






“I Have to Do Something About It” - An Exploration of How Dashboards Invoke Self-Reflections in Chronic Obstructive Pulmonary Disease Patients

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Abstract. Chronic Obstructive Pulmonary Disease (COPD) patients need to track their symptoms for health professionals to adapt treatments in a timely manner in case of health deterioration. Clinicians typically analyzed the tracked data and recommended actions to patients who acted as mere data collectors. Consequently, patients have little agency and motivation to self-track. Two studies investigated how digital dashboards influenced patients’ motivation, agency, and reflections. Study 1 (one week) focused on how five patients used a paper diary to self-track and reflect on their symptoms. Additionally, the patients evaluated a tablet-based digital dashboard using four data visualisations. Study 2 looked at how five patients tracked and reflected on their data using a tablet-based dashboard for two weeks. By using reflective questions to prompt patients to compare and reflect on time series charts with data annotations, patients gained new knowledge about what factors might influence their symptoms and identified actions to improve their health (e.g. increase oxygen supplements). This strengthened their sense of agency and motivated them to participate more in the management of their condition.

Keywords: Self-tracking · chronic obstructive pulmonary disease · COPD · personal informatics · data collection · reflection · dashboard

1 Introduction

To prevent the health decline of patients with chronic obstructive pulmonary disease (COPD), healthcare professionals need to monitor their condition and symptoms. Some countries (e.g. Denmark) and hospitals require patients to submit data on symptoms, so-called patient-reported outcomes (PRO), for clinician analysis and decision making on when to take actions [29,32,40]. This gives patients little agency or insight into their health, which reduces their motivation to collect health data consistently [17,25]. Patients also lacked knowledge on how to interpret and reflect on health data to

improve their condition which impeded their self-tracking [17,25,26,29]. Some studies hypothesized that providing instructions on self-tracking to encourage patients' reflection can increase their motivation to self-track and enable them to improve their health [25,26,29]. Current digital dashboards have employed visualisations, written guides, and reflective questions to instruct patients on how to collect and reflect on data [1,20,29]. While many studies investigated how patients interpreted dashboards in single sessions lasting no longer than one hour [3,24,29,32], only few investigated how reflecting on self-tracked data can impact COPD patients' motivation and knowledge over a longer period of one or more weeks [25,26].

This paper describes two studies investigating how a digital dashboard for COPD patients impacted knowledge and motivation for self-tracking after extended use. Our findings suggest that patients can gain new knowledge about how to track and alleviate their symptoms after using a dashboard promoting reflections for two weeks. We describe how reflections self-tracking gave COPD patients a sense of agency over their illness and motivated them to actively reflect on and improve their health.

2 Background

Healthcare professionals (i.e., clinicians) cannot cure or reverse COPD but can administer treatments to reduce symptoms. Clinicians relied on PRO measures through telehealth applications to initiate these treatments and prevent health declines [32,40]. In the absence of a model for such mandated use, we relied on Li's stage-based model of personal informatics systems [20] to define the activities of self-tracking. The model breaks down self-tracking into five stages: 1) determining variables, tools, and frequency of tracking (*preparation*), 2) logging data (*collection*), 3) preparing data for reflection e.g. by aggregating and analysing data (*integration*), 4) examining data to generate knowledge (*reflection*), and 5) deciding what actions to take (*action*) [20].

In the COPD case, clinicians prepared the collection stage by predefining relevant symptoms for tracking through objective numerical measures (e.g. oxygen saturation measures) and subjective binary measurements (e.g. yes/no answers to whether dyspnea has increased more than usual). Clinicians integrated and reflected on the patient-provided data to determine whether these fall into acceptable ranges and advise patients on possible actions [29,32,40]. Thus, patients only received feedback when clinicians identified declining health which demotivated some patients to incorporate self-tracking into their daily habit as they could not reflect on their data themselves [1,17,41]. To gain a sense of agency, patients recorded data for their own use using notebooks, diaries, and applications [16,27–29,31]. However, many patients lacked the knowledge and skills to reliably track data and identify variables impacting their results (e.g. weather) [1,7,11,30,40]. Both healthy users [2,13,36] and patients [17,25,29] did not know how to reflect on their data nor identify appropriate actions to improve their health (e.g. losing weight). Instead, self-trackers; including patients, needed actionable (expert) advice [20,30,41].

