

# Designing for Reflection: Chronic Obstructive Pulmonary Disease Patients as Self-Trackers in Telehealth

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## ABSTRACT

Telehealth (TH) 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 interview data from six Chronic Obstructive Pulmonary Disease (COPD) patients to improve understanding of user needs and concerns in the use of a state of the art TH solution. While patients generally felt taken care of, the system in many ways did not meet user needs. It included no access to previously entered data leading to difficulties assessing reliable subjective measures and provided no support on reflection and follow-up action.

## Author Keywords

self-tracking; personal informatics; reflection; telehealth; chronic obstructive pulmonary disease;

## INTRODUCTION

In response to ageing societies, there is an increasing need for people to take an active role in their own health and well-being. Designing technologies that support self-reflection, awareness and self-management of chronic conditions have particularly been of interest to HCI researchers to support quality of life issues. Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease in which the airways are damaged. People with chronic health conditions such as COPD occasionally experience exacerbations that, if not detected and treated early, result in an increased use of healthcare services and a decline in health-related quality of life. Previous studies have shown poor self-management among COPD patients, who do not respond to the early warning signs, because they have difficulties recognizing the onset of an exacerbation or its importance, resulting in delayed recognition and treatment of exacerbations.

Telehealth technologies where patients log and keep track of important variables and symptoms (e.g. self-reported shortness of breath or fluctuations in oxygen saturation measures) are widely used today by healthcare providers to remotely monitor patients and support early detection and initiation of treatment. We refer to the ongoing activity of logging data (objective or subjective) during concrete *episodes* over time

as *self-tracking*. Self-tracking is well-understood from literature on the Personal Informatics movement, where people voluntarily, self-initiate and successfully use technology to enhance self-awareness, self-reflection and thereby change behaviours, improve health or other aspects of life. While the health literature provides little information on, how patients are supported in their self-tracking efforts in the telehealth context, Personal Informatics literature investigates interaction design aspects of self-tracking important for the successful integration of technology in self-tracking interventions.

We synthesized findings from the disparate fields of telehealth and Personal Informatics and used it as an analytical lens for material from semi-structured interviews with COPD patients using a telehealth solution to understand, how we can support patients in their self-tracking efforts (Study 1). While patients generally felt safe, many struggled with subjective data entries that employed references to perceived baselines. The state of the art system they used provided little support on follow-up actions and reflection by excluding access to historical data.

We used findings from the literature and the study to propose design solutions through mockups, focusing on supporting self-reflection that could potentially support patients in the early detection and treatment of exacerbations. We conducted individual feedback sessions on design mockups with five COPD patients (Study 2) and found that not all patients were willing to engage in self-reflection and identified some major concerns related to the design proposals.

We redesigned and implemented a prototype to evaluate it in a real context during a two-weeks trial by six new COPD patients (Study 3). The trial informed, how four concrete design decisions affects reflection among COPD patients. This paper presents key findings on how telehealth systems in the future may be designed to support reflection, finish by drawing some key concerns for those intending to design and evaluate reflection.

## BACKGROUND

In recent years, Personal Informatics or Quantified Self (QS) tools have received an increasing interest in the field of human-computer interaction with the introduction of low-cost mobile applications, wearables and advances in sensor technologies. Personal Informatics help people understand themselves through self-tracking of personally relevant in-

formation for the purpose of self-reflection and gaining self-knowledge [5].

Researchers have proposed different models for understanding, how self-trackers concretely use Personal Informatics tools over time. Li et al. proposed the cascading five-staged *Personal Informatics Model* describing, how self-trackers transition between: (1) *Preparation* (determining variables, tools and frequency of tracking), (2) *collection* (logging data), (3) *integration* (preparing data for reflection e.g. by aggregating and analysing data), (4) *reflection* (examining data to gain self-knowledge) and (5) *action* (deciding what to do with said knowledge) [5].

Little is known about self-tracking practices around telehealth systems in the health context, but we found that despite telehealth does not completely reflect the practices of Personal Informatics (because there are multiple stakeholders/users in telehealth), the above-mentioned stages still apply. We have illustrated the differences between stakeholders roles in Personal Informatics and Telehealth on Figure 1.

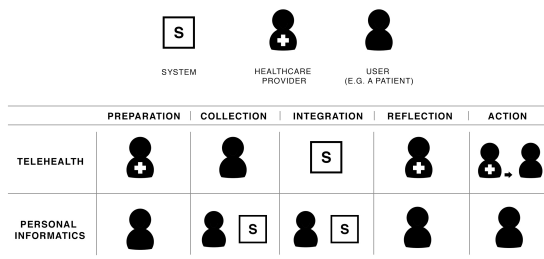


Figure 1. Stakeholders model bla bla

In telehealth, healthcare providers mandate and predefine what symptoms, how often and with what tool patients should track (*preparation*). Patients collect both objective numerical (e.g. oxygen saturation measures) and subjective binary data (e.g. yes/no answers to whether dyspnea has increased more than usual) (*collection*). The system integrates the data and based on predefined individual normal ranges flags data for follow-ups (*integration*). Trained nurses or physicians review the self-tracked data (*reflection*) in telehealth and if needed contact and advise the patient on potential initiation of treatment (*action*) [10, 8].

