# Exploring the potential benefits of digital health technology for the management of COPD: a qualitative study of patient perceptions

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ABSTRACT Engaging chronic obstructive pulmonary disease (COPD) patients to actively participate in self-management has proven difficult. Digital health technology (DHT) promises to facilitate a patient-centred care model for the management of COPD by empowering patients to self-manage effectively. However, digital health studies in COPD have yet to demonstrate significant patient outcomes, suggesting that this research has still to adequately address the needs of patients in the intervention development process. The current study explored COPD patients' perceptions of the potential benefits of DHT in the self-management and treatment of their disease.

A sample of convenience was chosen and participants (n=30) were recruited from two Dublin university hospitals and each underwent a qualitative semi-structured interview. Thematic analysis of the data was completed using NVivo 12 software.

Six themes were identified: symptom management, anxiety management, interaction with physician, care management, personalising care and preventative intervention.

In our findings, patients reported a willingness to take a more active role in self-management using DHT. They perceived DHT potentially enhancing their self-management by improving self-efficacy and engagement and by supporting healthcare professionals to practise preventative care provision. The findings can be used to inform patient-centred COPD digital interventions for researchers and clinicians who wish to develop study aims that align with the needs and preferences of patients.

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**COPD patients perceive potential benefits accruing from using digital health technology in self-management, including improved self-efficacy and perceived support for healthcare professionals to deliver preventative and personalised care** http://bit.ly/2DhPMW7

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## Introduction

By 2020, chronic obstructive pulmonary disease (COPD) is projected to be the third leading cause of death globally [1]. COPD adversely affects the quality of life of the patient, their family and caregivers, while also having a negative impact on their physical and social function [2]. Because COPD care is primarily undertaken by the patient in the community, self-management is a central component to managing the disease [3]. Self-management in COPD is linked with increased patient autonomy, reduction in hospitalisations and duration of exacerbations, decreased healthcare costs and improved health-related quality of life [4]. Yet, engaging patients to take an active participation in behaviours, activities and decision making related to self-management has proven difficult, with several barriers existing for patients and healthcare professionals (HCPs) [5–7].

Recently, there has been an emphasis placed on digital health technology (DHT), including remote monitoring devices, telehealth and telemonitoring platforms, to facilitate an integrated, patient-centred care model for the management of COPD [8–12]. These approaches focus on the tailoring of disease treatment and self-management to the needs of the patient by leveraging multimodal data sources, including those captured outside the clinic by the patient themselves in partnership with their care team [13]. The benefits of digitally captured health data such as activity and sleep data are gaining steady traction within healthcare policy [14–16], because of their potential to enhance patient self-management by increasing patient engagement and empowerment, to improve patient–clinician communication and to support clinicians with new forms of diagnostic and disease management information [17–20].

However, several studies and systematic reviews have been published regarding telemonitoring, mHealth and eHealth interventions in the management of COPD, with sparse evidence demonstrating positive improvements for patient self-management or treatment outcomes [21–25]. Issues with the development of self-management digital health interventions in COPD and for chronic diseases in general have been discussed [22, 26]. Particularly, this work has highlighted digital interventions that set pre-determined research goals, such as reducing admissions or resource utilisation, which tend to offer "one-size-fits-all" solutions that elevate the importance of clinical outcomes, with the result that patients' needs and self-management practices are often ignored in the development stages of interventions [22, 26]. Moreover, although post-study evaluations of patient perceptions are frequently part of COPD digital health studies [27–29], the usefulness of these findings has been questioned, primarily because digital interventions find it difficult to reflect the reality of day-to-day healthcare for a patient due to the complexity of self-managing a disease with such a variable symptomology [22]. It is thus unsurprising that patient adoption and satisfaction issues are still frequently cited [23, 30] and, although work is emerging that aims to gather patient perceptions of DHT pre-development [31], research remains sparse in this area.

