# Self-management of COPD supported by eHealth: Patients' attitudes towards monitoring, risk prediction and virtual coaching

Marian, Z.M., Hurmuz*
Roessingh Research and Development (NL), University of Twente (NL)
m.hurmuz@rrd.nl

Eline, te Braake
Roessingh Research and Development (NL), University of Twente (NL)
e.tebraake@rrd.nl

Stephanie, M., Jansen-Kosterink
Roessingh Research and Development (NL), University of Twente (NL)
s.jansen@rrd.nl

Christiane, Grünloh
Roessingh Research and Development (NL), University of Twente (NL)
c.grunloh@rrd.nl

## ABSTRACT

**Purpose**: Chronic obstructive pulmonary disease (COPD) has a high burden on patients, tremendously affecting their quality of life. For patients to be more pro-active, self-management is important. To support patients in their self-management, health data collection is needed for monitoring, which can be used for risk predictions and personalised coaching. Within the RE-SAMPLE project, we want to include these features in an eHealth technology. This study aims to investigate the attitudes of people with COPD towards health monitoring, risk predictions and virtual coaching. **Methods**: We conducted workshops and interviews with persons diagnosed with COPD. Six persons participated in the workshops which focused on topics for virtual coaching. Ten persons participated in the interviews focusing on monitoring, risk prediction and virtual coaching. **Results**: In general, participants were positive towards the concepts health monitoring, risk predictions and virtual coaching within a self-management eHealth technology. However, most participants felt that persons who are more recently diagnosed with COPD would benefit more from using such a technology. People who are dealing with COPD for several years already know or think they know how to self-manage their disease and what helps them and what not. **Conclusion**: Based on our findings, we discuss several implications for design of self-management eHealth technologies for COPD: personalization in context and level of details, supporting people to reflect on their behaviour and patterns detected in the monitoring, balance accountability and paternalism when it comes to coaching, and finally explainable AI concerning risk predictions. Furthermore, we want to argue that in these types of studies, it is also important to include people newly diagnosed with COPD to have more inclusive results.

*Corresponding author, M.Z.M. Hurmuz (PhD), Roessingh Research and Development, Roessinghsbleekweg 33b, 7522 AH Enschede, The Netherlands



*NordiCHI 2024, October 13–16, 2024, Uppsala, Sweden*

ACM ISBN 979-8-4007-0966-1/24/10
https://doi.org/10.1145/3679318.3685486

## CCS CONCEPTS

• **Human-centered computing**; • **Human computer interaction**; • **HCI design and evaluation methods**; • **User studies**;

## KEYWORDS

Chronic obstructive pulmonary disease, Self-management, Data collection, Monitoring, Risk prediction, Virtual coaching

**ACM Reference Format:**
Marian, Z.M., Hurmuz, Eline, te Braake, Stephanie, M., Jansen-Kosterink, and Christiane, Grünloh. 2024. Self-management of COPD supported by eHealth: Patients' attitudes towards monitoring, risk prediction and virtual coaching. In *Nordic Conference on Human-Computer Interaction (NordiCHI 2024), October 13–16, 2024, Uppsala, Sweden.* ACM, New York, NY, USA, 13 pages. https://doi.org/10.1145/3679318.3685486

## 1 INTRODUCTION

Parallel to the ageing population [61], the prevalence of chronic diseases also increases [60]. One chronic disease with a major societal and economic impact and which is often accompanied by other chronic diseases is chronic obstructive pulmonary disease (COPD) [34, 48]. In 2020, COPD was worldwide one of the five diseases with the highest burden of disease and one of the third with the highest mortality [56]. COPD is "*a heterogenous lung condition characterized by chronic respiratory symptoms (dyspnea, cough, expectoration) due to persistent abnormalities of the airways (bronchitis, bronchiolitis), and/or alveoli (emphysema), that often results in progressive airflow limitation*" [4]. COPD is accompanied by exacerbations and comorbidities. A problem here, is that symptoms of the comorbidities are very similar, making treatment difficult [15]. Thus, the treatment of COPD needs to focus on reducing symptoms and risk of future events (progression, exacerbations, mortality) [56].

As managing COPD among people with comorbidities is a difficult task, the RE-SAMPLE project (funded from EU's Horizon 2020 grant agreement No 965315) wants to create a shift in healthcare by predicting exacerbations to personalise treatment. Within this project, a multidisciplinary adaptive virtual companionship programme will be developed. To create an eHealth service that aligns with patients' and healthcare professionals' (HCPs) needs, we involve end-users in every development step.

This study aimed to investigate the attitude of people with COPD towards monitoring their health, receiving risk predictions and virtual coaching, and their usefulness within COPD care. In this paper, we report on the views of people with COPD (collected with co-design activities) on data collection, risk prediction and virtual coaching. By having insight into these topics and the needs of these persons, we can develop an eHealth service that supports them to effectively engage in self-management and which has the potential to transform COPD care.