Epstein et al. found that *collection*, *integration* and *reflection* are ongoing processes that can occur simultaneously and integrated *lapsing* (e.g. due to an oversight, holidays, injuries or when life habits change) and *resuming* into their *Lived Informatics Model* [3, 9].

Rivera-Pelayo et al.[?] and Mller et al.[?] discuss Personal Informatics in light of reflective learning theory (or learning by reflection) based on the work of Boud et al., who describe reflection as those intellectual and affective activities in which individuals engage to explore their experiences in order to lead to new understandings and appreciations [?].

Rivera-Pelayo proposed a framework that shows three dimensions in which technology can support reflection: (1) Tracking, (2) Triggering and (3) Recalling and Revisiting.

## STUDY 1

### Participants and Method

Six COPD patients (P1-P6), two male patients (P1, P2) between 64 and 65 years (M: 64.5) and four female patients between 54 and 74 years (M: 66.8), participated in our study. All patients had either severe or very severe COPD and multiple other health-related conditions (diabetes, heart disease, pulmonary oedema, asthma, bronchitis, osteoporosis and sleep apnea). Three of the patients used supplemental oxygen (P3, P5, P6). All of them lived in their own homes with a spouse, except one female who lived alone. P6s spouse (P6S) was her spokesman, as she had a speech disorder. We conducted audio-recorded semi-structured interviews in patients own homes. The participants demonstrated to an interviewer and a researcher who took field notes, how they used AF.

All six participants used the AmbuFlex (AF) solution for at least three months, while three previously had used Tunstall HealthCare (THC). AF is web-based and can be accessed by mobile or desktop. THC consisted of a monitoring box installed in the patients home. In both systems, patients submitted objective data (oxygen saturation, lung function (only in THC), pulse and weight) and subjective data (binary answers to whether dyspnea, cough and sputum color had been higher than usual) three times a week (Monday, Wednesday and Friday). AF provided confirmation of submission but no option for reviewing previous data.

## Results

All patients remembered to take their measurements consistently and routinely in the morning themselves (P6S took responsibility for P6). The majority of participants (P1-P5) found the sense of security from healthcare providers monitoring their data motivating. *They call you if you do not send in your readings .. it gives you a huge sense of security that you are not gonna lay at home ill* (P2). P4 felt obligated to take measurements due to the presence of a healthcare provider. Two patients tracked additional data on paper (P5, P6S). P5 used the data as documentation, e.g. when being admitted to the hospital to discuss it with healthcare providers. P6s spouse mentioned curiosity, self-satisfaction and sense of agency as motivations for tracking on paper.

### Collection

Patients found data collection easy, not requiring expert computer skills, and not taking too much effort or time. P5 stressed the importance of fast collection, *it must not take ten or fifteen minutes to do it everyday (...). This [AF] is really simple (...)* it is so simple you can add some more to it (P6S). Several patients found answering subjective questions difficult when it required comparisons with the usual baseline, (Are you coughing more than usual?). *What is usual? Isnt that also how I felt yesterday? Otherwise, I have misunderstood the question* (P4). Patients needed higher than binary granularity to answer, *When they ask if you have more*

*dyspnea than usual, then we say yes .. but how much is it? They [healthcare providers] cannot see (P6S). Some patients underreported baseline deviations and only answered yes in large or extreme deviations, if its just a little different, I do not mention it (P2), I would have to be coughing a lot and feel very ill, if I answer yes to that question (...) (P4). P2 asked for a scale instead (...) why dont they make a scale instead for example from 1 to 5 or 1 to 10? One day I could perhaps say its 5, the next day 6 and the day after I can go back to 5. P5 used the comment box to make small deviations go on record, (...) to me it is important that we take every small nuance. When to collect, was a concern for P4 whose oxygen saturation measure and pulse depended on her level of activity. She wondered why the system did not take into account external factors related to her condition, Do you feel more breathless today? But it does not say anything about the fog outside (P4).*