There is a need, therefore, to re-engage with fundamental questions regarding the role envisioned for COPD patients in the development of digital health interventions. Specifically, it is worth asking whether COPD patients actually perceive potential benefits accruing from the use of DHT in the first instance. Exploring this avenue may help to identify future areas of digital health research that align more with the self-management and treatment needs of COPD patients to ensure that smoother adoption and implementation occurs [22, 23]. Therefore, this study employed a qualitative study design to explore the following two research questions. 1) What are COPD patients' perceptions of the potential benefits of using DHT in the self-management of their disease? 2) What are their perceptions of how DHT may benefit how their disease management and treatment is delivered by their HCPs?

## Methods

### Study design

This study adopted a qualitative study design, namely one-to-one in-depth semi-structured interviewing of COPD patients.

### Recruitment and sample

Patients were recruited from respiratory clinics at two university hospitals (Tallaght and St Vincent's, both in Dublin, Ireland). The patient characteristics are shown in table 1. For pragmatic reasons, a sample of convenience was chosen. Respiratory consultants (M.W. Butler and J. Cullen) identified potential participants at clinic, who were then invited to partake in the study. The inclusion criterion was a confirmed diagnosis of COPD following Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines [32]. The GOLD stage classification of the patients in the sample is shown in table 2. Exclusion criteria were the existence of cognitive or psychotic disorders, or the existence of severe life-limiting comorbidities, for example lung cancer. Interested patients (n=30) received an information leaflet and consent form and were given a 48-h reflection period before being contacted by the researcher (P. Slevin) to confirm their participation. If they confirmed, a time and date convenient to the participant was

TABLE 1 Patient characteristics[#]

| Characteristics | Data |
|---|---|
| **Male/female** | 17/13 |
| **Mean±sd age years** | 68.2±10.1 |
| **Smoking history** | |
| Current smoker | 5 |
| Ex-smoker | 25 |
| **Occupation status** | |
| Homemaker | 1 |
| Carer's allowance recipient | 1 |
| Retired | 20 |
| Employed | 5 |
| Unemployed | 3 |
| **Marital status** | |
| Married | 19 |
| Widowed | 7 |
| Single | 3 |
| Separated | 1 |
| **Highest education level attained** | |
| Primary | 12 |
| Secondary | 6 |
| Third level and above | 12 |
| **Technology[¶]** | |
| Smartphone | 16 |
| Laptop and/or personal computer | 18 |
| Both smartphone and laptop | 15 |

Data are presented as numbers of patients, unless otherwise stated. [#]: data self-reported by patients at interview; [¶]: total n=30, some patients were in more than one category.

scheduled for the interview. The number of patients who were approached but declined participation was not recorded. Written consent was obtained before each interview and all 30 interviews were conducted at patients' homes. Ethical approval was granted by University College Dublin, St Vincent's University Hospital and Tallaght University Hospital (all in Dublin).

*Procedure*

In-depth interviews were conducted by the first author (P. Slevin), who is an experienced qualitative researcher. A semi-structured interview topic guide (table 3) was used to frame the discussion. Questions explored patients' perceptions about 1) the potential benefit of using DHT in the self-management of their disease, and 2) how DHT may benefit how their disease management plan and treatment is delivered by their HCPs. The topic guide and open-ended questions allowed for new areas of conversation to emerge, which were then explored with the patient [33].

*Data analysis*

Interviews were audio-recorded with a Dictaphone, transcribed verbatim and anonymised. On average, interviews had a duration of 60–90 min. NVivo 12 software (QSR International Pty Ltd, Doncaster, Australia) was used to conduct thematic analysis of the transcripts. The interview topic guide was used to develop an initial draft codebook [34]. A sample of the transcripts was then independently analysed by

TABLE 2 Chronic obstructive pulmonary disease severity classification

| | GOLD stage | FEV$_1$ % predicted | Patients n |
|---|---|---|---|
| **Mild** | 1 | ⩾80% | 2 |
| **Moderate** | 2 | ⩾50% and <80% | 16 |
| **Severe** | 3 | ⩾30% and <50% | 9 |
| **Very severe** | 4 | <30% | 3 |
| **Total** | | | 30 |

GOLD: Global Initiative for Chronic Obstructive Lung Disease; FEV$_1$: forced expiratory volume in 1 s.

