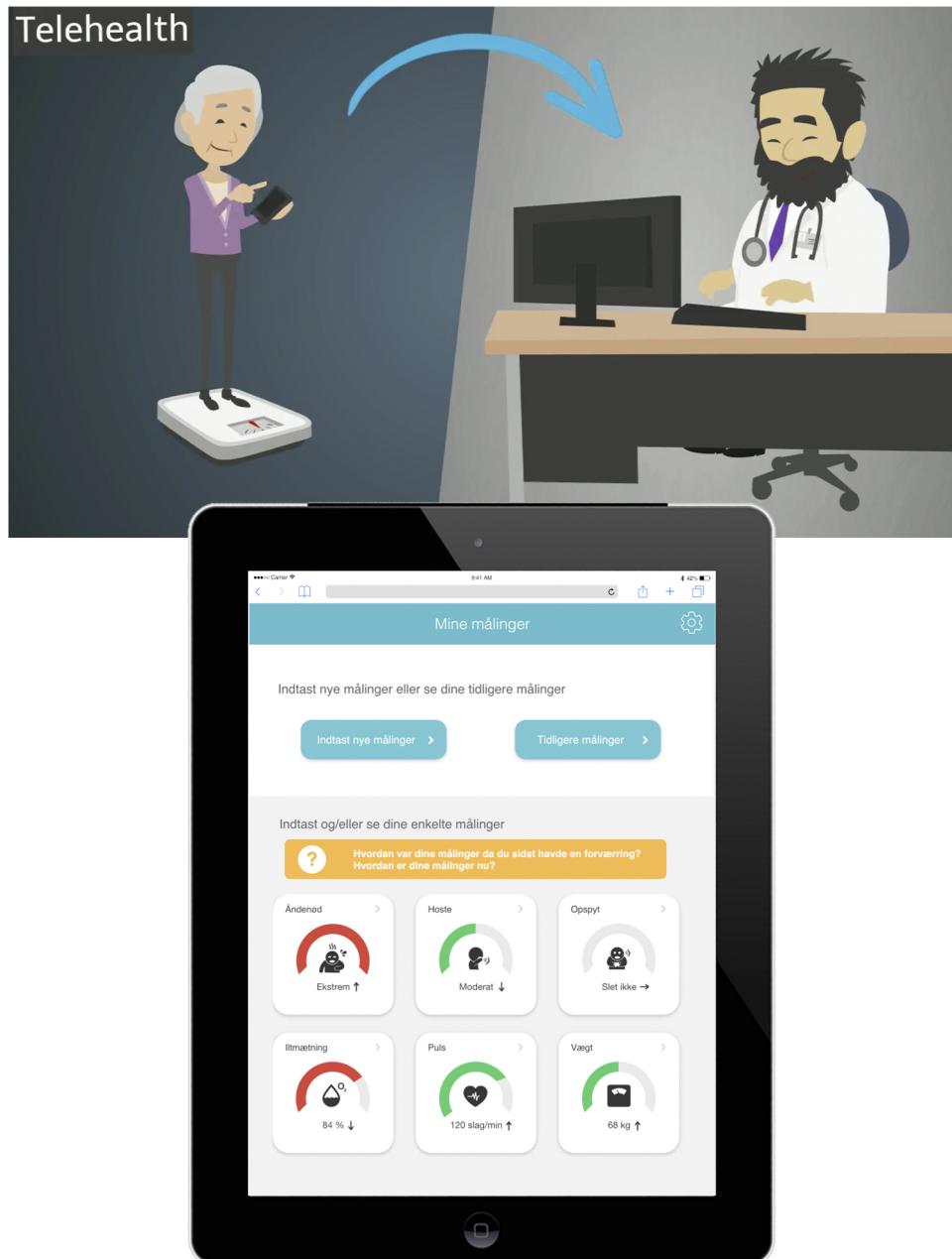




AALBORG UNIVERSITY  
DENMARK

# Designing for Reflection in Telehealth

Chronic Obstructive Pulmonary Disease Patients as Self-trackers



10th Semester, Medialogy, 2016  
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## Preface

The following portfolio was developed during Spring 2016 on the tenth semester of Medialogy at Aalborg University. The project is a specialisation in Interaction and will therefore have its main focus on understanding and analysing elements in human centred interaction, using relevant methods to design solutions and implementing an interactive system based on a design solution.

### Reading Guide

In the portfolio, all the source references are gathered in the *Bibliography* chapter, listed using the Harvard system of referencing. In the body text, a source is cited as [Surname, Year of publication]. The full details of the given source can be found in the reference chapter with the following information: *Author, title and publisher*. Web pages are referenced with: *Author, title and data*.

Figures and tables are numbered in accordance with chapter number. For instance, the first figure in Chapter 4 has the number 4.1., the second figure has the number 4.2., etc. Each figure and table is referred to in the body text and given an explanatory text in addition to the numbering. Abbreviations are introduced in their extended form the first time they appear. Enclosed with this portfolio is a CD containing the paper, portfolio, audio visual production (documenting the project) and other extra materials.

### Thanks

Thanks are given to Center for Telemedicin and head of the center Britta Ravn for entering in this project. Thanks to Silkeborg Sygehus and Consultant Frank Andersen, COPD-nurse Sanne Børgesen and Nurse Trine Juul Volshøj for professional discussion and making the final evaluation possible by lending us needed equipment. We would also like to thank all patients involved in this project for their big contribution in field studies, design sessions and interviews. Finally, we thank our supervisor Hendrik Knoche for continuously good feedback and professional discussion.



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## Motivation

In recent years, the proportion of chronically ill patients has increased in accordance with an expanding elderly population [WHO et al. 2011]. By 2030 the World Health Organization (WHO) has predicted that Chronic Obstructive Pulmonary Disease (COPD) will affect over 64 million people and will be the third leading cause of death worldwide [WHO 2008]. COPD is a progressive lung disease in which the airways are damaged and with COPD comes periods of exacerbations. Exacerbations are defined as "*a sustained worsening of the patient's condition, from the stable state and beyond normal day-to-day variations, that is acute in onset and necessitates a change in regular medication in a patient with underlying COPD*" [Rodriguez-Roisin 2000], where the worsening of the patient's condition refers to a worsening in symptoms or lung function. Patients with COPD experience symptoms, such as shortness of breath (known as dyspnea), phlegm, cough, wheezing and chest tightness [Kessler et al. 2011]. Research has shown that delayed treatment following the onset of an exacerbation results in increased use of healthcare services, readmission to the hospital and a decline in health-related quality of life [Rodriguez-Roisin 2000]. Early detection and treatment of exacerbations are therefore an important step towards preventing decline in patients' quality of life and healthcare utilisation.



CHAPTER **3**

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## **The COPD-patient**



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# Telehealth for COPD

Telehealth (support of health care using electronic information and communication technologies when patient and provider are in a separate location [6]) can play an important role in early detection and treatment of exacerbations. In spite of the interest telehealth interventions have gained, studies have produced conflicting results regarding the effectiveness of telehealth interventions [7]. One of the factors that may be linked to the cause of telehealth interventions failing to detect exacerbations early, can be addressed to difficulties assessing symptoms through self-report.

Previous studies support this finding and further report that binary self-report measures are not always intuitive for patients, who are constantly symptomatic [9]. Since physical symptoms are influenced by psychological and individual processes [8], self-reported binary measures might be biased and further not capture the relevant features necessary for clinical decision making.

## 4.1 Current Literature

The telehealth systems that we have looked at do actually not use validated questionnaires for detection of exacerbation.

