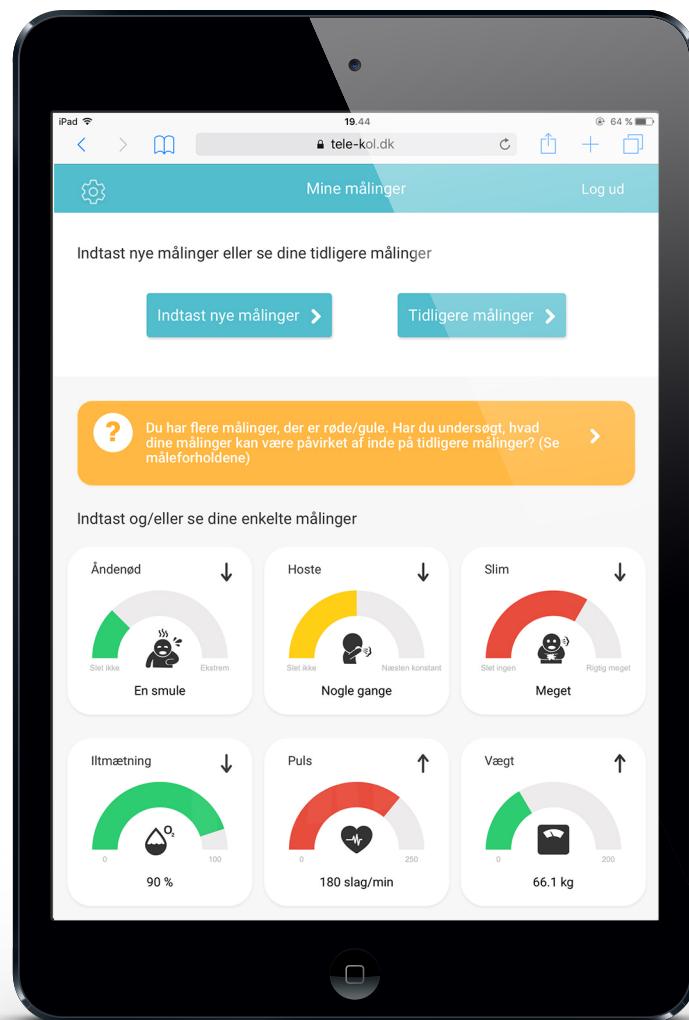




AALBORG UNIVERSITY
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Designing for Reflection in Telehealth

Chronic Obstructive Pulmonary Disease Patients as Self-trackers



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Abstract:

Telehealth systems for early detection and treatment of chronic conditions have seen increased use. But the effects on user needs and concerns when healthcare provider continuously monitor and patients provide subjective and objective data over time is poorly understood. Personal Informatics literature informed the analysis of interviews with six Chronic Obstructive Pulmonary Disease (COPD) patients to improve understanding of user needs and concerns in the use of a state of the art telehealth solution. While patients generally felt taken care of, the system in many ways did not meet user needs, e.g. due to difficulties assessing reliable subjective measures and no support on reflection and follow-up action. Interviews, workbooks and design feedback sessions with patients served as the foundation for redesigning the system to support data collection and reflection. Findings from a two week trial involving five COPD patients showed that the system supported one of two types of patients in becoming more informed and aware about their health status, leading to increased empowerment in their everyday life and motivation to set goals and improve condition.

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.

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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, resulting in periods of exacerbations among those affected. An exacerbation can be 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 shows 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.

Telehealth for COPD

Telehealth (support of health care using electronic information and communication technologies when patient and provider are in a separate location) 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 [Pedone & Lelli 2015]. 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 [Pedone & Lelli 2015]. Since physical symptoms are influenced by psychological and individual processes [Pennebaker 2000], self-reported binary measures might be biased and further not capture the relevant features necessary for clinical decision making.