## 2 BACKGROUND AND SETTING

### 2.1 Context of the case study

In 2021, there were an estimated 545.900 people diagnosed with COPD in the Netherlands [58], and these people are treated in three types of healthcare: primary care (general practitioner), secondary care (hospital), tertiary care (rehabilitation centre). The burden of disease on the individual is highest for people who need to be treated in tertiary care and lowest in primary care. However, even for the ones treated in primary care, the burden of the disease is already substantial [43]. Knowing that COPD is generally a progressive disease [56], the disease burden experienced will only increase over time.

Physical activity is an important aspect of the treatment of people with COPD [56]. However, due to for example shortness of breath, physical activity decreases [51]. Furthermore, an important barrier towards physical activity among people with COPD is on the one hand a lack of motivation [45], and on the other hand that people with COPD have to focus on conserving their energy [16, 49, 54]. These factors make it difficult to be sufficiently physically active. Behavior change techniques can help improve people's motivation to be physically active [27] and are often used in eHealth applications focusing on improving physical activity [7, 8]. However, changing someone's behavior to be more active is hard in general [39], but for people with COPD it is even more challenging as they need to conserve energy and stay within their limits.

### 2.2 Data collection and risk prediction

Persons with chronic conditions benefit from engaging in self-management [50]. While there is no standardised definition of self-managing a disease [3], self-management interventions have been defined as *"motivating, engaging and supporting patients to positively adapt their health behaviour(s) and develop skills to better manage their disease"* [9]. This definition focuses on self-management interventions (i.e. programs designed for health behaviour change, often from a clinical perspective). However, self-management of chronic diseases is more than only interventions. It is also about day-to-day management; everything a person does on a daily basis to manage their disease. For example, when a person decides to not engage in a particular healthy behaviour it is also a way of management: *"One cannot not manage"* [30]. Self-management is an important aspect for people with COPD. Educating them on self-managing their COPD, seems to improve their quality of life and reduce hospitalizations [42]. One aspect of self-management is monitoring their health [23]. For this, collection of real-world data (RWD) can be used [31, 38], supported by eHealth technologies [23, 31, 36, 38]. By enabling people with chronic conditions to track and monitor their RWD, they can take ownership of their disease progression and take actions based on the data [29]. By having access to this health data, Artificial Intelligence (AI) could be used to make risk predictions about the disease's progress [38].

In the past few years, we have seen an increase in AI in HCI within the healthcare sector (e.g. [1, 5, 18]). As reducing the risk of negative events is an important factor in COPD treatment [56], AI-driven risk predictions could be helpful in the management of COPD [11, 36]. For example, in the study of Fernandez-Granero and colleagues [11] people with COPD were telemonitored for six months and predictions about exacerbations were made based on AI. 78% of the exacerbations were predicted. Besides this, a lot of different studies are conducted to identify predictors for different negative events (like exacerbations, hospitalization, mortality) (e.g. [12, 24, 47]), which can be used in AI applications. However, to the best of our knowledge, little is known about the attitudes of people with COPD towards receiving risk predictions about COPD progress and how it supports them in engaging in self-management. For example, do people with COPD want to know these risk predictions and what kind of predictions would help them? Or how do these predictions need to be communicated and explained in a way that patients understand (e.g., human-centered explainable AI [10, 44])?

### 2.3 Virtual coaching

Besides data collection and risk predictions for monitoring chronic diseases, health coaching can be effective in changing people's lifestyles to prevent or delay the deterioration of disease [26]. For people with COPD, different coaching interventions focus among others on self-management training (e.g. action plans, goal setting), psychoeducation after COPD diagnosis, smoking cessation, physical activity, medication adherence, increasing self-efficacy (e.g. [20, 53, 59]). Nowadays, health coaching is increasingly being offered via online technologies. Virtual coaching systems are being developed for different target populations [52], also for people with COPD (e.g. [13, 46]). Previous studies focused mostly on the effectiveness, usability or acceptance of such an intervention [13, 37], or the look and tone of voice of the virtual coach [46] or the role of aligning the virtual agent with the conversational and expressive style of the interlocutor [2]. However, not a lot of studies investigated the topics people with COPD want to receive coaching about and their attitude towards eHealth technology including virtual coaching.

## 3 MATERIALS AND METHODS

This study was conducted according to the principles of the Declaration of Helsinki and the Medical Research Involving Human Subjects Act (Dutch Law). The Medical Research Ethics Committee CMO Oost-Nederland stated that no formal medical ethical approval was required (file number: 2021-13319). All participants signed a paper informed consent form. The participants were recruited from a cohort of people with COPD initiated by the authors previously.

## 3.1 Coaching workshop

We conducted 3 workshops with 2 people living with COPD per workshop. One of these workshops was conducted by three researchers (EtB, SJK and CG), another one was conducted by two researchers (EtB and SJK), and the third workshop was conducted by one researcher (EtB). We chose to have only 2 participants per workshop as they were conducted during the COVID-19 pandemic and its risk for our target population. The main aim of the coaching workshop was to identify potential topics for the content of virtual coaching. Building on their expertise of living with COPD, we wanted to explore whether people with COPD have received coaching on specific topics in the past, what topics they would have liked to receive coaching on and in which phase of the patient journey (i.e., shortly after diagnosis, the stable phase and/or exacerbation) they would have liked to receive coaching on.