## 4.2 State of the Art

hjkh

## 4.3 Interviews with Healthcare Professionals



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# Personal Informatics

In Personal Informatics people collect different kinds of personal data voluntarily for the purpose of self-reflection and gaining knowledge about themselves Li et al. [2010]. Personal Informatics have identified various aspects of self-tracking activities Li et al. [2010] and since self-tracking is a common denominator to the fields of both telehealth and Personal Informatics we (in the absence of technology knowledge in telehealth) use the literature of Personal Informatics as an analytical lens for the field of telehealth. We analyse the literature of Personal Informatics for different drivers for self-tracking, how people track and the barriers that typically arise in self-tracking activities. We distinguish between self-tracking that is initiated by oneself (henceforth referred to as discretionary tracking) and self-tracking initiated by a healthcare provider (henceforth referred to as prescribed tracking). While discretionary trackers take up self-tracking voluntarily, prescribed trackers are either recommended or required to track by a healthcare provider (i.e. a physician or a nurse), e.g. for a specific treatment, for long-term performance or approval for surgery. Common to both discretionary and prescribed self-trackers is that they collect data related to their health and well-being [Choe et al. 2014, MacLeod et al. 2013, Chung et al. 2016].

## 5.1 Why People Track

From the literature, we classified main motivations for self-tracking into five categories.

**Documentation:** Some discretionary trackers are mainly interested in documenting their activities, rather than changing them [Rooksby et al. 2014]. Self-tracking not for one's own purpose, but partly or largely to create records for the healthcare providers was a reason for imposed self-tracking in [Ancker et al. 2015].

**Life Experience** People tracking for life experience are mainly discretionary trackers who track out of natural curiosity about what their data might reveal about themselves [Li et al. 2010, Epstein et al. 2015] or because of an interest in quantitative data [Li et al. 2010, Rooksby et al. 2014]. Others aim to discover new tools or because of an interest in gadgets and technology [Li et al. 2010, Rooksby et al. 2014].

**Communication** Discretionary trackers tracking for documentation also used the data as a way of underscoring their effort through sharing, e.g. using a pedometer to convince a

friend that they walked a lot [Rooksby et al. 2014]. Others used it for direct social benefits (for practical reasons e.g. informing others about their location, for social engagement, etc. [Epstein et al. 2015]) and in response to gamification incentives, such as to score points or achievements [Rooksby et al. 2014]. Some self-trackers with a health-related condition use tracking to seek recognition from their healthcare provider. They also use it as evidence when they find empathy of healthcare providers lacking, or in order to show a complete picture of their life, when they do not find measurements taken in the clinic sufficient [Chung et al. 2016]. Some hope that self-tracking can help communicate their condition to family members [MacLeod et al. 2013].

**Self-Knowledge** Self-trackers in this category track to get a sense of the current state of their condition [MacLeod et al. 2013, Ancker et al. 2015]. Some are motivated to track in order to identify potential links between different factors, e.g. tracking medication and diet to identify what caused stomach problems [Rooksby et al. 2014]. They also self-track in order to learn what to add in their lives, in order to prevent undesirable health-related episodes (e.g. initiating medication to prevent a worsening of condition) or what to remove in order to reduce impact of such episodes (e.g. stop smoking to reduce symptom severity) [MacLeod et al. 2013]. These motives indicate that this type of self-trackers are also partially motivated to self-improve.

**Self-Improvement** Common to these self-trackers is a desire to change or maintain a behaviour in order to improve their well-being or lifestyle [MacLeod et al. 2013, Ancker et al. 2015, Chung et al. 2016, Li et al. 2011, Whooley et al. 2014]. Self-trackers in this category are goal-driven (e.g. have the goals "avoid drinking coffee X hours before sleeping" or "run three times a week") and regulate their progress towards their goal [Chung et al. 2016, Rooksby et al. 2014, Li et al. 2011]. MacLeod et al. found that prescribed self-trackers were motivated due to the resulting self-efficacy and sense of agency. Tracking made them feel they were helping managing their condition and empowered to take control of their own health. Despite being initiated to self-track by their provider, a majority of the self-trackers were motivated to continue self-tracking even after their provider did not require it anymore [MacLeod et al. 2013].

## 5.2 How People Track

Researchers have proposed different models for understanding, how self-trackers concretely use personal informatics systems over time. Li et al. proposed a five-staged model describing, how self-trackers transition between these stages: (1) *preparation* (user determines what and how to track data), (2) *collection* (user tracks data), (3) *integration* (user prepares data for reflection), (4) *reflection* (user explores data to gain self-knowledge) and (5) *action* (user decides what to do with newfound self-knowledge) [Li et al. 2010]. The *reflection* stage can further be divided into *maintenance* and *discovery* [Li et al. 2011]. Opposed to the *maintenance* phase, self-trackers in the *discovery* phase do either not know their goal and/or have not identified important factors yet to determine appropriate actions [Li et al. 2011].

Epstein et al. divided the *preparation* stage into *deciding* and *selecting*. Self-trackers first decide to track and then select a tool to support their self-tracking efforts [Epstein et al. 2015]. Li et al. describe the five-staged model as linear [Li et al. 2010], whereas Epstein et al. further

describe *tracking* and *acting* as ongoing processes of collecting, integrating and reflecting. Epstein et al. do not separate collecting, integrating and reflecting into stages as these activities can and do occur simultaneously [Epstein et al. 2015, MacLeod et al. 2013]. Epstein et al.'s model was developed using almost the same methods as Li et al. though (according to the authors) conducted on a more general population (recruited from an online crowdsourcing marketplace) [Epstein et al. 2015]. The *integration* stage can be more or less apparent to the self-tracker depending on type of personal informatics system. Both Whooley et al. and Li et al. write about two types; system-driven and user-driven. In a user-driven personal informatics system the self-tracker is responsible for the activities involved (e.g. aggregating and analysing data) in contrast to system-driven personal informatics system where the system is responsible of the activities, thus requiring less effort of the self-tracker [Whooley et al. 2014, Li et al. 2010]. Epstein et al. further included stages of *lapsing* and *resuming* into their model, accounting for users sometimes stopping to track for either longer or shorter periods (for instance because of forgetting to track and skipping maybe already known data) and the opportunity of resuming tracking later [Epstein et al. 2015]. The nature of lapsing and resuming during self-tracking was also confirmed by [Rooksby et al. 2014].

We use Epstein et al.'s model as a lens to discuss our own findings on user needs and concerns in the following section.

### 5.2.1 Deciding and Selecting

**Preparation** In the *preparation* stage, people decide what to track and how they want to track. One common problem people experience is not always knowing what to track or what questions to ask [Li et al. 2011, Choe et al. 2014, Chung et al. 2015, Patel et al. 2012]. Discretionary trackers might not have identified what goals they are trying to meet and/or might not have identified what factors influence their behaviour (*discovery* phase). This means that after an initial phase of tracking, they might have to redefine what to track and what questions to ask [Choe et al. 2014]. This mirrors Li et al.'s findings on self-trackers tending to transition between the *maintenance* and *discovery* phase [Li et al. 2011].

Prescribed trackers experience that healthcare providers recommend symptom tracking, but sometimes give little support on what to track and how to track (e.g. frequency of tracking) [Patel et al. 2012]. Some health conditions involve many symptoms that sometimes arise unexpectedly. Patel et al. found that patients who experienced symptoms that providers had not suggested tracking, had to figure out themselves, whether these symptoms were important and if additional tracking was needed [Patel et al. 2012]. Tracking the wrong data or not tracking well enough to gain benefits can according to healthcare providers lead to loss of motivation to keep tracking [Chung et al. 2015].