A	B	C	D	E	F	G	H	I	J
Title	Phone (f = fol)	Home visits (e =	Monitoring (h = hon	Instant feedback - o	Education (e =	Exercise (h =	Action plan	Reduces hospital admissions?	
Reduction of Hospital Utilization in Patients With Chronic Obstructive Pulmonary Disease	x	x (f, h)	x (e)		x (h)	x(h)	x	Yes (S)	
Self-management reduces both short- and long-term hospitalisation in COPD	x	x (f, h)	x (e)		x (h)	x(h)	x	Yes (S)	
Effects of telemonitoring in patients with Chronic obstructive pulmonary disease	x	x (f)		x(h)	x	x (e)		Yes (S)	
Care plans for acutely deteriorating COPD: a randomized controlled trial	x		x (e)			x (h)	x	No (S)	
Proactive integrated care improves quality of life in patients with COPD	x	x (f, h)		x(h)		x (e, h)		Yes (NS)	
Effects of Home Telemonitoring to Support Improved Care for Chronic Obstructive Pulmonary Disease	x	x (f, h)		x(h)	x			Yes (NS)	
(Cost)-effectiveness of self-treatment of exacerbations on the severity of exacerbation	x	x (f)	x (l)			x (w, h)	x	No (NS)	
A randomised controlled trial of the effect of automated interactive calling combined with home telecare	x	x (f)		x(h)				No (NS)	
Home telecare study for patients with chronic lung disease in the Sydney West Area	x	x (f)				x (h)		No (NS)	
Use and utility of a 24-hour Telephone Support Service for 'high risk' patients with COPD	x	x (f, h)				x (h)		Yes (S)	
Effects of nurse-initiated telephone follow-up on self-efficacy among patients with chronic obstructive pulmonary disease	x	x (f)				x (h)		Yes (NS)	
Evaluation of a self-management plan for chronic obstructive pulmonary disease			x (e)		x(w)		x	N/A	
Managing chronic obstructive pulmonary disease in the community. A randomized controlled trial of the effect of a community-based COPD management programme					x(h)	x(h)		Yes (S)	
Short- and long-term efficacy of a community-based COPD management programme			x (e, t)	x(h)	x (w, h)	x(h, c)		No (NS)	
Telemedicine-assisted home support for patients with advanced chronic obstructive pulmonary disease		x (f)			x (w, h)			Yes (NS)	
Evaluation of a Nurse-Led Educational Telephone Intervention to Support Self-Management of COPD		x (f)			x (h)			N/A	
Effects of telephone health monitoring in community-recruited chronic obstructive pulmonary disease patients			x(h)	x	x (e, h)		x	No (NS)	
Randomized Controlled Trial of an Internet-Based Versus Face-to-Face Dyspnea Self-Management Plan for Chronic Obstructive Pulmonary Disease		x (f, h)			x (w, h)		x	N/A	
1. Comprehensive self management and routine monitoring in chronic obstructive pulmonary disease		x (l)	x (c)		x (w, h)	x (c)		N/A	
2. Comprehensive self management and routine monitoring in chronic obstructive pulmonary disease					x (h)			N/A	
1. The Effects of Education Alone and in Combination with Pulmonary Rehabilitation					x (h)	x (h, c)		N/A	
2. The Effects of Education Alone and in Combination with Pulmonary Rehabilitation					x (h)			N/A	
The Effect of a Pulmonary Rehabilitation Program on self-efficacy, perception of dyspnoea and quality of life in patients with COPD		x (f)		x(h)	x (h)	x (h)		N/A	
Exploring User Experience of a Telehealth System for the Danish TeleCare North Trial		x (f)	x(l)	x(h)		x (h)	x (h, c)	N/A	
A RCT of telehealth for COPD patient's quality of life: the whole system demonstrator		x (f)			x (b, h)			N/A	
Intervention by phone calls raises domiciliary activity and exercise capacity in patients		x (f)				x(h)		N/A	

Figure 3.1. Research table with health-related outcomes of telehealth interventions

3.1 Current Literature

We made an extensive review on telehealth literature and found little on how telehealth systems have been designed to patients needs (See research tables on CD). Current literature primarily shows health-related outcomes of telehealth interventions in comparison with standard care.

We compared outcomes from different studies on telehealth studies (See Figure 3.1) and found conflicting results due to a wide range of different interventions used. From this it is difficult to assess what has an effect.

3.2 State of the Art

We observed the use of two telehealth systems. The first one is AmbuFlex and the other is OpenTele (used in a large trial in northern Denmark). The telehealth systems that we observed did not use validated questionnaires for detection of exacerbation.

In our study we chose to focus on AmbuFlex, which does not give the patients any feedback except of confirmation, when submitting the data. Screens of AmbuFlex can be found on the CD.

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) used the literature of Personal Informatics as an analytical lens for the field of telehealth.