Self-trackers often lost their motivation due to tracking fatigue caused by the continuous effort needed to measure and log data [6,20,28]. Chronically ill patients (e.g. with cancer) experienced fatigue more strongly due to their symptoms, prompting them to

stop self-tracking earlier than healthy users [1, 31]. Demotivation may lead to patients postponing the recording data [1, 23], which biased later entries and reduced data reliability [18]. Alternatively, patients measured symptoms in a disorganised manner resulting in poor self-tracking data (e.g. incorrect measures) [3, 19, 40]. Both healthy [11, 20] and COPD [17] self-trackers felt motivated by monitoring progress towards goals and their curiosity in the data which lead to concrete actions towards health improvement.

These actions stemmed from either short-term reflections where self-trackers reflected on their status immediately after data entry or long-term reflection where self-trackers reflected over trends after several days or weeks [20]. Long-term reflection allowed for higher levels of data exploration by comparing, exploring, and finding patterns [20]. Typically, reflections arose from discrepancies between actual and expected measurements (e.g. recommended levels, goals, and previous levels) [1, 13, 27, 35]. To trigger reflections, some systems guided patients' towards discrepancies in the data through reflective questions asking patients to explain discrepancies [17, 27, 29]. Presenting data through data visualisations aided healthy users in exploring patterns to discover discrepancies [6, 13, 20]. Therefore, self-tracking applications employed data visualisations to aid both healthy and chronically ill users in short-term reflections about their health [5, 12, 34, 44]. However, data visualisations must account for the users' condition, skill, purpose, and motivation to aid reflection [9, 28]. For example, data visualisation can support the questions self-trackers pose while reflecting: 1) What is my current status? 2) How does the current status compare to earlier values (history)? 3) How is it related to other variables? 4) What affects my current status? 5) What is an appropriate goal? 6) How does the current status compare to my goal? [21].

Single value charts provided self-trackers with a quick overview of their current status [28]. Time series charts visualized past experiences (history) to reflect on trends or deviations and triggered storytelling about experiences behind data [1, 28, 35]. Comparison charts with time series visualisations for multiple variables sharing the same vertical axis supported reflection on discrepancies between variables [9, 38]. Calendar heatmap visualisations can illustrate periodic patterns by color-coding variables [9]. Baselines (e.g. general averages) added to visualisations provided context to measurements when reflecting [15] and helped chronic patients determine the severity of their symptoms, which they previously found difficult as they were constantly symptomatic [17, 40]. However, self-tracking applications often limited reflections by only having either simple visualisations invoking short-term reflection or more complex charts (time series) invoking long-term reflection [21, 23].

Dashboards can contain multiple simple and complex visual visualisations of the self-tracked data [9]. Most dashboards only allowed for explanatory analysis through static charts which they could not create, search, or edit [6, 7, 20, 42]. While this limited users' knowledge generation, it simplified the task of reflecting for users unfamiliar with visualising and analysing data [37]. Both clinicians and patients valued dashboards for patients to reflect on their condition [15, 29, 39]. Despite this, only a few studies investigated how dashboards affected patients' self-tracking [22, 24]. Patients often struggled to generate knowledge from dashboards as they did not understand the medical terminology and data [22, 24]. When confronted with visualisations depicting worsening health (e.g. increased symptoms, decline in physical or cognitive performance, etc.),

patients tended to reject results or stopped reflecting [1, 15, 17, 29]. However, the majority of these studies investigated self-tracking contained in single sessions, typically less than an hour [15, 22, 24]. They focused on short-term use and did not investigate how patients adapted to tracking, knowledge development over time, and motivating factors of continued self-tracking [26].

This paper investigates how dashboards utilizing data visualisations, contextual annotations, and reflective questions can support COPD patients to reflect on their condition, thereby improving their sense of agency and motivation to self-track.

3 Study 1 - Reflecting on a COPD Dashboard

This study explored COPD patients' initial opinions of a web-based dashboard designed to encourage reflections. To track their health for a week, participants received a paper diary that utilized different ways to prompt reflection. Afterwards, participants reviewed four dashboards designed to promote short and long-term reflections using different, simple and complex data visualisations paired with reflective questions and contextual annotations to prompt reflection. We evaluated, which designs patients preferred through in-situ interviews.