Both Patel et al. and Chung et al. found that tools recommended for self-tracking by healthcare providers did not always meet the needs of the self-trackers e.g. tracking symptoms self-trackers want to track [Patel et al. 2012, Chung et al. 2016]. As a result, self-trackers found other tools or designed their own tracking systems, such as notebooks, health diaries and specific applications. If these tools did not support collaborative review or other requirements from the healthcare provider, it sometimes created tension between patients and providers later in the *reflection* stage [Chung et al. 2016].

## 5.2.2 Tracking and Acting

**Collection:** In the *collection* stage self-trackers collect data about themselves.

Even though self-trackers do not know how to track well or accurately enough [Chung et al. 2015, Patel et al. 2012], they develop their own systems for tracking. Prescribed trackers are only offered little support from health care providers, but do not know how to improve their systems. The self-developed systems are often cumbersome and incomplete and prescribed trackers who choose to track a breadth of health issues pose a significantly challenge on themselves [Patel et al. 2012]. Self-tracking too many things can lead to tracking fatigue [Choe et al. 2014].

Rooksby et al. questioned that people could or always wanted to do rational data collection [Rooksby et al. 2014], which leads to measures with low reliability. Self-trackers skipped tracking when data entries were too long or when data was known beforehand they did not always see the benefit of tracking it [Epstein et al. 2015]. Self-trackers might also simply forget to track [Li et al. 2010].

Prescribed self-trackers found tracking time consuming and requiring effort [Ancker et al. 2015] hampering incorporation of tracking into daily routines [Verdezoto & Grönvall 2015, Ancker et al. 2015]. Self-trackers do not want to spend too much time on entering data [Li et al. 2010]. This not only due to act of entering data but includes preparation to do so. For example, resting a number of minutes before taking blood pressure measures increased time and effort [Verdezoto & Grönvall 2015]. Incorporation difficulties lead to skipped primary tracking and secondary data, e.g. whether guidelines had been followed by smoking before taking a blood pressure reading. This reduced reliability and difficulties in data interpretation [Verdezoto & Grönvall 2015]. Among prescribed self-trackers, measurements were found not to be clinically useful because of insufficient frequency and detail in tracking [Chung et al. 2015].

Some subjective measurements also affect the reliability of the data. For instance, when a self-tracker subjectively quantifies expended calories when lifting weights or when self-trackers are required to subjectively assess without any standard (e.g. when wanting to rate relationship satisfaction and ratings are not consistent) [Li et al. 2010]. [Ure et al. 2011] suggests similar problems, where prescribed self-trackers subjectively assessed, whether they coughed more or experienced more dyspnea than usual. Some found it difficult to assess such questions, as they were constantly symptomatic and were in doubt of what standard they should compare them to. Data granularity impeded collection when self-trackers were overthinking, while trying to rate mood on a scale from 0 to 10 [Oh & Lee 2015].

Recall bias can reduce data reliability as prescribed trackers did not use a tool for tracking but relied on memory [Patel et al. 2012] or postponed manually entering data [MacLeod et al. 2013]. Self-trackers who do not enter data immediately or at specific times each day are less likely to remember making the tracking and they are also less confident in the accuracy of their own data [MacLeod et al. 2013]. [Li et al. 2010] found that one participant problematized the fact that s/he did not have ready access to her tracking device (a computer) at the time symptoms happened. Some prescribed self-trackers appreciate doing tracking in a notebook because of its portability even though it provides little structure [MacLeod et al. 2013]. Patel et al. tried to improve the reliability of the data and decrease recall bias by developing a smartphone application enabling prescribed self-trackers to do manual realtime tracking with use of self check-ins for logging symptoms. According to their qualitative evaluation their

app was successful but new user needs emerged [Patel et al. 2012]. Prescribed self-trackers appreciate the ability to collect a variety of data [MacLeod et al. 2013, Patel et al. 2012], which is why prescribed self-trackers appreciate flexibility of notebooks [MacLeod et al. 2013] and fortunately the smartphone application by Patel et al. supported prescribed self-trackers in tracking self-selected variables on a 0 to 4 scale, but some participants made a workaround to generate new units that were not initially supported, e.g. "took all pills". The authors report that their smartphone application was engaging, but it still required a great deal of effort for users to track. They end up recommending further simplification within tracking for instance by voice commands [Patel et al. 2012]. Another study tried to simplify tracking with use of an Android interactive widget, which allowed easy input of data. The widget was accompanied by an associated app in one condition and another condition, where they only had the app for inputting data. Participants in the condition utilized with the widget had a significantly higher adherence and they also captured an event significantly closer to its actual time than participants in the non-widget condition [?].

**Integration:** In this stage the personal data is "prepared combined and transformed for the user to reflect on" [Li et al. 2010], which involves data aggregation, data analysis, statistical tests and creation of data representations [Li et al. 2010].

Self-trackers that collect data with pen and paper face a problem, because they have to transcribe data into an electronic format, in order to visualize their data. Self-trackers has to do many things in order to prepare the data for reflection [Li et al. 2010], but if the integration is system-driven less effort is required by the self-tracker [Li et al. 2011, Whooley et al. 2014] making integration less apparent. There are different trade-offs in the integration stage, depending on whether the system is system-driven or user-driven. User-driven systems expect the user to be able to analyse the data and ascertain the best way of creating a representation, which is of interest to curiosity-driven self-trackers that want to integrate data manually and explore the novel insights that data can offer them. This is in contrast to outcome oriented self-trackers who know what they are looking for in the data, they strive at using automatic integration systems allowing them to concentrate on reflection. Self-trackers driven by self-improvement only manually integrate data when the system does not support them with their goals and when they are sufficiently motivated and skilled. The manual integration process is an iterative process of moving back and forth between representation creation and reflection [Whooley et al. 2014].

Previous work shows that that data exploration is sometimes postponed, since it involves tedious tasks, such as cleaning up data, formatting and running statistical tests [Choe et al. 2014, Chung et al. 2015, Li et al. 2010]. Rooksby et al. found that it is unrealistic to believe that self-trackers only act, when data has been validated and thoroughly analysed [?], while Choe et al. write that data interpretation is a key hurdle where self-trackers drown in information and a common barrier is self-trackers have poor skills in analysing data and creating (plus identifying) the most appropriate visualization [Choe et al. 2014].

Whooley et al. found that self-trackers might create many different visual representations for exploration of the same data, especially if they are driven by curiosity [Whooley et al. 2014]. Different types of visualization and data representations was identified by Whooley et al. where binary representations (distil data integrated into one of two results) and structured

representations (tables and graphs, which show a relationship between two or more variables) are typically created by self-trackers that are driven by self-improvement [Whooley et al. 2014].

Problems arise when collected data comes from multiple inputs. In such cases [Li et al. 2010] found that reflection happens in multiple outputs and it is not in a format for reflection. This finding of barrier is in agreement with [Rooksby et al. 2014], who found that people had trouble integrating data from more inputs. Another study specifically reported that different tracking tools do not support the exploration of the data in one place. Tools further do not support data exportation making aggregation a challenge [Li et al. 2011].

**Reflection:** People explore collected data to gain self-knowledge and reflection already occurs while entering data [Whooley et al. 2014, MacLeod et al. 2013, Epstein et al. 2015]. Regardless of whether self-trackers have a health-related condition or not, data collection can have strong emotional meaning [Li et al. 2010, Ancker et al. 2015]. Data can remind people of negative aspects of e.g. an illness, which can be depressing or scary, causing people not wanting to track or review their data [Ancker et al. 2015].