Categories	Subcategory	Needs/Problems	Article	Target group	Method
Reliability	Subjectiveness	tracking is often selective (confirms the concept of lapsing) Data rely on subjective estimation (e.g. how many calories were expended when)	16, 9,	16:General, Extreme QS users	16:Qualitative Qualitative/Quantitative
	Data-related	Data rely on subjective ratings with no standard (ratings not consistent)	9,	Extreme QS users	Qualitative/Quantitative
Recall bias		Data may be hard to find (sometimes life isn't interesting enough to make me write it)	9,	Extreme QS users	Qualitative/Quantitative
		Users might postpone manually entering data causing recall bias Users who do not enter data immediately or at specific times every day, less likely to do so	10,	Chronically ill	Qualitative
		Entering data in widget reduces recall bias compared to app	2,	General	Quantitative
	Skip tracking	Commonly most did not use a tool, but relying on memory	18,	18:Cancer patients,	Qualitative,
		People skip logging when tracking entries is too long	11,	11:General,	11:Quantitative/Qualitative,
		People skip logging everything they track, maybe already knowing the data before	11,	11:General,	11:Quantitative/Qualitative,
	Others	Forgetting to collect	9,	Extreme QS users	Qualitative/Quantitative
		Tracking behaviour sporadic (tracking many places, e.g. black notebook and the phone)	18,	18:Cancer patients,	Qualitative,
		Insufficient frequency and detail of measurements taken -> not clinically useful		(health care provider's point of view	Qualitative, Qualitative
		Does not understand meaning of value (e.g. if measurement is not correctly taken)	5,	Seniors at activity center	Qualitative
		Not following guidelines (e.g. do not eat or drink anything xx minutes before taking)	5,	Seniors at activity center	Qualitative
	Episodes	Users interested in collecting occurrence and frequency of episodes, including frequency	10,	Chronically ill	Qualitative
	Triggers	Users collect potential triggers (aspects of environment that could cause an episode)	10, 3, 14, 1,	Chronically ill, General, 14: Extreme QS users	Qualitative, Qualitative, Qualitative
	Medication	Users collect consumed medication to prevent an episode or to eliminate one in the future	10,	Chronically ill	Qualitative
		Users use information about medication consumption to determine if medication is effective	10,	Chronically ill	Qualitative
	Status	Users collect status indicators (e.g. blood glucose level) with the purpose of getting them	10, 15	Chronically ill, Multiple Chronic Condition	Qualitative, Qualitative
		Users collect status indicators to respond accordingly with treatment (action)	10, 15	Chronically ill, Multiple Chronic Condition	Qualitative, Qualitative
		Users collect status indicators to determine whether they were meeting a goal	2, 3,	General	Qualitative
	History	Users observe progressions in their condition and possible improvements	10, 15	Chronically ill, Multiple Chronic Condition	Qualitative, Qualitative
		Users identify trends (whether data is going up, down or remaining steady) and patterns	3,	General	Qualitative
Integration		The user has to do many things to prepare the collected data for the reflection	9,	Extreme QS users,	Qualitative/quantitative
	Analyse	Putting off data exploration, because the process involves tedious tasks, such as analysing data	4, 8, 9	Extreme QS users, (health care providers)	Qualitative, Qualitative, Qualitative/Quantitative
	Digitize	Need for novel methods to analyse alternative data types (photos, videos, unstructured text)	7,	Extreme QS users	Qualitative
	Aggregate	People collecting data with use of pen and paper faced a problem when having multiple inputs	9,	Extreme QS users,	Qualitative/quantitative
		when collected data comes from multiple inputs reflection of data happens in multiple places	9,	Extreme QS users,	Qualitative/quantitative
		people had trouble integrating data from more sources	16,	16:General,	16:Qualitative
		when collected data comes from multiple inputs, the format of collected data is not consistent	9,	Extreme QS users,	Qualitative/quantitative

Figure 4.1. Research table with user needs identified in Personal Informatics literature

We analysed the literature of Personal Informatics for different drivers for self-tracking, how people track and the barriers that typically arise in self-tracking activities (See Figure 4.1). 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.

4.1 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 use tracked data 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].

4.2 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.

4.2.1 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].

4.2.2 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 found 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].

Study I - Interviewing COPD Patients about Needs

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

All interviews were audio-recorded. Recordings can be found on attached CD.

5.1 Activity Plan

Each interview is estimated to last one hour. Two researchers are present during the interviews, one facilitates the interview and an observer is responsible for audio and taking notes. The interviews are conducted as semi-structured interviews. Questions will relate to the use and the experience of the telehealth system. The patients are asked to show how they use the system, which the researchers will observe to identify 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 (e.g. 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 the recommended level of your measures?
 - Are you interested in know it?
- 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 in 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?

5.2 Own tracking system

As presented in the paper, two of the six patients did parallel tracking on paper as AmbuFlex did not provide access to past measures. One example, can be seen on figure 5.1.

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	85	+
MAN 29/2	68,	93	86	

Figure 5.1. 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 were less mobile and easily got tired, we conducted the sessions as individual sessions in the patients' own homes. We asked the same COPD patients as in Study I to participate, 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.

6.1 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.

6.2 The Prototype

Our proposal for the telehealth prototype consists of three 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:

On Figure 6.1 and Figure 6.2 we have examples of the collection page for respectively objective and subjective measures.

Both types of the collection pages (subjective and objective) have a reference graph in the top, which shows previous measures. We provided the reference graph, such that current state can easily be compared with previous measures, which could help judging upward or downward trends. We hoped, by knowing previous subjective measures an increased consistency across measures would occur.

As literature suggest, annotation can foster reflection. We therefore included a note area in the bottom of both types of pages (subjective and objective), where the patient could 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 included toggle buttons of context variables that the patient could toggle on/off, if one/or more were relevant. We included this feature to ease casual explanation in later review and trigger reflection. Depending on type of collection page (subjective or objective), the page consisted of either check-boxes to provide a subjective measure or a text-field to enter an objective measure.

The prototype was developed in Adobe Experience Design and 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, how patients reflected on them and which one the patients' preferred.

Adnan et al. found that users prefer visualisations with clear textual tooltips over highlighting to facilitate identification of temporal location and quantitative value of a particular data point. Their findings indicate that tooltips are more effective than highlighting and that cartesian coordinate systems in general is comparable or more effective than polar coordinate systems. They also found that interactive time series visualisations enhances the user experience [Adnan et al. 2016].



Figure 6.1. User interface for collection of objective measure (in this example saturation).