| TABLE 3 Interview topic guide | |
|---|---|
| **Topic** | **Questions** |
| **Demographics** | Age; marital status; occupation status; highest education attained; technology (mobile or smartphone; personal computer; laptop); smoking history. |
| **Disease experience** | Can you discuss your experience of your COPD?<br>What is the role of family and friends when managing your COPD?<br>What types of self-management practices do you perform?<br>How do you feel about self-managing?<br>Can you discuss how you manage your symptoms?<br>Can you tell me about an exacerbation you had?<br>Can you discuss the last time you ended up in the GP clinic and/or hospital? |
| **Healthcare experience** | Can you tell me about the kinds of care you receive or have received for your COPD?<br>How do you feel about the care you receive for your COPD?<br>Is the care you are receiving meeting your needs? |
| **Health data and DHT** | Do you record/log information about your health? If so, why/how? If not, why?<br>Do you think you could provide HCPs (*e.g.* GP or consultant) with more information about your health day-to-day?<br>What types of information do you think your doctor should have about your health?<br>How would you feel about using a DHT (*e.g.* oximeter, COPD-related smartphone app, spirometer, self-reported outcomes platform, *etc.*), to generate health information/data about yourself?<br>What do you think about capturing information/data in the home?<br>How might collecting health information/data at home impact how you manage your COPD?<br>Can you discuss why you might share information/data you collect with your HCP?<br>How do you think these types of information/data could be used by your HCP to manage and treat your COPD?<br>Can you tell me how these types of data could be collected that would be suitable for you and your needs? |

COPD: chronic obstructive pulmonary disease; GP: general practitioner; DHT: digital health technology; HCP: healthcare professional.

P. Slevin and T. Kessie to iterate and finalise a comprehensive codebook [35, 36]. Thematic analysis included reading each transcript closely, identifying patterns, assigning codes, and formulating themes and sub-themes from the data [37]. To ensure optimal analytical rigour was practised, the data were analysed and coded independently by the researchers (P. Slevin and T. Kessie), after which they were scrutinised, compared and discussed, to resolve any discrepancies [38]. When no new data, themes or relationships were being identified, data saturation was reached [39].

## Results

All 30 patients completed an interview. The following themes emerged from analysis: 1) "benefits to patient self-management practices", which includes the three sub-themes "symptom management", "anxiety management" and "interaction with physician"; and 2) "benefits to HCP care provision", which includes the three sub-themes "care management", "personalising care" and "preventative intervention". The number of patients to influence each sub-theme with a response is presented in table 4.

### Benefits to patient self-management practices
### Symptom management

For many patients (n=15), DHT had the potential to improve self-management skills such as symptom management. They felt that capturing health-related data could help with recognising and understanding their symptoms to better inform the modification of their self-management regime.

> I'd say having that extra responsibility, you know, measuring those things, would give someone a more purposeful feeling with their COPD. Like, it's very hard to keep track of all the symptoms … so it can be frustrating not knowing why am I out of breath?
>
> Patient 122: age 68 years, GOLD stage 3, undergraduate education level

| TABLE 4 Numbers of patients influencing sub-themes[#] | |
|---|---|
| **Themes and sub-themes** | **Patients n** |
| **Benefits to patient self-management practices** | |
| Symptom management | 15 |
| Anxiety management | 13 |
| Interaction with physician | 11 |
| **Benefits to HCP care provision** | |
| Care management | 15 |
| Personalising care | 12 |
| Preventative intervention | 15 |

HCP: healthcare professional. [#]: total n=30.

> I would like to know what is going on with me, I don't know the odd day why I am feeling lowly, or sleepy or out of breath so I can look at what I did today that was different and maybe change that.
>
> Patient 101: age 62 years, GOLD stage 2, primary education level

It was also evident that patients felt that self-monitoring would encourage proactive responses to symptom change, leading to timelier decisions regarding seeking healthcare attention.

> Well, checking the levels would help keep your mind in an active state, to react to something sinister, to keep going.
>
> Patient 113: age 89 years, GOLD stage 2, PhD education level

> It's about seeing them moments when I might not recover quickly, because they are the times I really need to act fast so that I don't get even worse.
>
> Patient 106: age 67 years, GOLD stage 4, undergraduate education level

### Anxiety management

Patients also spoke about the worry and anxiety associated with their disease (n=13). For some, the worry of falling ill creates a source of apathy towards medication compliance and they see a potential for DHT to provide a reassuring status update that could ease such concerns.