Experienced self-trackers become frustrated by mismatches between subjective feeling and objective measures (e.g. when a health-related quantitative value spikes without a clear reason or matching subjective assessment) [Ancker et al. 2015]. These mismatches can reduce self-trackers' confidence that they understand and are capable of managing their disease. Some self-trackers resist their healthcare providers' interpretation but relying on their own identified "normal range", i.e. values that made them feel well [Ancker et al. 2015]. Self-trackers with a health-related condition further preferred to interpret their data in light of their own personal and medical history and/or symptoms rather than striving for provider-recommended values.

Another concern related to the language healthcare providers use, when they review data with the patients. Healthcare providers found that it was better to use non-judgmental language (e.g. high/low) rather than judgmental language (e.g. good/bad) about patients readings, in order to not discourage patients, who might think they are being judged [Ancker et al. 2015].

Sometimes patients need to share their data with multiple healthcare providers for review [Chung et al. 2016]. Some patients need support from providers in confirming their data interpretation, while others require expert assistance in understanding the meaning of numeric values [Verdezoto & Grönvall 2015]. For example, when taking blood pressure measures on a digital device, elderly initially needed assistance to understand the meaning of the numeric values. The provider had to explain that several readings were needed to compare and support their interpretation [Verdezoto & Grönvall 2015].

While discretionary trackers have difficulties interpreting large amounts of data [Choe et al. 2014], healthcare providers similarly sometimes struggle with interpreting data sets that include additional and not always relevant information [Chung et al. 2015; 2016]. Even though providers suggested tracking a specific factor, some apps encouraged self-trackers to input other information and displayed unnecessary information that hindered effective review by time-constrained providers [Chung et al. 2016]. Self-trackers sometimes also experienced not having collected enough data to observe trends (going up, down or remaining steady) and patterns [Li et al. 2011] or that data collection has been too intermittent to allow for meaningful visual representations [Li et al. 2010].

Self-trackers find visualizations helpful supporting them in understanding their data [Choe et al. 2014], but also experienced difficulties when visualization were overly technical or irrelevant to their interests. One self-tracker mentioned that she found the provided visualizations difficult to understand in relation to cutting her caffeine intake [MacLeod et al. 2013]. The representation consisted of two types of visualizations: (1) A timeline based graph showing goals momentum by period (over a week) and (2) a histogram showing goal success by period (over a week). She liked visualization that were quickly and easily readable.

Sometimes self-trackers are interested in review data over long term to identify trends and patterns, but not all tools supports that. E.g. one participant might collect information about sleep quantity, but the interface might present only the numeric values, where a simple bar graph might have been more useful to review past history [Li et al. 2011]. In the *maintenance* phase self-trackers need to see trends, in order to assess progress towards their goal. Additionally, MacLeod et al. found that tools do not support comparing factors by giving users the ability to sort and filter data, supporting them in reflecting in ways meaningful for them [MacLeod et al. 2013]. Self-trackers need tools to be flexible and allow for a holistic view of the collected data (e.g. showing information for several months at once), which was not always supported by tools with time filters [Li et al. 2010]. Some self-trackers want to focus on some specific information of interest. [Whooley et al. 2014] found that self-trackers with programming skills added interactivity to their tools in order to drill into information of interest.

**Action:** People decide what action to take based on the findings from the reflection stage. Sometimes people do not have the necessary knowledge, in order to identify appropriate action and improve their data, either because they have collected the wrong data [Choe et al. 2014, Chung et al. 2015] (e.g. collected food and symptoms, when it might be ingredients that trigger the symptoms) or because they are in need of more (expert) knowledge about their data and how it can be improved [Verdezoto & Grönvall 2015, Li et al. 2010, Oh & Lee 2015].

Verdezoto & Grönvall found that elderly interested in self-tracking were well aware of and understood if behaviour change was needed. But despite motivation to learn, they did not know what behavior change was needed to get better outcomes [Verdezoto & Grönvall 2015], suggesting a need for actionable advice. Most systems do not help self-trackers in drawing actionable conclusions from the data [Chung et al. 2015, Li et al. 2010]. Therefore self-trackers seek advice from their healthcare providers in case of having a health-related condition to manage [Li et al. 2010].

**Lapsing and Resuming:** Lapsing and resuming occur when a self-tracker temporarily stops tracking and later resumes. Some might even not resume, for instance when a self-tracker forgot to track several times, the self-tracker may decide it is not worth the trouble [Epstein et al. 2015].

Studies have found different reasons for lapsing aside from the abovementioned forget-related lapse. Rooksby et al.'s found from interviewing 22 people interested in activity tracking that several of them tracked everything they ate while others went through short periods of tracking revealing tracking as being selective to each self-tracker, which potentially can cause lapses [Rooksby et al. 2014]. Epstein et al. found that lapses typical begins with barriers to collection.

Lapsing can also be caused by barriers to integration or reflection. A self-tracker going on holiday is also a known reason for lapses as well as injuries or when life habits changes. Some also lapse tracking private things if the PI system emphasize sharing. When self-trackers already know the data they can decide not to track, especially when they do not see the benefit. Lapses can be provoked of different reasons depending on type of self-tracker. Curiosity-driven trackers lapse tracking when tracking tools often require maintenance (e.g. charging battery). Self-trackers driven by self-improvement lapse if collection becomes too much work [Epstein et al. 2015].

After a long lapse (stopped tracking for months) self-trackers will sometimes instead of resuming start integrating or reflecting on data and eventually later decide whether to resume. In relation to resuming, it is today unknown how a PI system should react when someone decides to resume after a lapse, especially when the system archives discouraging past data [Epstein et al. 2015].

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# **Study I - Interviewing COPD-patients**

To find out what parts of Personal Informatics that apply to the field of telehealth and what new parts that arise, we conducted interviews with six COPD-patients that used the AmbuFlex telehealth system. We here bring the Activity Plan developed prior to conducting the interviews. The results from the interviews are presented in the paper.

All interviews are audio recorded and the recordings can be found on attached CD.

## **6.1 Activity Plan**

We dedicate one hour for each of the interviews. Two researchers are present during the interviews, one will facilitate the interview and an observer is responsible for audio and taking notes. The interviews will be conducted as semi-structured interviews. Questions will relate to the use and the experience of the telehealth system. The interview also include the patient showing how to use the system, which the researchers will observe to find any potential user needs.

### **Agenda**

- Consent form (included on attached CD)
- Interview
- Observe use of telehelath system

A signed consent form is a prerequisite to the interviews.

### **Interviews**

Demographics:

- How old are you?
- Do you live alone?
- Do you have other diseases?
- What are your experience with technologies/iPad/tablets/smartphones?

COPD-related:

- Which degree of COPD do you have?
- Can you explain to me, how it is to have COPD?
- Have you experienced anxiety related to your COPD?
  - In what situations are you more anxious than others?
- How many exacerbations have you experienced? Describe the experience to me.

Self-management:

- How do you manage COPD?
- Do you receive home care?
- Do you receive any help from relatives or friends?
- Do you smoke?
- Have you attended any rehabilitation programs? If yes, which? If no, why not?
- Have you attended education at Lungeeskolen? If yes, has it helped you manage your COPD and how?
- Do you consider your diet?
- Is physical activity a part of your rehabilitation?
- Do you have a care plan? Do you use it? Why (not)?
  - What have you used it for? Or how have you used it?
- When do you take your medication?

Telehealth system:

- How often do you measure?
- What motivates you to measure?
- What happens when you have entered your measures?
- When are your entries monitored?
- How is the dialogue between you and your nurse?
- Do you assess your measures yourself?
  - For an exacerbation? If so, do you initiate medication yourself?
  - Do you wait for answer from the monitoring before initiating medication?
- How is the waiting time after you have submitted your measures until you get a response from the monitoring?
- Are you familiar with your measures' recommended level?
  - Would you like to know them?
- How has telehealth helped you in managing your COPD?
  - Has telehealth made it easier to recognise day-to-day variations?
  - Has telehealth made it easier to recognise an exacerbation?
- Do you learn anything about your COPD from using the telehealth system?
- Do you reflect on your measures?