4 Apparatus

The diary (see Fig. 1) consisted of three assignments conducted over a week (Monday, Wednesday, and Friday). On each day, participants recorded their: pulse, weight, blood oxygen level, and answered two questions: “*have you experienced shortness of breath today?*” (five-point Likert scale: 1 = none, 5 = extreme) and “*have you experienced more shortness of breath than usual?*” (yes/no). To encourage short-term reflection on the first day, participants could freely annotate external variables (e.g. weather, mood, physical activity, etc.) which may have influenced their dyspnea. To promote reflection on the second day, participants could only select predefined external variables using check boxes in place of annotations. Additionally, a question about their dyspnea using the



Fig. 1. Workbooks with assignments

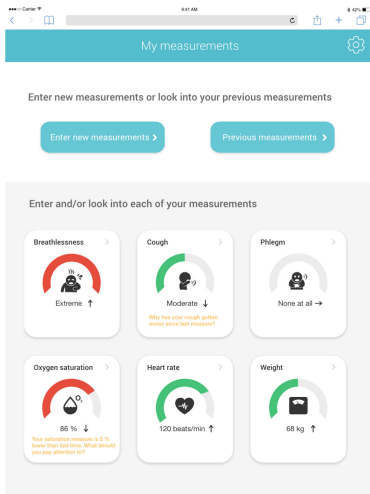


Fig. 2. Overview screen: top - buttons for data entry, bottom - overview of the six measurements' gauges

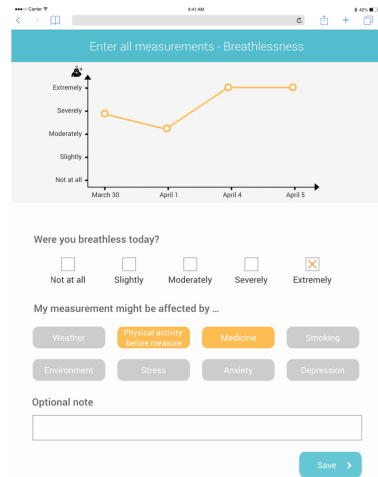


Fig. 3. Data entry screen: top - time-series line graph, middle - data entry, bottom - context-relevant variables

seven-point Dalhousie Pictorial Scale was included [33]. To promote long-term reflection on the final day, participants could insert the measurements they collected throughout the use of the diary for blood oxygen levels and the two aforementioned questions into time series graphs. The graphs displayed the participants' recorded measurements on the y-axis and the day along the x-axis. The graphs included a line depicting the recommended health level to trigger reflection in the case of discrepancies between current and target measures. The dashboard prototype consisted of three screens: 1. an overview screen (see Fig. 2), 2. a data entry screen for data collection (see Fig. 3), and 3. a previous measurements screen (see Figs. 4, 5, 6, and 7).

The data entry screen mimicked the diary page for entering pulse, weight, and blood oxygen level but only contained one question: “*were you breathless today?*” (five-point Likert scale: none, to extreme). To help patients' remember previous values during data entry, the data entry screen included a time-series line graph. For each data entry users could add context variables describing factors when the measurement was taken (e.g. being stressed, weather, etc.) to relate them to their measurements and aid in pattern identification.

Completing data entry returned users to the overview page, which encouraged short-term reflections and further data exploration by including reflective questions (e.g. “*Why are you more out of breath than last time you measured?*”) alongside a gauge. The six colour coded gauges seen in Fig. 2 indicated the latest measure (arc length) and whether patients were at or below (yellow, red) recommended healthy levels or not (green) to trigger reflections. Trend arrows indicated changes from the penultimate measure (up: improvement, down: worsening).

The comparison page aimed to support long-term reflection and included four different visualisations. The first comparison screen utilized a combined time series graphs



Fig. 4. Comparison screen 1: Top - select measurements to include in the dual axis time series graphs. Bottom - selection of context-relevant variables



Fig. 5. Comparison screen 2: Top - select measurement. Bottom - time series graphs vertically arranged with context-relevant variables to the right