> I worry from time to time that I'm going to get worse quickly, so I suppose if I have something showing me that I am as healthy as I can be, that can only be a good thing, because worry puts a stress on the body and I mightn't be as all action, and then if you aren't bothered you might forget to take the inhalers.
>
> Patient 104: age 73 years, GOLD stage 2, undergraduate education level

For others, a status update may help reduce symptom anxiety as they adjust to their new diagnosis.

> Imagine after my diagnosis I'd be given a device to help me see the differences in a good day of breathing against a bad day of breathing? I know that would have eased the worry I had about every little change I was feeling. I'm sure plenty do panic at the slightest sign of being breathless.
>
> Patient 132: age 61 years, GOLD stage 2, undergraduate education level

### Interaction with physician

There was a general feeling of dissatisfaction expressed by patients regarding their consultation experience (n=11). However, patients felt that having their own data in a consultation would create meaningful, personalised and collaborative discussion, while others felt these data could more accurately describe their symptoms when they feel they cannot satisfactorily provide this type of information.

> A lot of time is wasted in consultations talking about things I don't care about. If I was monitoring here at home then there would be plenty to talk about because the information collected would be about my COPD, about my symptoms, so that wouldn't be a waste of time, it'd be actually something to talk about and try to figure out, say if it was bad at the time.
>
> Patient 127: age 57 years, GOLD stage 4, secondary education level

> The type of monitoring we're talking about, it follows on into times when I am in the clinic with my GP [general practitioner], and he is asking me to describe how I have been feeling, that isn't easy to describe and

then he will be asking me what were you doing that day, anything different? And I won't be able to remember, I've a terrible memory. It all gets vague from my side, and it is frustrating.

*Patient 130: age 64 years, GOLD stage 1, undergraduate education level*

### Benefits to HCP care provision
### Care management

Patients spoke about the benefits that could arise from sharing their digitally generated data with HCPs (n=15). Some felt that their data could act as evidence of their compliance to self-management practices, while others commented that data presenting health status indicators may potentially reduce hospital visits by facilitating informed decision making.

I would feel they could see how the exercise doesn't change that much week to week, so they could be more confident that I am actually doing the right things.

*Patient 121: age 72 years, GOLD stage 3, primary education level*

If they were getting an idea for how my breathing is, say, if they knew that, "Yea, he's getting on well." Then they mightn't need to see me or that they could just tell me to head down to the GP instead.

*Patient 117: age 64 years, GOLD stage 2, undergraduate education level*

### Personalising care

Patients also suggested that sharing their data could help with personalising their treatment through progress tracking, for instance, to optimise their medication (n=12).

I'm sure hundreds of COPD patients are on the same inhalers, but they all can't work for each person the same, so if you are monitoring they might be able to tailor the inhalers for each person based on the information being gathered.

*Patient 131: age 46 years, GOLD stage 2, undergraduate education level*

So, imagine being a doctor and facing so many people every day, it must be impossible to know all of them? You couldn't know them too well or what goes on with them … if in the future I am using the phone and answering questions there's a chance they would know more about me.

*Patient 107: age 82 years, GOLD stage 2, apprenticeship education level*

### Preventative intervention

Patients articulated that HCPs could leverage the data captured to address the preventative care needs of individuals (n=15), but this was primarily spoken about in the context of ill health. For example, patients commented on the potential of these data to instigate a timely intervention that could help classify the seriousness of their symptoms.

I think if they saw that information, that might tweak something with them or they could ask why I am feeling that way, say if I'm wheezing for a few days then it's clear I am not well, but if someone got onto me to say, we don't like the look of that, then I might take it more seriously.

*Patient 105: age 65 years, GOLD stage 3, primary education level*

Meanwhile, it was the benefit of capturing multiple health-related data points that interested other patients, who felt that having comprehensive indicators would streamline their access to healthcare services.