## 3.2 Interviews

One researcher (MH) and one student (YD (see acknowledgements)) conducted one-on-one semi-structured interviews. The aim of the interviews was to identify the attitudes of people with COPD towards health data collection (in general and to monitor their health), health predictions, and virtual coaching. Starting with health data collection, we discussed four statements (e.g. "gathering my own health data by means of a wearable or another device is important to monitor my symptoms"). Then we discussed some mock-ups (see Appendix A) of a future health technology for self-managing COPD, showing several aspects of health data: physical activity (Figure 1a), mood (Figure 1b), positive health [21] (Figure 1c), visits to HCPs (agenda) (Figure 1d), and data about their visits (like a medical record) (Figure 1d). Next, we continued with the topic of health predictions. We asked some general questions about their attitude towards this, and we discussed mock-ups showing a technology with health predictions (mood (Figure 2a) and dyspnoea without (Figure 2b) and with explanation (Figure 2c). The final part of the interviews was about virtual coaching. Participants read a small conversation (Figure 3a-3e) and were asked some questions about this (e.g. "Do you think this technology could help you dealing with your symptoms?").

## 3.3 Data analyses

Descriptive statistics (such as mean, standard deviation and percentages) were used to describe the participants' demographics. The workshops were audio-recorded, transcribed and coded by one researcher (CG). The interviews were audio-recorded, transcribed and coded by two researchers (MH and CG) who coded different parts of those interviews. For coding of both the workshops and interviews, we used a mixed approach with deductive and inductive coding. The initial codes for the workshops were coaching content (themes patients find important during the different phases of their diseases) and coaching style (opinions and preferences regarding the different kinds of coaching styles). The initital codes for the interviews emerged from the interview format: data collection for COPD monitoring, predictions about health and virtual coaching. The results are also structured based on these three initial codes. Within these overarching groups we added additional codes inductively.

# 4 FINDINGS

## 4.1 Demographics

A total of 10 people with COPD participated in the interviews, with a mean age of 69 years and 7 of them were also diagnosed with other chronic conditions. In the workshops, 6 people with COPD participated, four of these also wanted to participate in the interviews. All were diagnosed with other chronic conditions, and the mean age was 67.2 years. Table 1 gives an overview of the demographics.

## 4.2 Data collection for COPD monitoring (interviews)

*4.2.1 Responses to statements about data collection.* This section describes the findings from the first part of the interviews in which we presented the participants four statements. The aim of this part was to gather their attitude towards collecting health data for COPD monitoring in general.

**Statement 1: "Gathering my own health data by means of a wearable of another device is important to monitor my symptoms"**

The majority agreed with this first statement because it can help them to adjust their treatment remotely, to inform the HCPs and to monitor the oxygen saturation. Three participants had some critical remarks regarding the statement. One said that it is important, but the health data gathered by, for example, a wearable does not always reflect how you feel. Another one felt that it is not important for them, but for persons with more severe COPD it is. The last one indicated that it is not important, but it is useful to gather if you are interested in your health. This last person also indicated they rather measure health data during physical therapy appointments: *"I take another path* [to measure health data]. *In this way* [going to physical therapy], *you get among people again, and you have a conversation. You're moving again, which is good for a lung patient."* [P9].

Almost all participants measure their oxygen saturation to check, when they are not feeling well, whether this is due to the oxygen saturation, just out of interest, or to monitor their activities. Some participants also measure other parameters: sleep, blood pressure, heart rate and steps. Only two participants indicated they do not measure anything on their own. Most of them do not write down the measurements they take: *"I did for a while, but at some point, it was no longer necessary because one time it is very high, another time it is very low again.* [...]. *I wasn't diagnosed with it yesterday or today, but already a couple of years ago."* [P11]. Only two participants do write the measurements in a notebook and share them with their HCPs.

**Statement 2: "I think it is important to have access to my health data gathered by my healthcare professional"**

Almost all participants agreed with this statement. Reasons mentioned why they think it is important to have access are: (1) they and their HCPs have more control over their health, (2) just to check the data/results, (3) to keep track or to have an overview of how they are doing, (4) to share data with other healthcare organisations which do not have access, (5) to check what is written down, if it is not correct, they can contact the HCP, and (6) these