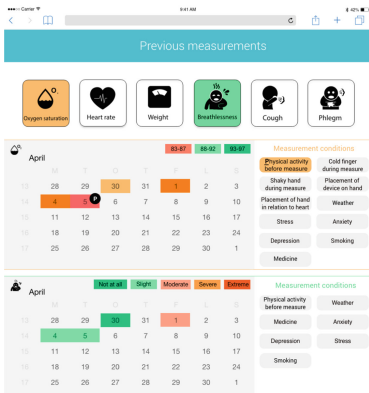


Fig. 6. Comparison screen 3: Top - select measurements. Bottom - Calendar heatmaps with context-relevant variables to the right

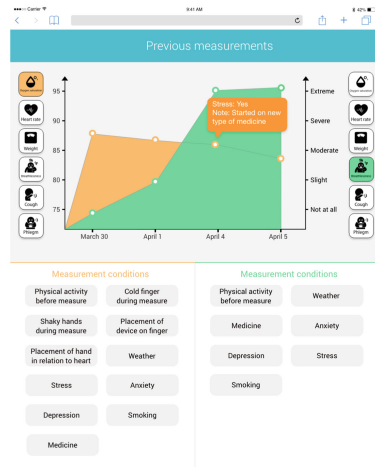


Fig. 7. Comparison screen 4: Top - select measurements to include in the dual axis area graphs. Bottom - select context-relevant variables

to show multiple measurements (see Fig. 4) while the second comparison screen separated and vertically stacked the time series graphs (see Fig. 5). The third comparison screen contained a calendar heatmap to visualise periodic patterns using color shades

to indicate daily deviations from recommended levels (see Fig. 6). The fourth comparison screen contained area graphs visualising multiple measurements (see Fig. 7). The visualisations aimed to promote reflections on patients' health trends and increase awareness of possible worsening conditions. The visualisations allowed for comparisons of multiple measures and context-relevant variables to trigger reflection on how measures impacted each other. Recommended levels on visualisations aimed to increase awareness of discrepancies and trigger reflection.

4.1 Participants and Method

We recruited participants through a local hospital. A nurse involved in the currently used COPD telehealth service made initial contact over the phone and upon agreeing provided us with their contact information. We introduced them to the details of the study over the phone, and after consenting, the participants received an information letter and consent form prior to an initial in-person meeting.

Five COPD patients, two men (age M: 64.5) and three women (age M: 66.8), participated in the study. Three used supplemental oxygen (P3, P4, P5) and all lived in their own homes with spouses, except for P3 who lived alone. P5 had a speech disorder so her spouse (P5S) spoke on their behalf. All patients had multiple co-morbidities (asthma, diabetes, heart disease, etc.). We required that all participants were currently using a mandated self-tracking telehealth application - in this case ambuflex - to collect data for their healthcare professionals. Ambuflex did not provide the patients with any feedback on their condition.

The participants received the paper diary one week prior to the session evaluating the dashboard. On the day of its evaluation, we collected the data from the patient diaries and updated the prototype using the patients' measurements to allow reflections on their own data. First, patients provided feedback on the diary in an unstructured interview. Afterwards, the patients went through each dashboard screen while completing tasks such as entering blood oxygen saturation data, comparing measures, etc. in a think-aloud manner [43], followed by a short debrief interview. The entire evaluation was limited to less than an hour and required minimal physical activity from the participants as co-designing with COPD patients using generative techniques (e.g. post-it notes and sketching activities) was often too demanding for them [10]. Nadarajah et al. similarly experienced that COPD patients within an hour of interviewing experienced breathing difficulties requiring a slow pace and long breaks [29].

4.2 Results

Collecting Data. Patients varied in terms of when and how they took measures. Three patients had specific schedules for recording data (e.g. always before breakfast) while others recorded inconsistently. We identified two types of patients in this study: Passive patients (P1 and P3) who took the role of data providers without further reflections and proactive patients (P2, P4, and P5) who engaged and reflected on their data. Passive patients lacked knowledge on how the context of recording data influenced their measures. For example, they did not understand how a cold finger when measuring oxygen saturation reduced the validity of their data. Alternatively, proactive patients ensured

taking measures under comparable conditions and noted additional variables relevant for their measures (e.g. mood, supplemental oxygen, etc.). P2 and P5S asked for guidelines on taking reliable and valid measures: *“For some measures, an explanation would be good. For example, do not take measure if this and that”* (P5S).