- What problems have you experienced from using telehealth?
- What symptoms do you experience related to COPD? Do you experience the symptoms that the system cover?
  - Is it easy to answer yes/no to "Do you cough more than usual?"
- What do you gain from using telehealth?
  - Do you feel secure? Why?
  - What is needed for you to feel more secure?
- When are you in doubt?
- Are there any concrete situations where you get confused?
- What do you think is hard?
- Can you show me how you use the telehealth system?

## 6.2 Own tracking system

As presented in the paper, two of the six patients did parallel tracking on paper as AmbuFlex does not provide access to past measures. One example, can be seen on figure 6.1.

Dato 2016	Vægt	HIT	Puls	Mff.
Søn 14/2	68,3	94	87	+
MAN 15/2	68,6	92	87,	+
TIR 16/2	68,6	93	86	+
ONS 17/2	68,1	94	93	+
Tors 18/2	67,6	94	80	+
FRE 19/2	68,3	93	91	+
Søn 20/2	68,3	94	90	+
Søn 21/2	67,8	92	92	+
MAN 22/2	67,9	91	95	+
TIR 23/2	67,7	90	89	+
ONS 24/2	68,0	91	86	+
Tors 25/2	67,7	92	86	+
FRE 26/2	68,2	92	80	+
Søn 27/2	68,2	92	82	+
Søn 28/2	68,1	95	195	+
MAN 29/2	68,	93	86	

**Figure 6.1.** A parallel tracking system developed by a spouse to one of the patients.

Besides tracking the measures from AmbuFlex this tracking system also include another variable that was found relevant by the patient and the patient's spouse themselves.



---

# Study II - Design Feedback Sessions with COPD-patients

During previous co-designing events researchers have experienced limited ability among COPD-patients to interact with co-designing tools due to the physical limitations of their disease. While conversing some patients are even not able to participate in other activities [Das et al. 2015]. Based on these experiences we scaled down our initial idea of the patient as an active partner in a co-designing event. We made a concise plan where patients only were expected to either talk or interact with a prototype. To further reduce the workload on the patients, we gave/sent each patient a workbook with minor assignments for completion over three days prior to the actual design session. The idea with the workbook was to spread out work from the design session on more days, freeing up time for talking and sharing thoughts during the session and sensitize the patients to the topic, promote reflection about collection and reflection. Initially we wanted to develop a prototype with them, but with the co-designing experience from [Das et al. 2015] we decided to developed a prototype that simulates our proposal of a telehealth system, which the patients could try and criticize. Ideally we wanted to gather all the patients in one room for a common design session but since the patients are less mobile and easily gets tired, the sessions were conducted as individual sessions in the patients' own homes. We used the same COPD-patients as in study one, which enabled us to ask some follow-up questions that had arisen since study one. However one patient was hospitalized and could not participate meaning the study included five COPD-patients.

## 7.1 The Workbook

The workbook assignments dealt with collection, data reliability and reflection. We wanted to know more on how patients collect objective and subjective data (both in relation to binary and granulated subjective questions). We also wanted to know if patients understand the meaning of the values and while collecting reflect on whether the readings are reliable and if they repeat measures. We wanted to see if selected binary subjective measures were based on estimation or recall. Further, we wanted to know if visualizing measures relative to a normal area trigger any reflection and if access to previous subjective measures (both binary and granularity) affect the assessment. We therefore made assignments to all these areas and we also included measuring assignments to include their personal measures in the prototype. The workbook is included on

attached CD.

## 7.2 The Prototype

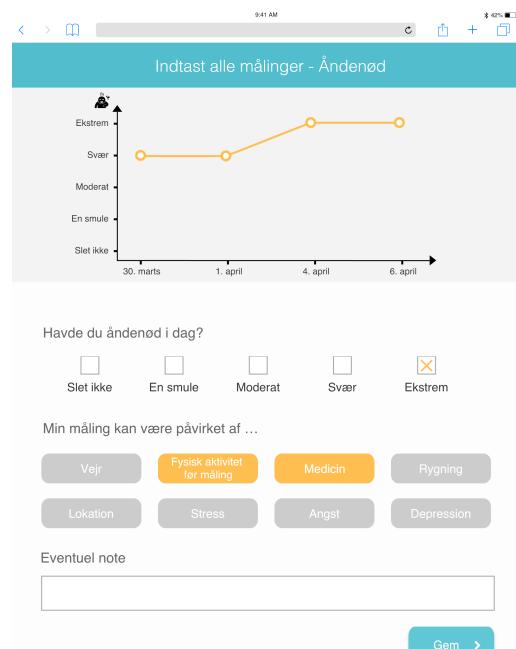
Our proposal for the telehealth prototype contains three types of pages. 1) Collection, a page for entering measures, 2) Visualisation, a page for seeing past measures and 3) Dashboard, a page for fast (not detailed) visualisations of the data, giving current state, e.g. downward and/or upward trends of the measures.

*add 1, Collection:*

In 7.1 and 7.2 we have examples of the objective and subjective collection page (respectively). Both types of the collection pages (subjective and objective) have a reference graph in the top, which shows previous measures. We think, by giving a reference graph, current state can easily be compared with previous measures, which could help judging upward or downward trends. We hope, by knowing previous subjective measures a better consistency across measures will occur. As literature suggest, annotation can foster reflection, we therefore have a note area in the bottom of both types of pages (subjective and objective), where the patient can add further reasoning, e.g. "my oxygen supply is 2" or "I just started the ventilation system, it is so hot, hopefully it will make my breathing easier". Above the note area, we have toggle buttons of context variables that the patient can toggle on/off if he thinks one/or more is relevant. Hopefully, the context variables makes casual explanation easier and starts reflection. Depending on type of collection page (subjective or objective), the page contains check-boxes to provide a subjective measure or a text-field to provide an objective measure.



**Figure 7.1.** Shows the user Interface for collection of objective measure (in this example saturation).



**Figure 7.2.** Shows the user interface for collection of subjective measure (in this example dyspnea).

The prototype was developed in Adobe Experience Design and the project can be found on

detached CD as well as an example url to the running prototype.

*add 2, Visualisation:*

We included interactive visualisations of previous measures to facilitate long-term reflection. We developed four types of visualisations and wanted to see, which one the patients' preferred.

In terms of facilitating the identification of temporal location and quantitative value of a particular data point, the authors of "Investigating time series visualisations to improve the user experience" found that users prefer visualisations with clear textual tooltips over highlighting. Their finding also indicated tooltips as more effective than highlighting and that cartesian coordinate system in general is comparable or more effective than Polar coordinate system. They also found that interactive time series visualisations enhances the user experience [Adnan et al. 2016].

The authors of the paper "Financial Visualization Case Study: Correlating Financial Timeseries and Discrete Events to Support Investment Decisions" find visualising discrete events on time series problem-free only when multiple discrete events visually do not overlap and when the visualisation of the discrete event does not overlap an axis which holds important information (e.g. price). They also present an alternative visualisation if wanting to visualise multiple discrete events simultaneously, which has proved successful in practice [Sorenson & Brath 2013].