**Table 1: Overview demographics of participants and their digital skills**

| Demographic | Sub-category | % or M (SD) \| Min-Max | |
|---|---|---|---|
| | | Interviews | Workshops |
| Gender | Male | 70.0 | 50.0 |
| | Female | 30.0 | 50.0 |
| Age | | 69.0 (3.9) \| 64.0-75.0 | 67.2 (4.6) \| 61.0-75.0 |
| Number of years diagnosed with COPD | 0-5 years | 0.0 | 0.0 |
| | 6-10 years | 40.0 | 33.3 |
| | > 10 years | 60.0 | 66.7 |
| Highest level of education | Primary school | 0.0 | 0.0 |
| | High school | 30.0 | 16.7 |
| | Trade school | 40.0 | 16.7 |
| | University | 30.0 | 50.0 |
| | Other | 0.0 | 16.7 |
| Health literacy [a] | | 4.1 (0.6) \| 3.0-4.7 | 4.1 (0.8) \| 3.0-5.0 |
| Digital skills [b] | | 3.1 (0.7) \| 2.0-4.0 | 3.3 (0.5) \| 3.0-4.0 |
| Devices in use | Computer/laptop | 90.0 | 50.0 |
| | Smartphone | 100.0 | 100.0 |
| | Smartwatch | 10.0 | 0.0 |
| | Tablet | 60.0 | 33.3 |

[a] Person's ability to find and understand health-related information, measured on a scale from 1 (low literacy) to 5 (high literacy).

[b] Person's ability to use and understand technologies, measured on a scale from 1 (low skills) to 5 (high skills).

data are about their health, so it is their data. Two participants did not agree with the second statement. One participant explained that their HCP explains everything already during the consults which was considered sufficient (*"the more one knows, the more worried one becomes"* [P8]). Another disagreed with the statement because for them it was not necessarily important, but nevertheless added that it could be useful to have access as a look-up tool for, for example, checking your blood values, but not important to have access.

**Statement 3: "I trust the health data I receive from my healthcare professional more than the health data I gather myself"**

Participants who gathered health data themselves did not agree with this statement. Almost all have the same trust in both health data (*"No, both equally, there is no.. Yes I have trust in both."* [P3]), except for one participant. This participant experienced previously that health data which has been sent from an HCP to another HCP was not correct. Due to this, their trust in health data from the HCPs fluctuates.

**Statement 4: "It is difficult to receive the requested health data from my healthcare professional"**

Even though most participants think it is important to have access to health data gathered by their HCPs, most of them still do not have access to their medical records of the hospital. Some do have access to the records of the general practitioner (GP). Participants mentioned they either never requested health data from their HCPs (*"I'm not curious enough to go and ask for this."* [P1]), they were not aware of whether it is possible to request this, or it was very easy to receive this through an app or by logging in into a website with their digital identity.

*4.2.2 Feedback about mock-ups for health monitoring.* This section describes the findings from the second part of the interviews in which we presented the participants different mock-ups of a future health technology for monitoring health data. The aim of this part was to be informed about their attitude towards using such a health technology with different aspects.

When going through the different mock-ups for monitoring their health, participants were asked about their first impressions. The majority reacted positively, describing the mock-ups as being nice, organised, funny, looking good, amazing, and interesting. With such a technology, one thought the number of visits to the HCPs could decrease, because: "You can share data with your GP and pulmonologist through the app." [P4]. Another one said it is educational, you can check your own progress. It was seen as a positive prompt or nudge to be physically active. Two participants had some critical comments: it gives too much information, which can work counterproductive, and something is lacking, which was having a personal average for the different aspects. By having insight into the average, people could better accept their condition and learn how to deal with it.

The mock-ups with physical activity (Appendix A, Figure 1a) and with positive health (Appendix A, Figure 1c) were considered as most favourable. Several reasons were given for preferring the physical activity mock-up: (1) to check whether you were active enough and if not, to think about why not, (2) to have a clear overview of the number of steps per day in an app which can be shared with an HCP, and (3) to have an incentive to be more active. The reason given for preferring the mock-up about positive health was because it shows your mindset in your life and how you deal with COPD. After these two, the calendar with visits to HCPs

(Appendix A, Figure 1d) and the overview with mood (Appendix A, Figure 1b), were liked second best. Furthermore, one indicated to prefer the data of their healthcare visits (Appendix A, Figure 1e) the most, and another one indicated having no specific preference for any.

The mock-up which gives an overview of mood (Appendix A, Figure 1b) was mentioned by most participants as the least favourite because: "Yeah, the mood. I'm actually never feeling down or whatever. Yesterday, I also had to complete some forms with a question: 'Do you ever feel down?' Well, no actually." [P6]. Furthermore, the mock-ups with the calendar (Appendix A, Figure 1d) and data (Appendix A, Figure 1e) of their healthcare visits were also mentioned as least favourable.

Furthermore, participants were asked what their goal would be with using a technology to monitor their health, and whether having such a technology would help them deal with their symptoms. Goals mentioned were: just out of curiosity, to continue staying positive, to have a nice overview of all health data, to be more active, and to gain stability in life. We found a discrepancy between whether this example technology would help them deal with their symptoms. Some think it will help them, but others commented they already know how to deal with this. Participants do think that for someone who was recently diagnosed with COPD, such a technology which they can use to monitor their health, would have added value.

