puls/blodtryk
        - Puls
            - gennemsnitlig puls over hele dagen
        - Symptomer
            - træthed
            - forpuste
            - åndenød
            - fatigue
        - Målgruppe
            - folk der arbejder
- Blodprøve derhjemme
    - Nyretal
    - Blodtal
        - hæmoglobin
    - Kan ikke måles ved telemedicin
        - skal ud til hospitalet
    -

Spørgsmål til Herlev fra Helene og Morten (AAU)

Nuværende praksis/Feltet

- Hvor meget tid afsættes på nuværende tidspunkt ift. patientinformation/instruktion?
- Hvor lang en periode indsamles patientens sundhedsdata over på nuværende tidspunkt?
- Hvilken betydning har den indsamlede data for patientens behandlingsforløb?
- Hvem står for feedback, handlingsplaner m.v. ift. patienterne?

- Hvor ofte rapporterer patienten data til hospitalet på nuværende tidspunkt?
    - Hvordan foregår dette rent praktisk lige nu?
- Hvor ofte er patienten i kontakt med hospitalet. Er denne kontakt altid fysisk?
    - Hvis ikke hvordan foregår kontakten da? fx e-mail, telefonisk kontakt, mv?
    - Hvem håndterer denne kontakt?
    - Hvad er årsagen til patientens kontakt?
- Være OBS på hvad der sker på hjertesvigtsklinikken (hvis ingeniørerne ikke har formidlet svaret på det)

Feltet

- Oplever I efterspørgsel fra patienterne ang. alternative (evt. mobile) løsninger til den nuværende tilgang? Hvis ja, er det muligt at tegne en særlig profil på patienter, der efterspørger disse løsninger, eller er det en demografisk bred gruppe?
- Oplever I efterspørgsel på udredning af patienter på baggrund af data genereret ved selvinitieret selvmonitorering?
- Oplever I efterspørgsel blandt personalet på nye monitoreringsløsninger?

Tidligere erfaringer

- Har I tidligere erfaringer med implementering af lignende teknologiske løsninger på afdelingen?

Forventninger fra afdelingens side

- Hvor ofte forventer I, at data vil blive rapporteret med en ny løsning?
- Forestiller I jer, at en ny løsning vil ændre på de tidsmæssige ressourcer der bruges på den enkelte patient (mere eller mindre tid)?
- Hvilke patientkategorier ift. hjertesygdomme forventer I, at en velfærdsteknologisk løsning kan henvende sig til?
- Er der andre patientkategorier fx ift. aldersgrupper, sociale grupper o.lign. som I forventer vil have særligt glæde af den en velfærdsteknologisk løsning end andre?
- Forestiller I jer at konfigurationen/mulighederne ift en velfærdsteknologisk løsning vil have betydning for modtagelsen på afdelingen og/eller blandt andre aktører?
    - Vil der fx blive lagt særlig vægt på, at den i forhold til nuværende praksis er; tidsbesparende, omkostningseffektiv, giver større patienttilfredshed, tilfører nye elementer til behandlingen fx større tilgængelighed til sundhedsfremme blandt patienter eller andet.
        - Er nogle af disse elementer vigtigere end andre?
        - Ser I en forskel på, hvad der vil tilføre størst værdi for patienter og personale?
- Hvordan vægtes tilfredsheden blandt patienter og personale og evt. økonomiske interesser?
- Hvordan ser i en ny løsning med mere monitorering hos patienterne spille sammen med jer som hospitalsafdeling? Hvad skal sådan et samspil indeholde?
- Forestiller I jer, at en ny velfærdsteknologisk løsning vil tilføre yderligere information og/eller yderligere kvalitet i data (fx i antallet af observationer af irregulær

hjerterytme), at informationen vil være den samme, men mere effektiv og/eller omkostningseffektiv.

-

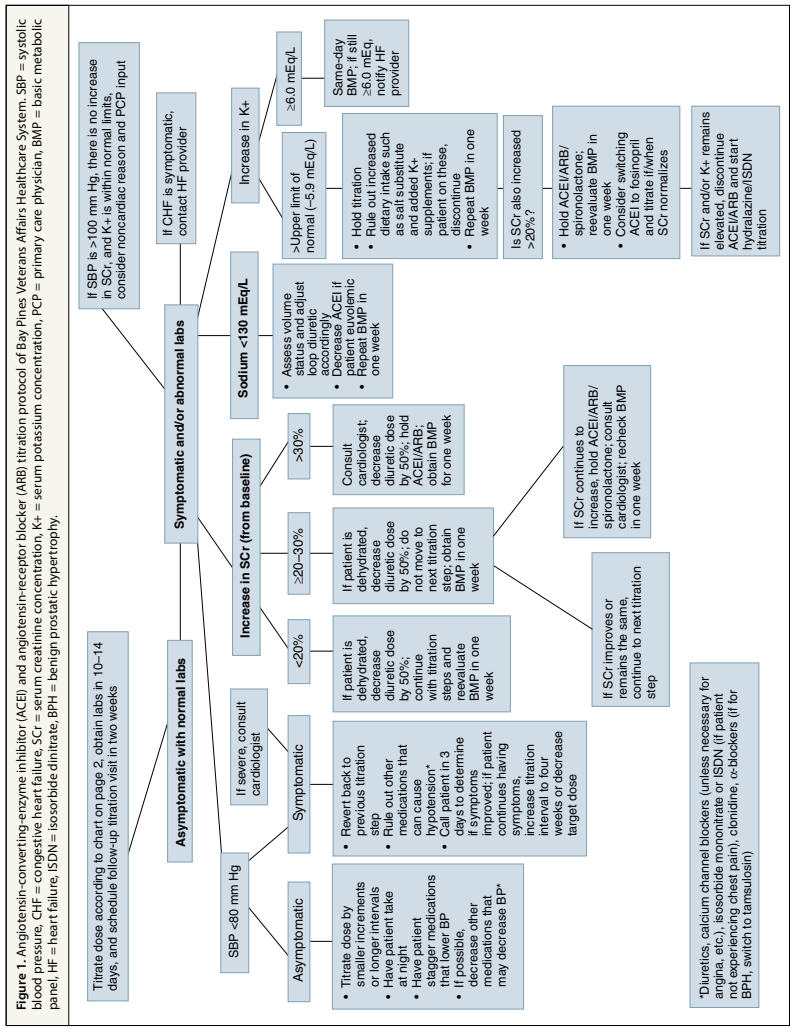


Figure 1. Angiotensin-converting-enzyme inhibitor (ACEI) and angiotensin-receptor blocker (ARB) titration protocol of Bay Pines Veterans Affairs Healthcare System. SBP = systolic blood pressure, CHF = congestive heart failure, SCr = serum creatinine concentration, K+ = serum potassium concentration, PCP = primary care physician, BMP = basic metabolic panel, HF = heart failure, ISDN = isosorbide dinitrate, BPH = benign prostatic hypertrophy.

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