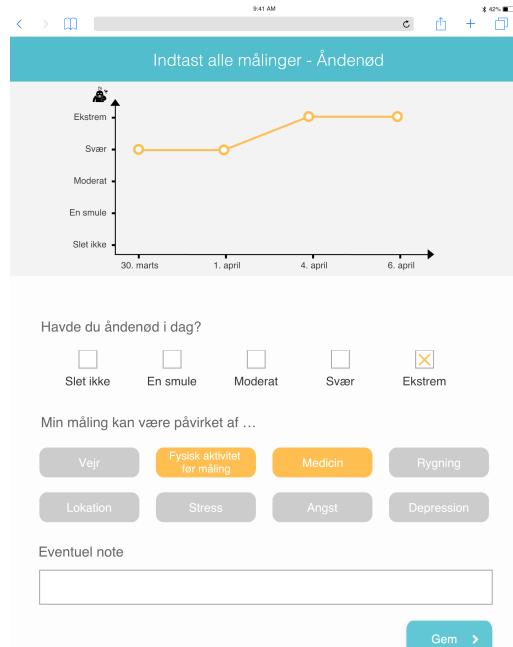


Figure 6.2. User interface for collection of subjective measure (in this example dyspnea).

Sorenson & Brath found visualising discrete events on time series problem-free only when multiple discrete events visually did not overlap and when the visualisation of the discrete event did not overlap an axis which helded important information (e.g. price). They also presented an alternative visualisation to visualise multiple discrete events simultaneously, which has proven successful in practice [Sorenson & Brath 2013].

Inspired by these two studies, we included interactive time series, containing textual tooltips in different types of cartesian coordinate systems. Discrete events were visualised one at a time (when toggled on) to avoid overlapping. We also included a calendar heatmap to support visualisation periodic patterns [Cuttone et al. 2014]. The calendar heatmap was similarly interactive and showed discrete events with same functionality as previously described (See Figure 6.6).

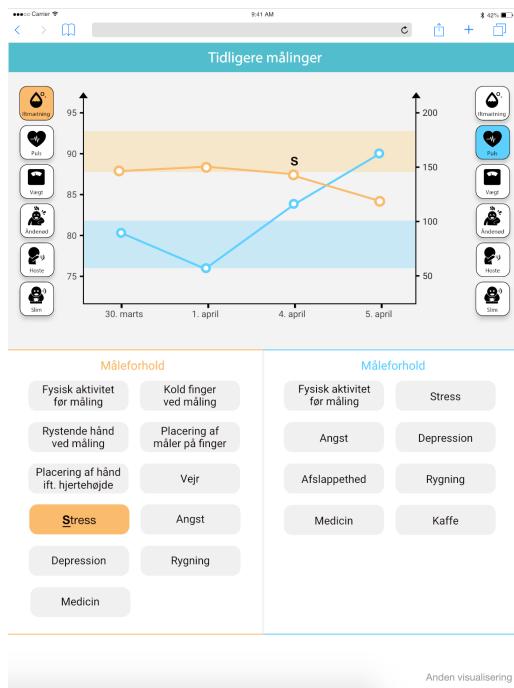


Figure 6.3. Visualisation 1.

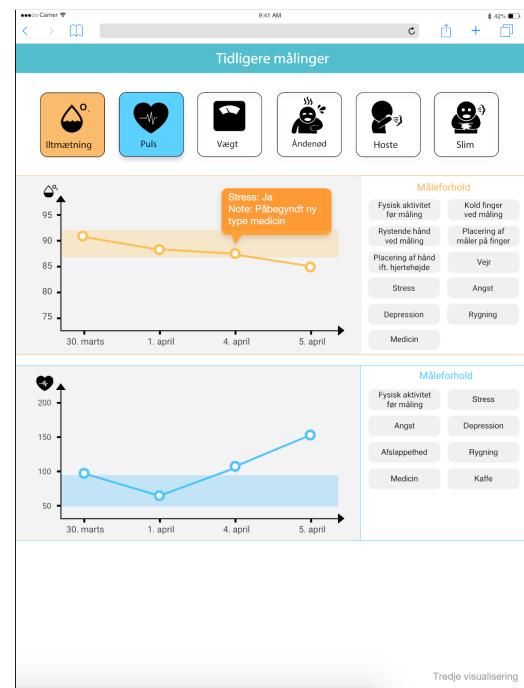


Figure 6.4. Visualisation 2.

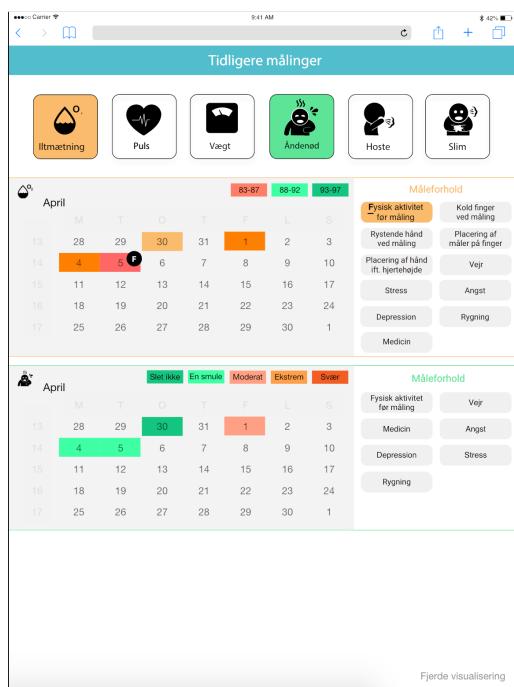


Figure 6.5. Visualisation 3.