Almost all participants were interested in seeing their health data in a technology to monitor their health, except for two who did not see added value in having this. The participants who were interested would use their health data to check how it is going with their health, and maybe to change some lifestyles if necessary. When asked whether they want to see other information not shown in the mock-ups, they found it difficult to answer. One said: "I don't know if there are any other important aspects concerning COPD. But then I would actually like to have all the information as far as that applies to me." [P7]. But what this information then really would be, they could not answer. Besides this, most of them wanted to know everything, and only two mentioned something could be left out of the future technology: "I think that part about depression, that's nothing for me. [. . .] When I see that mock-up, I think: 'Oh no, go away'." [P4].

If the participants would use an app to monitor their health, most of them would share the health data with their HCPs. Reasons for this are: "Because my healthcare professional also needs to know how I'm doing. I'm feeling bad and I say: 'I want to have medication'. He should be able to see what is causing this. At least, that is my opinion." [P3], "That data should be available. And I have little value considering privacy. I rather have convenience, that another doctor can see everything with just one touch." [P7]. Two participants would not share their health data gathered through an app, because of privacy concerns, or thinking it has no added value to share those with the HCP.

## 4.3 Attitude towards and needs related to health predictions (interviews)

Participants were asked how they felt regarding receiving predictions about their health. Some participants were positive about this, because: *"That is nice of course. Because you can check it out for yourself. [. . .] You learn a lot more about your health with this."* [P4], *"Fun! And no more and no less. I won't get upset."* [P9]. However, others were reluctant, because: *"Because I think, well something will be predicted I'm not ready for."* [P8]. One participant was partly positive about this because with having a prediction, they could prepare themselves. But it could also make this person anxious. Furthermore, one participant believes it is not possible to predict your health, and another one thinks a prediction is unnecessary as one would notice oneself how one feels.

The topics participants came up with to receive predictions about were: specific factors such as age and weather (e.g. humidity) and general health predictions like well-being, dyspnoea and COPD health in 10 years. Two participants did not want any predictions. One participant could not think of any topics, but after asking about well-being, fatigue, dyspnoea and exacerbations, they indicated they would want to have those predictions. Concerning exacerbations, most participants thought it is not predictable: *"You get that all at once.* [...] *It is actually unpredictable, you just get it, even though you're still being very careful."* [P3]. Overall, participants thought it would be nice to have predictions about different kinds of topics, but they do not always think it is predictable: *"That seems very difficult to do because it depends on so many factors."* [P2].

Most participants want to receive the prediction as a notification or within the home screen of an application as a short message. It differs how often they would check the prediction. Some would like to check it every day, others once a month, and one participant would only check it as a one-time thing. Participants would want to know the reasoning behind the prediction: *"Yes, then I'll know what I, for example, it's my fault you know, then I know I shouldn't do that again next time."* [P6]. When asked whether they would use an online tool including health data monitoring and predictions, some would and others would not. The added value of using such a tool is: *"That you can focus on your COPD.* [. . .] *Your life is controlled by it anyway. With everything you do, you notice that you have COPD."* [P7]. Participants who want to use such a tool indicated they would not need incentives to be motivated to use the tool. Participants who do not want to use it, also indicated incentives will not change their attitude.

After the first discussion about predictions, we showed participants three mock-ups of predictions. In general, participants had a positive opinion: *"I do think they are funny, or well funny, I think they are interesting. I'm actually very curious about it."* [P2]. Only one participant was less positive about having this for themselves: *"Maybe it's nice for Linda to know, but I don't want it."* [P10]. This same person said the following when seeing the mock-up about mood predictions (Appendix A, Figure 2a): *"That's terrible!* [. . .] *If it had been here* [pointing to a bad mood], *I would think: 'Well it's better if I stay in bed all day'.* [. . .] *In my opinion, it's not good to know this in advance."* [P10]. Most participants preferred the mock-up of dyspnoea with the reasoning behind the prediction (Appendix A, Figure 2c), because: *"I'm constantly thinking about that, like how come today I have less air than yesterday, why is that? Is it because I had two alcoholic drinks, or ate too much, or didn't move enough or whatever?"* [P2]. Opinions were divided on whether such a predicting tool would be helpful in learning how to deal with symptoms. Some were positive because one might be able to act

upon those predictions. Others were less positive because they already knew their body and their symptoms. They considered that such a tool would have more added value for persons who have been recently diagnosed with COPD.

## 4.4 Attitude towards coaching (workshops and interviews)

During both the workshops and interviews, we focused on coaching. During the workshops, we aimed to identify the topics the study population wants coaching using deductive and inductive coding. During the interviews, we aimed to identify the study population's attitude towards receiving virtual coaching using deductive and inducte coding.

*4.4.1 Topics for coaching.* From the coaching workshops, we identified several potential topics for coaching: exercising, receiving information, smoking cessation, mental well-being and coping with losses. In terms of exercising, almost all participants mentioned exercising as an important topic. Participants continuously got the advice to keep exercising as much as possible, and one participant wanted to learn to recognise their limits: *"To know your limits. In that initial phase, I was like, what do I do with this?"* [P5].