All patients preferred higher granularity options (e.g. Likert scales) when rating symptoms as opposed to binary scales (yes/no): *“How much is a no? If we say yes or no to the hospital, they still do not know what we are thinking. They’ll call us and we’ll have to explain the severity”* (P5S). However, rating symptoms on a Likert scale without a baseline (*“Did you feel breathless today?”*) caused difficulties for four patients as the severity of their symptoms varied during the day: *“I have been through all of the provided options that day. How do you want me to answer that?”* (P4) and *“If she [P5] is not more breathless than yesterday, then we’ll just submit a no [when as asked if they feel breathless today]”* (P5S). They also had different perceptions of how to rate the severity of their symptoms: *“I base that [rating] on when I’m at my best”* (P3) and *“usual is when it is an ordinary day”* (P4).

Reflecting on the Dashboard. While patients diligently recorded data, only P5 responded to the reflective exercises in the paper diary. When given the dashboard, the passive patients felt unmotivated to reflect on the visualisations, reflective questions, or data history: *“I do not care what my status is. I just submit the data. I do not walk around and think every day about how I am feeling”* (P3). In contrast, proactive patients reflected on their data to determine actions to take: *“I’m more concrete. Where am I right now and what can I do about it?”* (P4). However, four patients found the data too complicated to reflect on: *“I do not know what they use it for, the scales they use and the language. I do not understand it. I count on them [nurses, doctors, etc.] to react if there is anything”* (P2). These participants relied on healthcare workers to review the self-tracked data and explain any negative results: *“I have a nurse who is good at keeping an eye on me”* (P4). Additionally, passive participants did not feel the need to reflect on their data due to relying on their healthcare workers: *“I do not need it [access to history data]. If it [measure] is too low, they call and ask me why”* (P1).

The overview screen helped patients understand their health status: *“[I can] quickly see if it [a measure] is going up or down”*. Additionally, according to three patients, the gauges of recommended healthy levels for each measure simplified the process of identifying unhealthy measures and taking actions to improve: *“If it starts to go over here [below recommended], we have to do something”* (P5S) and *“[my health] is not that bad if I keep it [a measure] above that lower threshold”* (P2). However, three patients felt demotivated by comparing their data to thresholds when they understood the consequences of falling outside healthy ranges but not how to avoid this: *“I prefer not to be told in the morning that I’m gonna get an awful day”* (P4) and *“It’s OK if it’s just a single measure [outside of health thresholds], but if it is constant, I would start thinking it [my health] is going away fast now”* (P2). To avoid this, they suggested personalizing the dashboard e.g. setting recommended levels based on the severity of their condition.

Active patients valued looking at line graphs showing their health over time in the overview screen: *“This gives more information about me (...) it’s nice to be able to go*

back. *Is it better than 14 d ago?*” (P2). However, one proactive patient needed a purpose to reflect to gain any benefits from history data: *“There might be days where I sit with it and have an idea about what I’m looking for, which might trigger some thoughts”* (P4). Passive patients did not see the benefits from reflecting on the data themselves: *“this [overview screen] is only for people who have to sit and analyse the numbers”* (P1). The reflective questions in the overview screen did not trigger any reflections in the passive patients who ignored the questions. While proactive patients did answer the reflective questions, they did not find an answer using the data but instead proposed one from their previous knowledge (e.g. to the question *“Why are you coughing more than last time you measured?”*, P4 answered: *“Right now it is likely because I talk too much”*).

When looking at the comparison screens, four patients preferred the dual axis time-series line (see Fig. 4), which simplified finding discrepancies and relations between measures: *“you can have them [measures] together and see how they affect one another”* (P2). Three patients felt that the calendar heat-map in Fig. 6 provided a simple explanation of their health over time: *“it [Fig. 6] is the one I understand the quickest”* (P4).

In summary, patients struggled to understand how to collect measures under reliable circumstances and interpreted questions regarding the severity of their symptoms differently. Patients’ initial thoughts on the dashboard varied depending on whether they had a passive or proactive attitude towards their treatment. While passive patients felt the visualisations offered little benefits for them, proactive patients liked to reflect using the time-series line charts and calendar heat-maps. However, Study 1 only provided insight into patients’ initial and potentially - to please the researchers - biased thoughts. A two-week follow-up study investigated attitudes about and behaviour changes from using a self-tracking dashboard over time.

5 Study 2 - Evaluating Reflection During Use

Based on the results from Study 1, we redesigned the dashboard to only include the time-series line chart. In this study, we explored how using the new dashboard over a 14-day period impacted reflection among COPD patients and their activities in managing their condition.