Figure 6.6. Visualisation 4.

add 3, Dashboard:

The dashboard supported short-term reflection by showing current state relative to normal areas by color coding and showing upward/downward trends using arrows. We also included reflective questions (written in orange) for each a measure (See Figure 6.7).

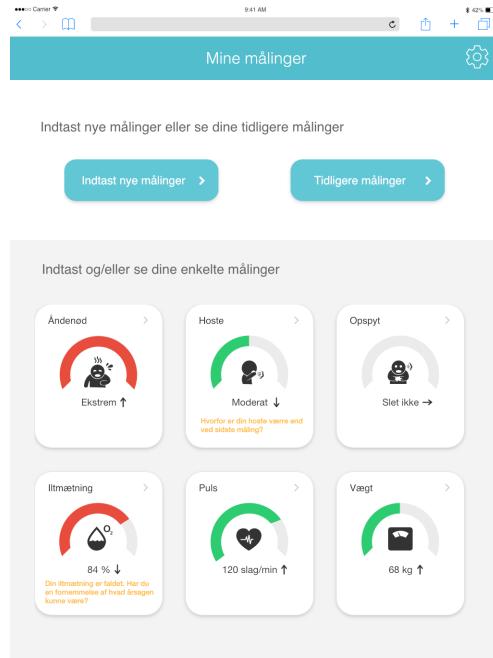


Figure 6.7. The dashboard.

6.3 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 Recorder for iOS" to record the screen, the front camera and the audio. The recordings are all to be found on enclosed 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. Are there any entered measures you do not want to share with the hospital? Why/why not?

6.4 Post Methodological Considerations

In retrospect, we have gained new experiences from the methods used in this study. 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 when using it for evaluation in the context. The tool did not provide us with an offline functionality, which meant that we needed to use our mobile hotspot from our phones in order to conduct the prototype parts. At one patient's house, we even needed to connect to her Wi-Fi, due to the 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.

There was a mismatch between our expectations in terms of user needs and the users' actual needs, not allowing us to gain as much knowledge from workbooks as we had hoped for. Many assignments related to reflection and the time series visualisations, which most patients were not interested in reflecting on. In the workbook, we asked patients if the time series triggered any thoughts, but more specific questions, e.g. asking about feelings triggered by the time series, could potentially have provided better and more useful outcomes.

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-recordings by showing which element the patient tried to interact with, which was not always from audio alone.

Implementation

We developed the system as a web application using both server-side and client-side programming. This chapter presents both sides of the programming, starting with describing the adjustments made to the design based on findings from Study II. Security considerations and implementation are described at the end of the chapter. The developed application can be found on attached CD.

7.1 Design Changes



Figure 7.1. Dashboard used in Study II

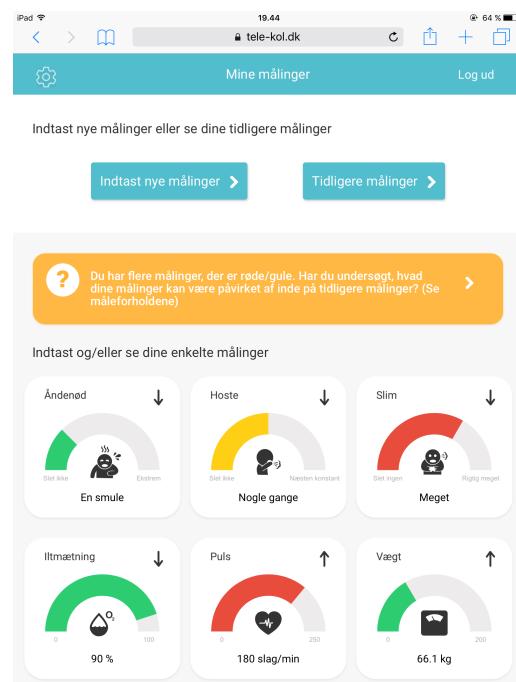


Figure 7.2. Redesigned dashboard

Reflective Questions

Reflective questions were measure-specific in our first design proposal as seen on Figure 7.1. We found in Study II that patients did not notice the reflective questions and thus decided to redesign the reflective questions as seen on Figure 7.2.

Reflective questions were redesigned to target overall health status and updated depending on following conditions:

When all color indicators were green (or only one yellow/red)

- When should you be extra aware of your symptoms?
- What is the status on your measures?
- Is there any improvement in your latest measures? (Look at the arrows on each measure)
- Have you explored what your measures might have been affected by in previous measures? (See measurement conditions)
- Have you examined whether your normal range is adjusted to your needs? (Look at settings gear in the upper left corner)

When at least two measures were yellow/red

- (You have multiple measures showing red/yellow.) Have you previously been able to improve your measures? How?
- (You have multiple measures showing red/yellow.) Which measures should you be aware of?
- (You have multiple measures showing red/yellow.) How are your responses when you feel well?
- You have multiple measures showing red/yellow. How long have your measures been like this? Is there anything you should be aware of?
- You have multiple measures showing red/yellow. Is there any improvement in your latest measures? (Look at the arrows on each measure)
- You have multiple measures showing red/yellow. Have you explored what your measures might have been affected by in previous measures? (See measurement conditions)
- You have multiple measures showing red/yellow. Have you examined whether your normal range is adjusted to your needs? (Look at settings gear in the upper left corner)

The reflective question updates after one or more measures are entered.