All participants mentioned receiving information as an important topic for coaching. Participants missed, among other things, information regarding COPD in general, exacerbations, comorbidities, and social participation. Participants wished to receive better information during all phases of their disease: *"I think it* [receiving information] *must be continuous. But in the beginning, I think it is important that if you diagnose someone with COPD, that they know what it is about and give it proper time and attention to also tell what it is and what is behind it and what the course can be, because that is different for everyone"* [P2].

Smoking cessation was also mentioned as a potential coaching topic during disease management. All participants got the advice to quit smoking. Some participants managed to quit smoking with help from smoking cessation therapy. However, this was not easy for the participants: "Quitting smoking, that was a thing for me. That was very, very intense, but I'm 14 years away from that [smoking]. I went to smoking cessation therapy at the hospital. I had guidance for a year and that was great." [P4].

In terms of mental well-being, participants in the workshops mentioned experiencing difficulties with this. They still receive either therapy or talk to a social worker. However, this support is not available for everyone. Another important topic for coaching mentioned was how to cope with losses, as this is a reoccurring event during everyday life of people living with COPD: "How you deal with the loss of everything. Because it remains a loss. Every time you lose something and have to say goodbye to something again. I have an electric bike that has been in the shed for two years. Yes, I have to say goodbye to that now. And yes, things like that. It's actually a continuous theme. So more and more disappears. Saying goodbye to the vacuum cleaner is not so bad [though]." [P5]. This participant also mentioned struggling with finding meaning after having to quit work: "There's so much to work. What you lose when you stop working, just like exercising. If you don't do that anymore, you'll lose everything around it. That way, a lot disappears from your life. How do you deal with that? It remains painful and the loss remains, even after all these years" [P5].

During the workshops, some participants explicitly mentioned the need for guidance on what actions to take when it is not going well. "Well, for example, to get advice if it turns out that things are not going so well. To get advice on what I can do about it to ensure, quote/unquote improvement. That it doesn't get worse. Say you're suffering from shortness of breath, what you can do to make sure that the shortness of breath gets less." [P7].

*4.4.2 Virtual coaching.* When looking at the mock-ups during the interviews, most of the participants missed the current context in the dialogues, especially when there was a concrete recommendation that due to their decrease in physical activity, they could ask the neighbour to go for a walk (Appendix A, Figure 3d). Several participants commented that there was no question about the underlying reasons for why they might have been less active but instead, the coach made recommendations on how to increase activity. This is especially important when people with COPD are not feeling well and physical activity might worsen this. Besides the specific reference to a neighbour that might not fit their context, one participant also commented on the recommended activity itself, because for them biking is easier.

Participants considered the coach useful in terms of stimulation and motivation and raising awareness. For example, the coach raising awareness that the steps count is dropping was seen positively. Such a coach could help to be more active, because *"it kind of forces you to face the facts"* [P6]. The coach adds accountability which can help with commitment. *"It's more an incentive. God, Marc sees that I haven't walk much today. I better should go for a bit."* [P10]. However, the coach should not be commanding: *"You know, with most people, if people come and say 'You must do this. You must do that.' We merely ask 'Would you, please.' This 'You have to' does not exist for me. I don't have to do anything."* [P9].

Another important role is to encourage reflection in relation to current behaviour or predictions. Participants emphasized the importance of inviting subjective reflection about potential causes and how they are currently feeling. Several participants reported that they already know quite well how they feel and would not need technology to tell them that. It was suggested that the coach asks how it is going and that they also can express how they feel: *"Yes, that, that you can indicate how or what, especially with that it says: 'Well, the coach has collected this data and that next week the shortness of breath can increase', what can be the cause of that."* [P6]. Next to adding subjective information that may contribute to the cause, one participant also commented that they wanted to know what the prediction is based on to learn from.

When discussing virtual coaching, some participants again mentioned that this program would be specifically beneficial for people newly diagnosed with COPD: *"With COPD just starting, it is a little bit more important that you really stimulate movement. And whether that's biking or walking or something else, that's the most important thing."* [P3]. However, also people with COPD who already know a lot might still benefit from a virtual coach: *"I have already learnt to deal with my symptoms. Still, maybe he has a different perspective from me, that there is still room for improvement, I don't know."* [P9]. Furthermore, the aforementioned aspects of raising

awareness and motivation might also be useful for persons who already live with their condition for a longer time. One participant was unsure whether they would use it daily and suggested it was most useful when it is not going very well.

# 5 DISCUSSION

This study aimed to investigate the attitude of people with COPD towards and the usefulness of monitoring their health, receiving risk predictions and virtual coaching within an eHealth technology. This study showed us that overall, people with COPD have a positive attitude towards these topics and their usefulness for COPD healthcare, except for risk predictions participants had a more diverse attitude. Explanations of risk predictions seemed to be important to understand the cause and whether their behaviour played a role in the worsening of symptoms.