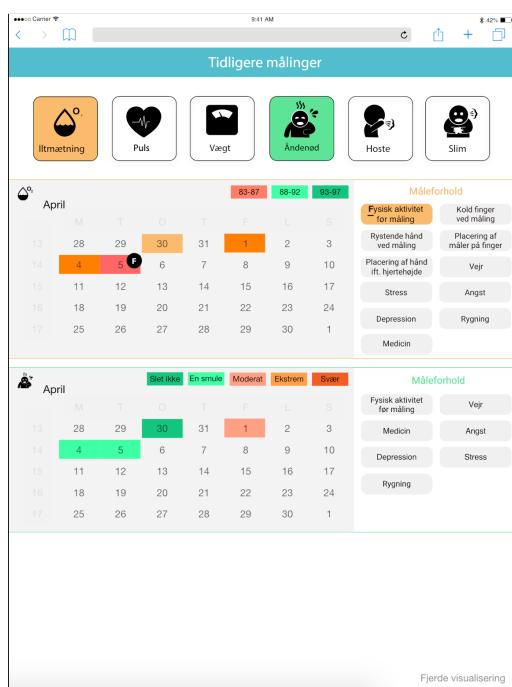
Based on these two papers we included interactive time series, containing textual tooltips in different types of cartesian coordinate systems. Discrete events are visualised one type at a time (when toggled) to avoid overlapping. We also included a calendar heatmap to support the visualisation of human behaviour, which often are characterized by periodic patterns [Cuttone et al. 2014]. The calendar heatmap is also interactive and shows discrete events with same functionality as just described, see figure 7.6.



**Figure 7.3.** Visualisation 1.



**Figure 7.4.** Visualisation 2.



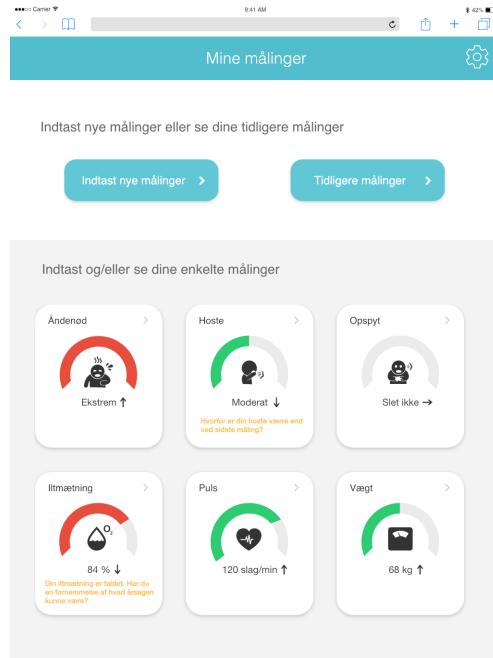
**Figure 7.5.** Visualisation 3.



**Figure 7.6.** Visualisation 4.

*add 3, Dashboard:*

The dashboard supports short-term reflection by showing current state relative to normal areas by color coding and upward/downward trends with use of arrows. We also included reflective questions written in orange in relation a measure, see fig 7.7.



**Figure 7.7.** The dashboard.

### 7.3 Activity Plan

We here bring the activity plan from the study.

#### Agenda:

- Consent form (included on attached CD)
- Part one - Follow-up questions from first visit
- Part two - Workbook
- Part three - Prototype

#### Process:

Two researchers were present during each session. The researcher that facilitated study one continued the interview from last time with the follow-up questions while the other researcher prepared part two by looking through the patient's workbook. During part two the first researcher prepared the prototype by adding in personal measures from the patient's workbook in the prototype (sometimes this process was done right before the session if the researchers arrived early to the patient's house).

#### Data collection:

We audio recorded the whole design feedback session. During the prototype part we used UX Recorded for iOS to record the screen, the front camera and the audio. The recordings are all to be found in detached CD.

### **Part 1 - Follow-up**

Time:

- How long time have you used Tunstall Healthcare and/or AmbuFlex?
- How long time do you spend on measuring and sending data through AmbuFlex to the hospital?
- How much time are you willing to spend on measuring and sending data?
- How long time did it take to learn to use AmbuFlex?
- How does the weather influence your COPD (if it influences)?

Guidelines:

- Have you been taught how to do correct measures? (e.g. when to use the saturation device?)

Collection phases:

- How do you prepare for using the pulse oximeter?
- Would you like to have access to your previous measures?

Reflection:

- Anything specific you need to better reflect on your measures?
- Do you miss visualisations of your measures?

In case the patient do parallel tracking:

- Have you improved your tracking system while tracking?
- What do you think of your own tracking system?
- Is there anything you miss?
- Is there something that could be easier?

Other:

- In cases of exacerbation, do you start medication earlier when having telehealth?
- What motivates you to use AmbuFlex?

### **Part 2 - Workbook**

Purpose: Feedback on improved collection and understanding of how it fosters reflection while collecting.

1. Discussion on time of measurement (afternoon or morning) - pros/cons
2. Discussion on use of context variables on page 4 + 10
  - a) Identification of level(s) of reflection:
    - i. When annotating context-related variables in the comment boxes
    - ii. When checking context-related variables in the check-boxes
  - b) Discussion on differences between above-mentioned two methods in terms of use, reflection and preference
  - c) Discussion on relevance (e.g. cold finger) and priority of variables.
    - i. Were you aware that these context variables could influence your measure? Discussion on need for explanation on context-related variables (in guidelines)
    - ii. Any new-found variables?
    - iii. Discussion on shorter versions
    - iv. Subjective measure: Dyspnea
  - d) Discussion on what the assessment was based on (recall or estimation). Identification of level(s) of reflection, when assessing:
    - i. Binary
    - ii. Granularity (5 ordinal categories)
      - A. How is it different from binary? Better/worse? Why?
    - iii. Numbers (presented in workshop)
    - iv. Visuals
  - e) Comparison of above-mentioned methods
3. Objective measure: Normal area
  - a) Ask about previous experience with graphs (control)
  - b) Identification of level(s) of reflection :
    - i. What thoughts did the graph trigger?
    - ii. How are you measurements in relation to the normal area? What do you think of that? What do you think of the normal area shown?
4. About having a reference graph when assessing binary measures (Identification of level(s) of reflection)
  - a) What thoughts did the graph trigger?
  - b) How does it affect your answer to whether you feel more breathless than usual when you can see your previous answers?
5. About having a reference graph when assessing more granular answers (Identification of level(s) of reflection)
  - a) How does it affect your answer (to whether you felt breathless today) (assessed on 5-point), when you can see your previous answers?
  - b) Is there any benefit in seeing your previous measures?

### **Part 3 - Prototype**

Purpose: Primarily for usability purpose and feedback on visualisation part.

Dashboard:

- You are on the dashboard. What do you notice first?

- What does the arrow besides your oxygen saturation measure tell you? What does the arrow besides phlegm tell you?
- What does the status indicator besides oxygen saturation tell you?
- How do you feel about the color indications on your health status?
- Imagine that you want to input a single oxygen saturation measure. Show me what you would do.

Collection:

- You want to go back now. Show me what you would do.

Dashboard:

- You want to enter all your measurements. Show me what you would do. (OBS: In this version you will only be able to enter two measures.)

Collection

- You have taken your saturation measure and it is 84 today. Enter it in the system.
- You want to take the next measurement. What do you do now?
- You had extreme shortness of breath today. Enter it in the system.
- Mark that you have taken your medicine that affects your shortness of breath. Then mark that you have been physical active.
- You want to save your measurement.
- Do you want to send your measurement to the hospital? If yes, proceed.

Dashboard:

- Now you are back on the dashboard.
- Now you want to see all your previous measures. What do you do?