Visualisation Choice

We provided patients with four visualisations in study II and from the feedback found that patients had different preferences. Based on findings from literature and patients' statements about the visualisations, we chose Visualisation 1 for long-term reflection (See Figure 7.4).

Normal Area

Based on findings from previous research and findings from Study I showing that patients preferred their own normal area we provided the patients with a settings option to individualize the normal area for each objective measure (See Figure 7.3).

7.2 Server-side Programming

We used PHP to create sessions and to manipulate the user's data on the server-side.

Indstillingerne for normalområderne
Ved at ændre tallene nedenfor, kan du tilpasse normalområderne, så de passer til dig personligt. Ved ikke, hvad dit normalområde typisk er, så tal evt. med din sygeplejerske/lege.

Vær opmærksom på at et normalområde kan ændre sig over tid.

Puls
Personer med svær eller meget svær KOL har typiske en hvilepuls på 76-88.

Fra **89** Til **90**

Iltmætning
Det typiske normalområde for personer med KOL er 88-92.

Fra **88** Til **92**

Vægt
Dit normalområde for vægt er beregnet ud fra din højde og din alder (medmindre du har ændret det).

Fra **45** Til **74**

Fortryd **Gem ændringer**

Figure 7.3. Settings.

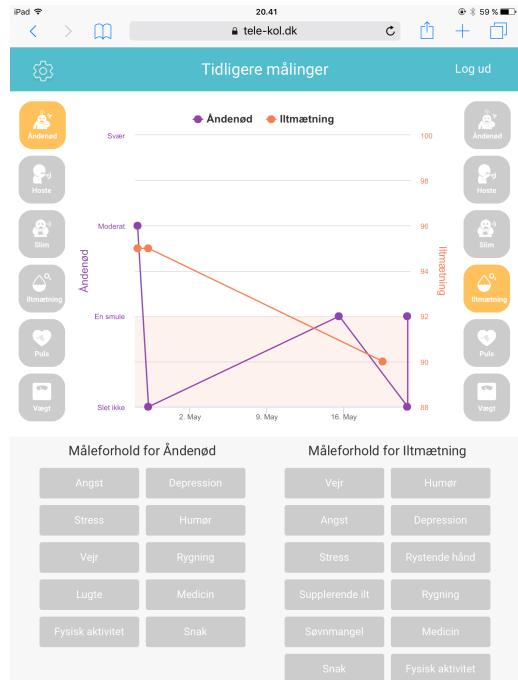


Figure 7.4. Visualisation 1.

7.2.1 Session

We created a session, when the user logged into the system. A session is a way to store variables across multiple pages, which is the case (e.g.) when a patient navigates from the dashboard to collection. By saving an identification variable in the session, the system knows, who logged in across multiple pages. We programmed the session to automatically end after an hour. We created two types of directories, one for the patients and one for administration purposes. The administrator directory was made inaccessible to users (using the session).

Administrator Access

The administrator page provided access to our log, where we had a live view of the current use. We used it as investigation tool when we had a minor mix-up with user credentials and to see if patients had started using the system (in case any patients needed a reminder). We also made it possible to do manual logging, which we used when logging in as a patient.

We also made an administrator page for adding data to the different user's profiles, which we used when we entered the patients' measures from the paper template, which they filled out prior to the study. We also used it to add patient information to each user profile, where the system automatically calculated normal areas for weight.

7.2.2 Data

We stored the patients' data in JSON, which is easy to navigate within when working client-side (in JavaScript). We developed a data-structure (See Figure 7.5). The data structure holds information of the user's normal areas, the measures, whether latest entry was all measures or just one (which decides if a reflection note will be stored on a single measure or on all six) and a reflection part that hold information of what reflective questions the user has received and

the latest reflective question (in order to visualise it again when a user returns to the system).

```
{
  "user": {
    "properties": {
      "type": "p",
      "gender": "male",
      "age": 70,
      "height": 170,
      "weightMin": 45,
      "weightMax": 75,
      "pulseMin": 70,
      "pulseYellowMin": 71,
      "pulseYellowMax": 76,
      "pulseGreenMin": 76,
      "pulseGreenMax": 88,
      "pulseMax": 89,
      "ownPulseRangeMin": "",
      "ownPulseRangeMax": "",
      "satMin": 88,
      "satMax": 92
    },
    "measures": {
      "pulse": [],
      "sat": [],
      "weight": [],
      "dyspnea": [],
      "cough": [],
      "phlegm": []
    },
    "latestEntry": {
      "allMeasures": "",
      "latestMeasure": ""
    },
    "reflection": {
      "latestWasSession": "",
      "pSessionsReceived": [],
      "aSessionsReceived": [],
      "dashboardQuestions": [],
      "latestQuestion": "Hvordan har du det?"
    }
  }
}
```

Figure 7.5. Data structure.