Even though the participants were quite positive in general, most did mention that having such a technology, is more useful for newly diagnosed persons who do not have a good understanding of their symptoms yet. This is also the reason why some participants were less positive regarding the use of such a technology for themselves, as they are already self-managing their COPD. When looking at previous literature, we do not see the participants mentioning this difference between newly diagnosed persons and persons living with COPD for a longer time (e.g. [33, 57]). A reason for this could be that in our study the technology was not yet ready to use and in others participants could already use it and could already experience the added value of using it. Furthermore, some participants in our study were also in doubt whether such a technology would have enough information to make decent individual risk predictions or to make any recommendations to users.

During our study, we noticed that when discussing data collection, monitoring and risk predictions, participants focused more on physical aspects (e.g. activity). When talking about their mood, a lot of them mentioned they do not need that within a self-management eHealth technology. However, when discussing virtual coaching, participants were more positive about the psychological aspects. They mentioned that during their patient journey, they needed support regarding their mental well-being. Also, when talking about positive health, they were also more positive about the whole holistic view which shows their mindset in life. So, this shows a discrepancy towards the need for psychological aspects. This leaves us questioning whether there still is a taboo regarding talking about psychological aspects. Literature shows us that there are stigmas around psychological problems (e.g. [17, 25, 32]), with discrepancies around different age groups. For example, Hafford-Letchfield and colleagues [17] show us that for older adults, it might be more difficult to talk about psychological struggles. As it is more common nowadays to seek support, younger adults are more used to this than older adults [17]. On the other hand, Mackenzie and colleagues [32] show that this topic is still stigmatized, but less among older adults compared to younger and middle-aged adults. Overall, this taboo could have influenced the needs participants expressed during this study.

## 5.1 Implications for design of self-management eHealth for COPD

Based on our findings, we propose several implications for design of self-management eHealth technologies for people with COPD. By incorporating these implications, the technology's usefulness could increase and the interaction between humans and computers could improve. First of all, we need to include personalisation. This personalisation needs to focus on the context (e.g. what is the preferred activity?), and on the level of detail persons want to see. For some, too much information would be overwhelming, others prefer to have all information to feel in control. This information needs to differ per person and might change over time, thus they should have the option to customize this. Furthermore, personalisation should focus on where people with COPD are in their patient journey. This might be related to what is asked of them in terms of data collection, which could add workload to their existing disease burden [14]. For example, if persons are quite experienced and in a stable phase, they might not be interested in completing questionnaires and being constantly reminded of their disease. Thus, during the design of the technology, we should not only focus on novice versus expert *users*, but also on novice versus expert *patients*. They might have learned a lot during their time since diagnosis. So, when designing a self-management eHealth technology, it should reflect this level of expertise. This is also supported in previous HCI literature, in which it is noted that the need for information differs between persons with multiple chronic conditions based on where they are in their patient journey [6]. Personalisation within eHealth is an important factor which affects usefulness and behaviour change [28, 55]. To be able to develop a technology which could transform COPD care, the technology needs to fit a diverse group of users.

Secondly, the self-management eHealth technologies need to support people with COPD to reflect on their behaviour and patterns. During this study, we noticed the importance of this several times. For example, when going through the virtual coaching dialogue, participants wanted the coach to ask them why-questions instead of receiving general tips to change a behaviour. This shows that these eHealth technologies should not only give off-the-shelf advice, but also help people with COPD reflect on what may be the cause. In particular, when patients are experts, they know what they are doing, but the technology did not take that into account and gave generic advice. The importance of more in-depth coaching content was also shown previously within virtual coaching for health behaviour change in general [22].

Thirdly, when the self-management eHealth technology includes a virtual coach, this coach can give some form of accountability which can be motivating. However, this should be balanced, in other words not too commanding. The technology needs to be more of a supporting/reflecting tool instead of a paternalistic tool. People with COPD want to draw lessons from technology to understand why something happened. Previously, it was also suggested that this learning from eHealth coaching needs to be step-by-step, not overwhelming the person [40].

Drawing the lessons learned from a self-management eHealth application for people with COPD also relates to our final implication: explainable AI. Participants wanted to know the reasoning

behind the risk predictions. HCI designers needs to incorporate explainable AI to enable the users to learn which factors contributed to the prediction. This also raises the trustworthiness of the AI within the eHealth technology and increases users' understandability [19, 35, 41]. We think that this is especially important in relation to self-management: people with COPD then know what led to the predicted improvement or worsening and whether they contributed to this. This could prevent demotivating them in striving towards a particular behaviour. For example, if a person tries to follow all recommendations but given the progressive nature of COPD, their symptoms still worsen, explainable AI could help them understand, that it was not action that caused this, but for example, the current weather or air pollution. Understanding which factors contributed to the prediction can help them to maintain/change their health behaviour, and to learn to accept the factors they have no influence on. COPD is of course a progressive disease, so not everything is preventable.