Visualisations:

*Visualisation 1*

- You see the graph of your oxygen saturation. You also want to see dyspnea, what do you do?
- Instead of dyspnea, you know what to see cough, what do you do?
- You want to see when stress has affected your oxygen saturation measures. What do you do?
- What do you think about this visualisation? What do you notice on this visualisation?
  - Identification of level(s) of reflection

*Visualisation 2*

- You see the graph for your oxygen saturation. You also want to see dyspnea, what do you do?
- You also want to see pulse. What do you do?
- You want to remove the graph for dyspnea. What do you do?
- You want to see more details on the oxygen saturation measure made on the 4th of April. What do you do?
- What do you think about this visualisation? What do you notice on this visualisation?
  - Identification of level(s) of reflection

*Visualisation 3*

- You see the graph for your oxygen saturation. You also want to see dyspnea, what do you do?
- You want to see whether physical activity before the measure has influenced your saturation. What do you do?
- What do you think about this visualisation? What do you notice on this visualisation?
  - Identification of level(s) of reflection

*Visualisation 4*

- You see the graph of your oxygen saturation. You also want to see dyspnea, what do you do?
- You want to see more details on the oxygen saturation measure made on the 4th of April. What do you do?
- What do you think about this visualisation? What do you notice on this visualisation?
  - Identification of level(s) of reflection

Other questions

- Visualisation of weather. How does weather affect you?
- Currently, you share your measures with the hospital. Imagine a system, where it is not required. Can you imagine you entered measures, but did not want to share them with the hospital? Why/why not?

## 7.4 Post Methodological Considerations

When considering the methods used from this study in a retro-perspective light we have gained new experience. We used Adobe's brand new prototype tool Experience Design. Even though the process of developing the prototype was streamlined (only showing few limitations) we discovered some limitations related to the context of our use. The tool did not provide us with an off-line functionality, which meant that we needed to use our mobile hotspot from our phones in order to conduct the prototype parts. At one patient we even needed to connect to her Wi-Fi due to slow hotspot connection. Sometimes we experienced lack and delays while

having good hotspot connection because the software loads a lot of assets per view. This sometimes frustrated patients, which made them doubt in either the prototype's functionality or whether they were interacting in the right way (and therefore also doubted their own skills). On use, we concluded, that Adobe Experience Design is a good tool with limitations when using it in the field.

We had hoped to gain more knowledge from the workbooks but there was a mismatch between our expected user needs and the user's actual needs. Many assignments related to the time series, which most patients were not interested in reflecting on. In the workbook, we asked if the time series activated any thoughts. We could have asked into feelings generated by the time series, which potentially could have generated different answers.

Having both audio recordings and video recordings (of screen and front camera) from part two (prototype) was redundant. The patient interacted with the iPad in such a way, that the front camera did not capture facial expressions (the iPad was typically placed on a table and not hold). The video recording added new information to the audio recording by showing which element the patient tried to interact with, which from the audio recordings often was clear.

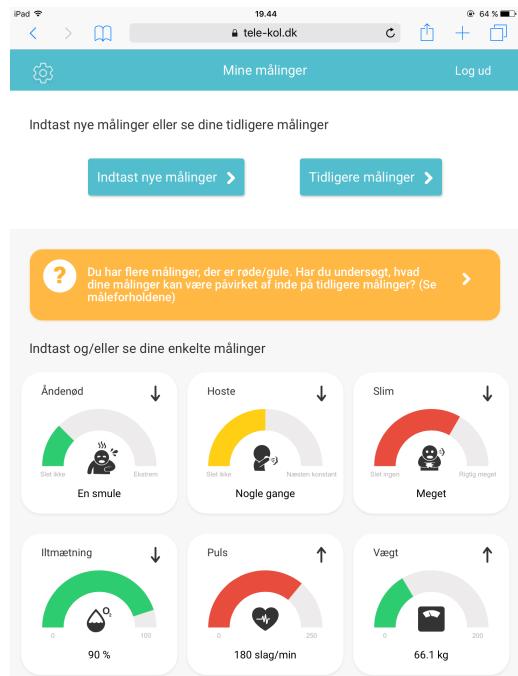
# Implementation

The application is developed with use of both server-side and client-side programming. This chapter will therefore present both side of the programming but firstly the needed changes found in study II is described. Security considerations and implementation is described at the end of the chapter. The implemented application can be found on attached CD.

## 8.1 Design Changes



**Figure 8.1.** Shows the dashboard used in study II.



**Figure 8.2.** Shows the dashboard and its design changed made as result of findings from study II.

new interface - reflective questions (when they are updated, what are they?) - visualisation choice - normal areas? what are they based on, individualisation

## **8.2 Server-side**

### **8.2.1 Session**

#### **Admin Access**

admin features

### **8.2.2 Data Manipulation**

data structure (json, log) webservice - saveLatestQuestion

## **8.3 Client-side**

### **Get user data**

In order to get each user's data on login, we use ajax from the jquery library.

**User interface elements** one example - bootstrap

## **8.4 Security**

anonymous https .htaccess - flaws - sufficient for trial, .. in operation use of database, programming convenience based on previous experience

---

# Study III - Trial with COPD-patients

The purpose of study III is to evaluate the implemented telehealth system in a real context. We here bring details on methods used.

## Preliminary Data Collection

We collected preliminary data prior to the study of two reasons, one being the system's dashboard only function when having two measures to compare in order to show upward or downward trends, the other was for the participants to have data to reflect on from the start of the trial, which we found important because of the relatively short trial period. The template used to collect the preliminary data can be seen on attached CD. The dates in the template varied depending on when a patient was enrolled in the study.

## Diary

During the trial period, the patients were asked to write in a diary after each use. To provide inspiration on what to report on in the diary, we taped questions on the first page of the diary. The questions were:

- What did you think while using the system? (e.g. on page for entering data, page showing previous measures, page for overview and the system's question)
- What in the system generated thoughts?
- How was the experience of using the system?
- What puzzled you in the system?
- What did you learn from using the system?
- How has the system helped you?
- Suggestions for improvements.

When patients were given the diary before starting using the system, the patients were told that the questions only functioned as inspiration and it was not required to write, only if they had something on mind.

## Activity Plan

Demographic questions (from the questionnaire) and the questions from the interview are both listed in the Activity Plan, which is attached as appendix, A.1.

## *Demographics*

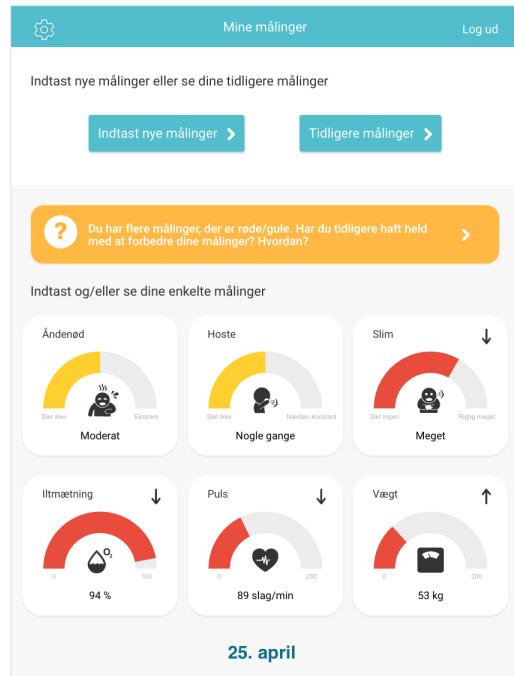
Demographic data of each patient completing the study can be found on attached CD (in Final Evaluation.xlsx).