Webservices

We made multiple webservices to manipulate the user's data. With use of an example, we explain the principles of the webservices and how they are used to manipulate data. As an example we will save the latest reflective question the user has received in the user's data:

The server gets a call from the client with the latest reflective question received. By using a data class (which we developed for all webservices that manipulates user data) the data class, based on the session, finds the path to the user's JSON and returns the user data. The webservice now updates the data and saves it using the same data class again. The process can be seen on Figure 7.6.

```
include 'UserData.php';

$userData = new UserData();
$profileData = $userData->getUserData();

$profileData['user']['reflection']['latestQuestion'] = $_POST['latestQuestion'];
$userData->setUserData($profileData);

echo json_encode($profileData['user']['reflection']);
```

Figure 7.6. Webservice for saving the latest reflective question the user received.

7.3 Client-side

Get user data

In order to get each user's data on login, we used ajax from the jQuery library. By updating HTML elements with use of jQuery we provide the user with visualisations matching the measures entered.

When wanting to add a line in the log (which is a simple .txt file), we called the server using ajax and sent the needed information (to log), whereafter the server added a line to the log (the server knows from the session who made the call).

User Interface Elements

The interface was built on the Bootstrap front-end framework [Bootstrap 2016]. Bootstrap is open-source and provides HTML and CSS templates along with JavaScript components to design and build responsive web applications. For dashboard gauges we made use of the JavaScript plugin *JustGage* [JustGage 2016], while we used *Highcharts JS* [Highcharts 2016] for visualising history data.

Figure 7.7 shows an example of creating the gauge for cough with parameters customized for each measure (number of options for the value, colors depending on current value, min and max text labels)

```
var cough = new JustGage({
  id: "cough",
  value: coughToday,
  min: 0,
  max: 4,
  minTxt: "Slet ikke",
  maxTxt: "Næsten konstant",
  customSectors: [
    {
      color: "#2ECC71",
      lo: 0,
      hi: 1
    },
    {
      color: "#FFCF15",
      lo: 2,
      hi: 2
    },
    {
      color: "#E74C3C",
      lo: 3,
      hi: 4
    }
  ],
  textRenderer: function (val) {
    if (val == 0) {
      return 'Slet ikke';
    } else if (val == 1) {
      return 'Sjældent';
    } else if (val == 2) {
      return 'Nogle gange';
    } else if (val == 3) {
      return 'Ofte';
    } else if (val == 4) {
      return 'Næsten konstant';
    }
  }
});
```

Figure 7.7. Javascript code for creating a gage. In this case for cough.

7.4 Security

As we were working with patients' data, we had an ethical responsibility. We handled all the patients' data anonymously, such that no patient could be identified from the data on the

server.

In principle this should be sufficient, but we added additional security to the system, which we consider as good practice. First of all we used a SSL certificate to keep sensitive information encrypted, when the user sent data to the server. This made sniffing of data less easy. Since we used JSON files on the server to store patient data, we also restricted the access to the JSON files with use of .htaccess files and .htpasswd files thus when trying to access the files a username and a password is needed, in order to get access to that directory on the server. This system is not at all considered as a highly secure website, but sufficient for a two week trial trial. A database setup would be a good consideration for future use.

Study III - Trial with COPD Patients

The purpose of Study III was to evaluate the implemented telehealth system in a real context. We here present details on methods used.

Preliminary Data Collection

We collected preliminary data prior to the study of two reasons. 1) System's dashboard needed two measures in order to show upward or downward trend and 2) the participants needed history data to reflect on from the beginning 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 enclosed CD. The dates in the template varied depending on when a patient was enrolled in the study.

Diary

Patients were encouraged to write in a diary after system use during the trial period (See Figure 8.1). 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.

We told patients that the questions were only meant as inspiration and that it was optional to write in the diary, e.g. 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 (See Appendix A.1).