5.1 Prototype Redesign

We implemented the dashboard as a web-application accessed through a tablet or phone. An introductory dialogue box provided information on how to measure data under comparable conditions and report context-related variables that can impact measurements. Reflective questions targeted patients’ overall health instead of specific measures (e.g. *“Have you previously been able to improve your measures? How?”*). Some reflective questions aimed to increase patients’ awareness of symptom changes (e.g. *“You have multiple measures showing red/yellow. Have you explored what your measures might have been affected by?”*). A setting allowed patients to adjust thresholds indicating recommended levels for each measure to their own preference. The visualisations on the comparisons screen were limited to the dual y-axis time-series line graph seen in Fig. 4 as patients preferred it most in Study 1.

5.2 Participants and Method

Five COPD patients, two male (age M: 71.5) and three female (age M: 75), participated in the study - none of whom participated in Study 1. Patients were diagnosed with COPD between seven and 25 years ago (M: 12) and experienced either moderate, severe, or very severe COPD. Two patients (P3, P5) used supplemental oxygen and three (P3, P4, P5) suffered from multiple co-morbidities (diabetes, osteoporosis, and fibromyalgia). P4 reported colour blindness but could distinguish between the colour used in the dashboard. Using the same procedure as Study 1, we recruited participants through a local hospital with the help of nurses.

During an initial meeting, the patients received both a written and verbal explanation of the study once more and consented that no healthcare professional would review the data collected through the study's equipment. They received a self-tracking kit consisting of a pulse oximeter, weight scale, diary containing a template to track measurements, and a tablet with internet access. Patients measured and recorded oxygen saturation, pulse, weight, self-reported dyspnea, cough, and phlegm into the dashboard prototype for 14 d. We encouraged the patients to also record their measures in the diary but made it optional to reduce the effort required from the patients. We suggested recording measures three times a week and asked those currently using self-tracking to use our dashboard on days on which they did not use their existing system.

A facilitator instructed the patients on the use of the system such as: Opening the application, submitting data, accessing previous measures, and adjusting settings. For each session in which the dashboard was used the system automatically logged all user interactions: 1) time spent on each screen and total time per session, 2) where, what, and how many times the screen was clicked. The data was anonymised and stored on a secured server.

After 14 d, we conducted semi-structured interviews in participants' homes. Each interview lasted between 53 min and 1 h and 45 min revolving around: COPD-related activities for managing disease, context of use, and comparisons with previous self-tracking methods. We prepared screenshots of patients' dashboards showing events of interest (e.g. worsening or improvement in measures between two days) and scanned the patients' diaries for significant events before the interview. The resulting interview data were analysed using grounded theory methods [14].

5.3 Results

The patients entered data 4–5 times during the 14 d except one patient who did so nine times. Usage sessions took on average nine and a half minutes. The longest came from P4 who used 32 min to enter measures, answer reflective questions, and interact with visualisations. The shortest (3 min), consisted of only entering measures. Most sessions consisted of patients spending approximately 75% of their time on the data entry screen, afterwards they used the overview and comparison screens. While three patients only viewed these screens after entering data, two patients consulted the dashboard without data entry. Four patients acted on reflective questions on the overview screen by exploring their measures to identify factors that could explain their negative health.

Five themes emerged from the analysis: 1) Motivation for reflection and system use, 2) using measures as health status indicators, 3) feeling empowered in everyday life, 4) gaining self-knowledge, and 5) becoming motivated to self-improve.

Motivation for Reflection and System Use. Four patients cited their agreement to participate in this study as motivation for using the dashboard while the last felt motivated by reflecting on their health and taking actions to improve it. Similar to Study 1, we classified three patients as proactive (P1, P3 and P4) and two as passive (P2 and P5).

Similar to Study 1, passive patients lacked the knowledge to improve their health through reflection: “*we can not do anything except measure*” (P2) and “*if the bright minds can not make sure that I get better, then neither can I do anything about it*” (P5). These patients doubted that they could improve their health long-term: “*I do not worry about things that I can not change*” (P2). However, they still reflected on the dashboard for short-term improvements such as adjusting their supplemental oxygen levels.