### 5.2 Limitations

This study also had some limitations. The first one is that we interviewed people with COPD about their attitude towards a future technology, which we visualised with mock-ups. Due to its low-fidelity, participants could not try out the technology, which can make it difficult to envision its usefulness and to form and explain an opinion in depth. Secondly, the participants were all diagnosed with COPD several years ago. No recently diagnosed persons were included, who might yield different attitudes. Finally, the stigma surrounding psychological issues could have influenced the needs participants expressed.

## 6 CONCLUSION AND WHAT'S NEXT?

Based on our findings, we propose the need for personalisation in context and level of details persons want, the need to include support for persons to reflect on their behaviour and patterns within self-management eHealth technologies, the need for accountable, motivating virtual coaching, and the need for explainable AI. Furthermore, we identified several opportunities for future HCI research. More investigation is needed towards the importance of raising awareness of their lifestyle and supporting reflection within eHealth, and how this enables personalization of a self-management eHealth technology for COPD. Furthermore, a more diverse group of people with COPD (novice and expert) needs to be included and participants need to have the opportunity to try out a self-management eHealth technology before investigating the attitudes. Finally, future research should focus on the mental/psychological aspects of self-management of COPD and take potential stigmas into account that might prevent people to openly discuss this in a group setting.

To conclude this paper, we want to argue that self-management eHealth technologies are promising for people with COPD. By implementing a self-management eHealth technology, which supports reflection, people with COPD can become more aware of their habits and symptoms and could feel more in control and empowered. This can support them to take an active role in their care process.

## ACKNOWLEDGMENTS

The authors want to thank all participants for their time, input and support in the study. Furthermore, the authors want to thank Yfke Dotinga for her help in conducting and transcribing interviews. This work is supported by the RE-SAMPLE project that has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 965315.

## COMPETING INTERESTS

The authors declare no conflict of interest.

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# APPENDIX A – MOCK-UPS OF EXAMPLE TECHNOLOGY


**Figure 1: Mock-ups of example technology – part health data collection for health monitoring.**


**Figure 2: Mock-ups of example technology – part risk predictions.**

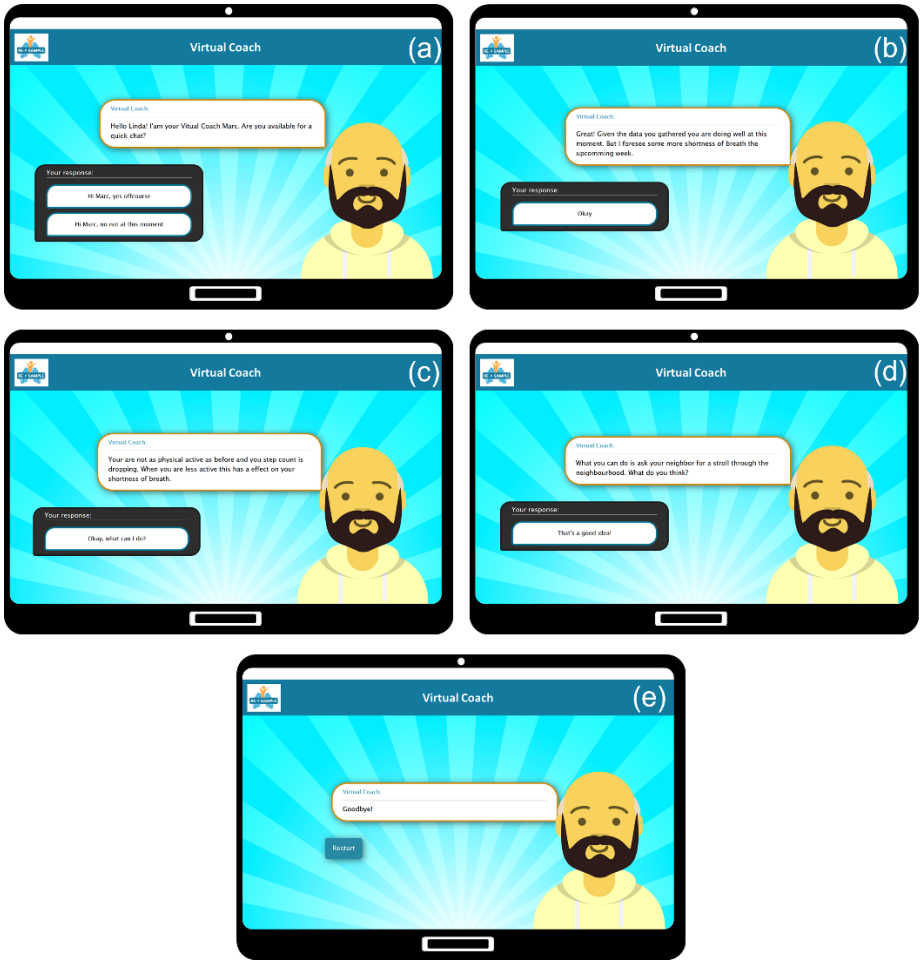


**Figure 3: Mock-ups of example technology – part virtual coach.**