## *Interview*

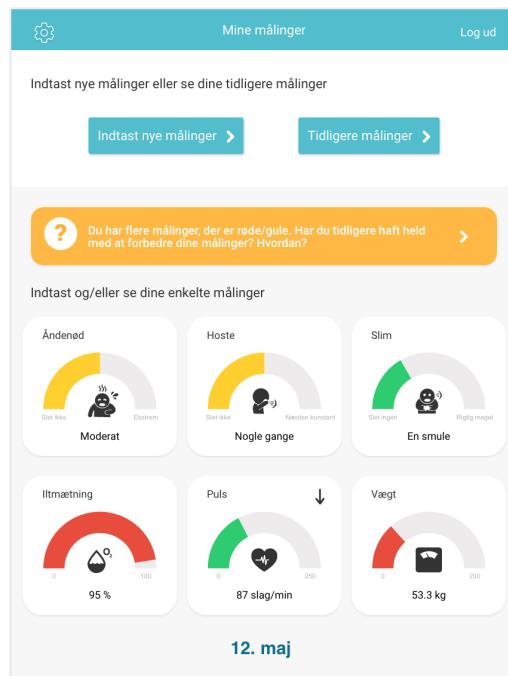
The interview was conducted as a semi-structured interview with focus on typical COPD-activities such as use of pulse oximeter, medication use etc. We searched for a change in COPD-activities during the use of the system. When a change was identified we drilled further down, asking why it was changed to see if it related to the system use. If it related to the system use we again drilled further down to find possible features in the user interface that fostered reflection and provided a change in perspective and activity. All the interviews were audio-recorded. The recordings can be found on detached CD.

## *Cue recall*

To cue recall from using the system during the interview, we made two initiatives. First, we prepared screen-shots of patients' dashboards showing events of interest (e.g. worsening or improvement in measures between two days). We here bring an example of the two screen-shots that was prepared for P4.



**Figure 9.1.** Shows status from first day of use (April 25) for P4.



**Figure 9.2.** Shows status from last day of use (May 12) for P4 before evaluation.

Above pictures show an improvement in health status. We hoped it could help replaying the situation between the two days and reveal the reflection that potentially occurred and the feelings related to the development. All the prepared screen-shots can be found on attached CD.

Our second initiative in the effort of cueing recall was to get an overview of each patients' use

of the system by going through the system log and find situation where reflection potentially could have occurred. For instance we looked for an outlier in measures, what reflective questions each patient had received and what the patient turned to when the reflective question pointed at a design feature. The overview also included basic information as number of entries, what pages the user had visited and what features the patient had used. This overview is also included on the detached CD (called Overview.pdf). The system log can also be found on the CD (in Final Evaluation.xlsx).

### **Data processing**

We transcribed the interviews from the audio recordings and coded the interviews. This data is included on attached CD (in Final Evaluation.xlsx).



## **Future Research**

We have also discussed the use of different media types for detailing different granularities of e.g. dyspnea. This could be on different levels, introducing sound, visuals, a/v and interactions that could actually expand to a whole study in itself



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APPENDIX **A**

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# **Appendix**

## **A.1 Study III - Activity Plan**

## **Study III - Activity Plan**

### **Agenda**

*One hour is allocated per session/patient*

- Consent
- Diary
- Demographics questionnaire
- Interview
- Get borrowed equipment back

### **Consent**

Participants of the study are asked to fill out a consent form asking for permission to audio-record, video-record and take pictures during the interviews.

### **Demographics Questionnaire**

1. How old are you?
2. Are you educated? What level?
3. Do you live alone?
4. Do you currently work?
5. What is/was your profession?
6. Technology
  - a. How often do you use a computer, tablet (fx iPad) or similar?
  - b. What do you use it for?
7. COPD
  - a. For how long have you had COPD?
  - b. What is the severity of your COPD?
8. For how long have you used the telehealth system that you used previous to this?
9. Do you have any notable issues with your vision (impaired vision or colorblindness)
10. Do you have any other diseases?
11. Do you use supplemental oxygen?

### **Interview**

#### **General talk about COPD-activities**

*Purpose: With COPD-activities as point of origin, we explore if any changes has occurred the last 14 days and if it relates to reflection, potentially triggered by the system.*

#### **To the patient:**

- 1) We will ask follow-up questions on the use of the system and on your experience with the system.**

**a) We write some post-its during the interview related to your normal activities and the system to visualise your reflection during the trial period.**

**2) Please take time to consider your answers.**

**3) There are no wrong answers.**

How have you been since our last visit?

How has the weather influenced your COPD since last visit?

- How do you know that?
- Have you explored that in the system?

Has any of your habits changed the last 14 days? Maybe unconscious? Which? Why?

- Are you more/less physical active?
- Eating habits?
- Use of breathing techniques? Cough techniques? Pep device?

Has your symptoms changed since our last visit? Worse or better?

- C4: How do you become aware of changes in symptoms?
- How do you assess whether you are feeling good or bad?
- How can you use the system for that?
  - Is that better/worse in TH/AF? How?
  - Do the visualisations generate any negative feelings?

Do you use your pulse oximeter? Why? How has your saturation changed during the last 14 days? What does that tell you?

How has other measures developed since our last visit?

- How can you use the system to recognise changes?
- Is that better/worse in TH/AF? Why?

C5: Is there anything that affects your measures?

- How did you become aware of that?
- What can you use that knowledge for? / Why is that interesting?

C6: What are your measures normally?

- How have you become aware of that?
- What can you use that knowledge for? / Why is that interesting?

Do you have a care plan? How have you used it the last 14 days?

Have you discussed with your nurse or doctor your COPD since our last visit?

- If yes, what did you talk about?

Have you initiated medication lately? (within the last 14 days?) Or adjusted it?

- If yes, what made you do that?

Have you adjusted your oxygen supply?

- Have you studied, in the system, how your saturation fluctuates?

Have you discussed your COPD with your relatives the last 14 days?

- How did you discuss your COPD with your relatives? And what did you discuss?

Have you showed the system to any one?

If anyone ask about your COPD, what questions can the system help you answer?

*Standard follow-up question focused to the system:*

Have you studied that in the system?

## **Conditions/Barriers for reflection**

*Purpose: Understand if patients experienced any barriers for reflection by not having conditions for reflection fulfilled while using the application*

- Time and space (Context of use)
  - How much time did you allocate to use the system?
  - Where did you use the system (physical space)?
    - Were there any exceptions? Which?
- Willingness/Motivation + Skills
  - Did you see any advantages in using the system?
  - Were you motivated in using the system?
  - Was the system easy to use without help?
  - When using the system, did you miss education in
    - *Collecting, understanding and knowing, what meaning they have (how/when you measure)?*
    - *The system, to use it?*
- Is there anything else that hindered you in using the system?

## **Refoster reflection**

*Purpose: Gain insight in what reflection that was generated from the interaction.*

*Replay the situation by showing development in dashboards or ask into an outlier in the data.*

Identify data of interest for each participant.

Regular/typical data

Irregular/not typical data

Do you remember this situation?

What did you think?

How did you explain it?

What feelings did it elicit?

What did you do?

## **Comparing systems:**

*Purpose: See if the system has improved. Maybe a change in reflection?*

For current AF-user, open both system. For TH-user, play video of TH.

- TH: How much do you remember of TH?
  - How was it different to enter measures in the new system compared to X?
  - How has the system changed your understanding of your health compared to X?
    - What aspects have you gained a better understanding of compared to before?

- What parts in the system would you miss, if you should use the system you used before?

### **Other**

- Diary → walk-through (if interesting parts are written)

### **Recommendation/future use**

- Of what reasons would you recommend the system to other patients?
- Of what reasons would you recommend the system if the system was not monitored by healthcare professionals?
  - How often would you use the system? For what? Why?
- If the system was monitored by healthcare professionals, would you use it instead of X

## **List of Corrections**