### Reflection

Several patients mentioned that an exacerbation comes within a few hours or even minutes, and that they were not able to recognize an onset by using AF. P1, P2, P3 and P5 measured oxygen saturation several times a day to verify their subjective feeling of well-being (P2, P5) or lack thereof. None of the patients felt they learned anything about their disease using AF. *I can feel it [an exacerbation], even if I did not have the monitoring device (P3). Patients did not express any concerns waiting for a (potential) call. Most of them had identified the hours of the reviewers at the hospital and several a mental model of when a call would ensue. They usually do it [review the data] before noon (P3). I already know when there is going to be a call (...) when the oxygen saturation is too low, the pulse is high and your measures fluctuate, they react (P2). P6S found benefits in tracking data on paper, allowing for understanding his wifes baseline and whether she was deviating from it and getting worse. You can see how stable it is .. (...) Lets say she loses weight then I become alert that something is wrong (P6S). Patients had not been informed by their healthcare providers about their normal range and the AF interface did not communicate it either. Half the patients wanted to know these in numbers. Some of the patients had identified their own normal range of oxygen saturation that mapped to not feeling well (usually below 90).*

### Action

All patients had received education in self-management of their condition (e.g. breathing techniques), but not all patients gained the same benefits from it and needed actionable advice. To that end some patients (P2, P5) added questions to the comment box. P2 acted on the basis of his oxygen saturation measures, *when it [oxygen saturation measure] is lower than 93, you do not feel fine (...) then I walk a little slower and take it a bit more easy. P2 was interested in knowing additional methods to increase oxygen saturation. P6S wanted recommendations on duration for supplemental oxygen use based on her oxygen saturation measures and information about variables e.g. the weather, that could influence her symptoms. P3 and P4 used their oxygen saturation measures adjust their supplemental oxygen. However, P3 preferred not to initiate treatment including drugs before*

*consulting a healthcare provider, unless in extreme cases of symptoms or unavailability of staff. I might to do it [initiate medication treatment] if it [sputum color] was very green, if it was a Tuesday [a day not monitored by healthcare providers], otherwise I wouldnt (...).*

### Discussion

Our patients were highly motivated to track potentially due to the active role of the healthcare provider that provided them with a sense of security not present in previous studies [5, 1, 2]. One consequence was that one patients relied too much on the monitoring and delayed treatment, waiting for confirmation from the healthcare provider. Based on our findings and literature review, we revised the *Lived Informatics Model* [3]. We broke down a data collection episode into *pre – collection* (deciding on whether to log or skip), *acquisition* (ready required artifacts), *calibration period* (satisfy guidelines for tracking), *entry* (providing scale based ratings, absolute or relative to a baseline, or qualitative comments), *submission* (submitting data), and later *review*. The patients reflected during multiple stages of collection before entering both subjective and objective measures.

AF did not meet the needs of users in terms of (1) scope, (2) reliability, (3) validity, and (4) actionable advice. AFs scope focused only on submitting variables directly related to the condition at time of entry, but two patients tracked additional and one submitted data on paper (c.f. [7, ?]). Having access to their previous data made them feel in control.

None of the patients described the tracking activity requiring too much effort or time. However, effort seemed to be an aspect that should be considered when designing TH systems, as patients both expressed willingness to spend more time than AF required (approximately two-three minutes) but not wanting to spend more than ten minutes.

In terms of reliability, patients were unsure whether they were collecting data under the right conditions. They sought specific guidelines and/or options for annotating context in which they had taken measurements as in [11] to ensure valid data entry. Subjective questions with a baseline comparison requiring dialogic reflection (c.f. [4]) proved difficult due to: no access to the baseline and the low granularity of the answer options. Patients had insufficient access to their usual subjective feelings and tried to remember previous events to establish their usual baseline (c.f. [10]) and AF provided no access to historical data. Even if AF provided access previous data this might prove difficult due to the low granularity. The binary answer options resulted in reduced validity of data by underreporting significant increases from the baseline. One patient specifically asked for rating on a scale instead, which requires more cognitive effort and time [6].

Due to the absence of data access, patients did not interact with the data they had collected and expressed not having learnt anything from TH. Several patients mentioned not being able to recognize onset of an exacerbation from AF use, suggesting that the system poorly supported reflection. Patients did not know their provider-recommended normal range and therefore used their own identified normal range.

Some patients wanted to know the provider-recommended normal range to become more empowered, while others were not interested. One reason for that could be that patients get reminded about the negative aspects of their health when reviewing data or that they rely more on their subjective feeling than on quantities, as in [1].

Several patients were interested in actionable advice from the system as in [2, 5]. Apart from during subjective data entry, patients needed two types of support, (1) confirmation from healthcare providers to act (e.g. initiation of medication) and (2) actionable advice on self-management strategies (e.g. coping with breathlessness). We believe that one of the barriers to action was the lack of support for reflection during entry and review of data - a prerequisite to action according to Li et al. [5].

## STUDY 2

### Method

Workbook design

Prototype design

### Results

### Discussion

## STUDY 3

### Method

### Results

### Discussion

## CONCLUSION

## FUTURE WORK

## ACKNOWLEDGEMENTS

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