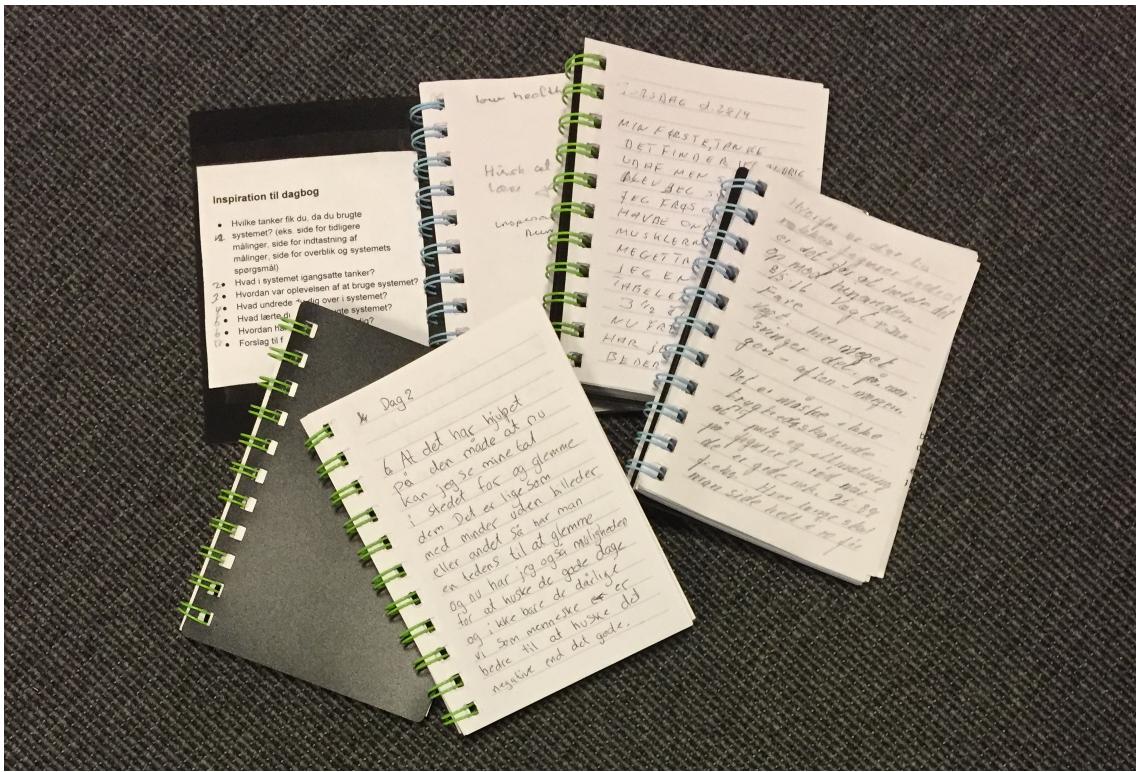


Figure 8.1. Data collected using diaries

Demographics

Demographic data of each patient completing the study can be found on the 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 identify 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 the CD.

Cue recall

To cue recall from using the system during the interview, we made two initiatives. First, we prepared screenshots of patients' dashboards showing events of interest (e.g. worsening or improvement in measures between two days). Figure 8.2 and Figure 8.3 show an example of the two screenshots that were prepared for P4.

Figures show an improvement in health status. We hoped that providing screenshots could help patients recall the situation and reveal the reflection and feelings that potentially occurred. All the prepared screenshots can be found on attached CD.

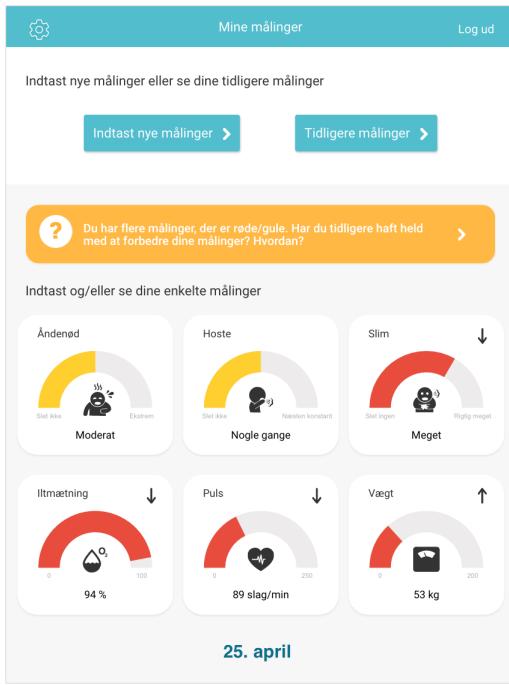


Figure 8.2. Status from first day of use (April 25) for P4.

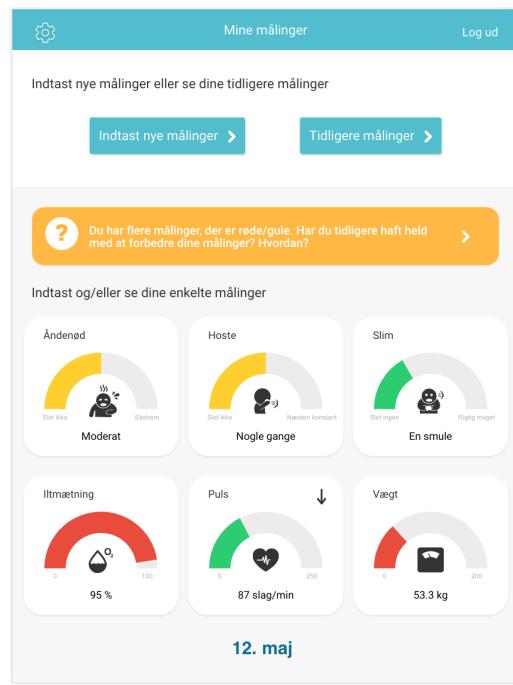


Figure 8.3. Status from last day of use (May 12) for P4 before evaluation.

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 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 continuously considered different interesting research areas related to this project during this semester. We here bring a list of potential areas:

- Introducing different media types for detailing different granularities related to a subjective question.
- In relation to previous bullet, what happens when you introduce interaction?
- According to patients an exacerbation comes quickly (within 1-2 hours) but they only submit measures 3 times a week. Would continuous assessment of saturation with use of wearable improve early detection of exacerbations?
- We found no decision support systems targeted COPD patients. How could such a system be designed?
- How does active prompting based on context variables affect reflection and reliability?
- What patient types emerge when entering the Action stage? What is needed to take action?

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APPENDIX **A**

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