Using Measures as Health Status Indicators. All patients reflected on their health on days of bad health: “*[when] I actually feel good, I do not worry about how I felt yesterday*” (P3). Four patients did not reflect on past data when they felt well to avoid remembering bad days: “*that’s not something I walk around and think about. Life gets too strenuous if you walk around and think about that [bad days in past]*” (P1). However, four patients reflected on their data to explore possible reasons for why they felt unwell: “*if I do not feel like everything is fine, I might start thinking why (...) it depends on how I am feeling*” (P4).

All patients reported that self-tracking and reflecting increased their awareness of how they felt: “*I start noticing three times a week, how am I feeling right now?*” (P4) and used their pulse oximeter to check their current status and took action to improve their condition (e.g. performed breathing exercises after measuring low oxygen saturation). According to them the dashboard provided a quick and simple overview of their health for short-term reflections: “*it [the dashboard] is a measure of one’s symptoms (...) altogether it of course becomes how you are feeling*” (P1). Proactive patients used the dashboard to identify reasons for feeling unwell “*you can not always go to the doctor and learn about your status and why you feel that way (...) you can do that here [dashboard]*” (P3).

Questioning and Gaining Self-Knowledge. Proactive patients gained insights by asking themselves questions and increasing their awareness of what caused their symptoms to intensify. For example, the reflective questions in combination with annotating measures with context variables triggered reflection in proactive patients: “*with dyspnea, I had not thought there could be other [reasons]. I just had breathlessness, done. (...) suddenly I realized how much I was affected by the heat (...) it happened when I sat with the system and those questions asking ‘why?’*”. Annotating measures with context variables supported evaluating different causal explanations: “*I have started thinking about it (...) I think, ‘no it’s not that [stress]’, ‘Talk? No I haven’t talked today’ and then I think ‘it’s the weather’*” (P3). Some proactive patients would like the dashboards to identify

and highlight the important contexts which influenced their symptoms. These patients reflected on previous days to identify changes that effected their health: *“I become very conscious about, how did I feel yesterday? Do I also feel like that today? What caused that?”* (P4).

Empowered Through Reflection. Through reflections, three proactive patients learned how previously ignored measurements impacted their condition in everyday life. These patients felt empowered by self-tracking and gained agency over their health: *“I thought that is just how it is. You give up a little and get tired of it [COPD] (...) without doing anything about it, nobody says anything, but this [the system] does. It makes you aware of the situation (...) My doctor always told me that it [their negative mentality] is all because of my condition. The system makes me think that he is not right”* (P3). Two patients felt empowered by identifying correlations between their symptoms and contextual variables (e.g. warm weather may result in breathing difficulties) which they used to inform their actions: *“now I can make up my mind beforehand [whether to go outside in the heat], because I know how it will end”* (P3). Similarly, these patients aimed to keep their measures within recommended levels and felt safer knowing that their health has not deteriorated to dangerous levels: *“I’m on the right track then”* (P3). Three patients felt empowered by preventing family members from witnessing bad symptoms: *“I can become unsure about how I am feeling.. (...) I do not want to expose my husband and daughter unnecessarily [frightening events] (...) I learn more about that now, so that I do not expose them”* (P3) and *“I have to be self-centred (...) I have to do things right for myself and in time, so that I also treat others right”* (P4).

Becoming Motivated to Self-Improve. Active patients used the dashboard to set goals for improving their health which motivated them to seek new knowledge that can aid their goal: *“I’ve tried to acquaint myself with BMI because I wanted to have a goal to follow. [because] I wondered about the arrows [in the system]”* (P4). One proactive patient learnt about the severity of their weight problem and gained awareness about the need to improve: *“I have not thought about it before, but when you suddenly get it in writing (...) being confronted with it, I have to do something about it (...) it’s for my own good”* (P3). That patient used the dashboard to track their progress as they tried to improve their diet: *“that’s about getting better at using the device [tablet with the dashboard]. Not just saying, ‘oh, you are running into a pneumonia, now you have to use it, it’s about using it [the dashboard] several times a day”* (P3).

Three patients stated that the overview screen containing the colour indicators and arrows provided them with a concrete goal to pursue: *“I want all of them [days] to be green and that things are making progress”* (P3) and *“when the arrows are pointing down I assume it is not so good, that’s the wrong way”* (P4). For example, one proactive patient used the dashboard to help reduce medication intake, which had been a struggle despite the doctor’s encouragement: *“They [doctors] had difficulties easing me off because I have had high doses for so many years (...) but this time I thought now you have to stop (...) I did, I needed some days and then it was over”* (P3). Two patients

stated that the dashboard should contain advice on actions to take that can improve their health. Specifically, they wanted advice tailored to their own goals and health problems: *“to get help when you also have diabetes, that would be nice”* (P3).

6 Discussion

The proactive patients in our study felt motivated to self-track their symptoms, unlike the chronically ill patients in larger scale studies, who, however, could not review or interact with their entered data [1,41]. Our prototype supported such activities and as previously hypothesized [1,41], the ensuing reflections empowered the proactive patients to reduce their symptoms over time boosting motivation for tracking. Using reflective “why” questions in our dashboard overviews to highlight measurements that had changed since last time, prompted comparing the contextual annotations to the change in measurements illustrated in time series graphs. This triangulation of reflected questions, context annotations, and time series graphs proved instrumental in providing the proactive patients with agency, similar to findings with healthy self-trackers [13,20]. However, the passive patients lacked motivation to self-track as they felt unable to reflect and doubted the application’s efficacy to empower them to that end. Our proactive patients shared this doubt until they could identify concrete actions and improvements (see [19]).

Contrasting previous studies [1,25,32,40,41], all our patients tracked their symptoms with some proactive patients submitting more data than asked of them. They attributed much of their motivation to start using the application to the social contract they had entered by participating in the study. However, the proactive patients’ increased sense of agency additionally motivated them to self-track, supporting suggestions from previous studies [1,6,20]. The patients had to identify worsened health and reflect on visualisations - a common approach in this application type (see [25,26]). Similar to stroke patients, all our patients had a bias against reflecting on data reminding them of bad health and either disregarded the results [15] or temporarily suspended self-tracking [1]. Once our proactive patients learned to reflect and identify actions to potentially improve their health, they analysed their negative health data in relation to their contextual annotations (see [1,17]). The proactive patients used their newfound insight to improve their condition, e.g. by not going outside during bad weather, adjusting oxygen supplements, and reducing their condition’s impact on their social lives - similar to COPD patients in previous studies [17,32].

However, this gained agency did not come without risks. Patients could reach incorrect conclusions through their biases, assumptions, and misunderstandings, which is a common concern in interfaces relying on users to create insights from data visualisations [37]. For example, our patients preferred dual y-axis time series charts to compare different measure(s) to identify potential reasons for changes in their health. However, these charts are known to suggest correlations where none might exist [4]. This points to more general design dilemmas pointed out by Correll [8] regarding the degree of agency users should hold to be empowered while protecting them from arriving at potentially spurious conclusions. This was further exemplified by the articulated need for automated analysis from proactive patients, who felt burdened by searching through every

variable presented in the dashboard. Adaptive dashboard could automatically highlight pertinent variables relevant to goal setting and problems. How much guidance should these systems provide and should they limit users' explorations? Other future work should investigate how novel telehealth interfaces (e.g. virtual assistants) can establish social contracts with patients as well as help with on-boarding, measuring health reliably, and reflecting on results using visualisations, reflective questions, and contextual annotations.

While our findings are based on a smaller number of patients than studies relying on short interaction sessions [15,22,24], our numbers are similar to studies investigating usage of telehealth dashboards for longer, e.g. fortnight, periods [25,26]. Our participants had all received their diagnoses multiple years ago, adapted their lives to accommodate their condition, and self-tracked prior to the study. Therefore, our results may not apply to novice users, who still adapt to their condition and lack self-tracking experience.

7 Conclusion

When used longer term, tablet-based telehealth dashboards utilizing reflective "why" questions to highlight change in measurements, and contextual annotated time-series graphs can encourage proactive patients to reflect, self-track, and improve their quality of life through an increased understanding of their health. However, patients needed knowledge about measuring health parameters and how to follow up results indicating poor or declining health with concrete actions to reflect. Visualisations of tracked data and reflective questions might not motivate patients, who understand their role to be mere data providers. Future studies should investigate how to create adaptive dashboards that can promote reflections and actions relevant to each patients' circumstances and how to navigate the inherent design dilemmas between the empowerment of vulnerable users and protecting from taking action based on incorrectly drawn conclusions in interventions that promote taking an active role.

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