With my GP everything is done by appointment. If they say to me it's going to take 2 to 3 days before I can see you, I can become incredibly worse and if so what should we do now? So, I can say to the secretary, tell the doctor my oxygen level is 88 and it was like that last night and the morning before and tell him that my temperature is 101, so I really need to see them. No doctor can ignore them signs, so then I would be either brought in, or they could make the call to send me to hospital.

*Patient 108: age 65 years, GOLD stage 3, secondary education level*

## Discussion

This study provides new insights about the perceptions of COPD patients regarding the potential benefits of using DHT in the self-management and treatment of their disease. Recognition and understanding of symptoms have been shown to affect COPD patients' ability to detect exacerbations [40] and, in this study,

patients perceived that their capacity for symptom management could be improved by capturing data from DHT. Patients also expressed that using DHT could help to encourage proactive responses to symptom change, such as prompting more effective decision-making behaviours regarding accessing healthcare resources. By enhancing these skills and behaviours, the findings suggest that DHT could foster a greater sense of self-efficacy, referring to the patients' confidence in their ability to actively perform tasks associated with managing their disease [41, 42]. It has been found that a decreased sense of self-efficacy can hinder the development and execution of fundamental self-management skills such as problem solving, self-tailoring, decision making and self-monitoring [5, 43]. These findings support previous work that identified improved patient engagement and self-efficacy as an outcome of using data generated by DHT [44, 45]. The findings of the current study reveal that patients perceive a role for data generated by DHT to reduce feelings of anxiety associated with their COPD. Anxiety is closely linked to the experience of deteriorating symptoms and a dyspnoea-related fear, which can impede the confidence of patients to self-manage, leading to non-adherence with treatment [46, 47]. Interestingly, the opportunity to leverage digital health data to enhance patient self-efficacy could have a positive cascading effect on COPD-related anxiety.

Patients also spoke about how digital health data could help optimise the consultation experience by empowering them to partake in collaborative conversations concerning their self-management. For the patients, these data have the potential to ensure patient-centred communication and shared decision making, which are known to have a positive impact on patient satisfaction, adherence and self-management outcomes [48, 49]. Furthermore, patients felt their data could help with answering physician questions when, for instance, they were not satisfied they could provide an accurate account of symptoms from memory alone. This type of application could find traction in addressing recall issues experienced by patients. Prior research has found that COPD patients' recall of exacerbations over a 6-month period is overall inaccurate, which can lead to imprecise decisions regarding appropriate therapy [50, 51].

Additionally, the findings suggest that patients perceive several potential benefits accruing from sharing digital health data with HCPs. Particularly, findings relate to the opportunity for the capture of ongoing data to provide information about the patient's status during the inter-appointment period, where traditionally a knowledge gap exists [52]. It was felt that these data could act as a form of progress reporting that leverages indicators of health status, such as therapy compliance or symptom updates, to inform case management decisions including determining the necessity for hospital or GP visits. Moreover, the progress-reporting capability of the data generated by DHT was perceived as a possible mechanism for informing preventative interventions [53]. Patients felt that data would help HCPs identify suboptimal medication outcomes, which could facilitate the tailoring of inhalers based on personalised information. This finding speaks to the previous research investigating the self-management needs of COPD patients, which found participants expressing a desire for the provision of personalised care [54]. From the provider perspective, findings elsewhere have demonstrated that HCPs recognise that the provision of personalised care is a significant factor affecting the self-management behaviours of COPD patients [7].

Some studies have found the presence of consistently poor reporting behaviours among COPD patients, resulting in most exacerbations being unreported [55, 56], while other work has highlighted that 50% of asthma and COPD patients were found not to receive GP intervention prior to presenting to hospital [57]. Therefore, early detection of exacerbations and prompt intervention is preferred as they have been shown to reduce recovery time, improve health-related quality of life and reduce the risk of hospitalisation [55]. Such findings correspond to the types of self-management needs patients perceived digital health data helping to address in this study. Patients commented upon the potential for this data to stimulate collaboration with HCPs in the early detection of worsening symptoms. It was felt that data may encourage the timelier input of HCPs to help patients determine the seriousness of their symptoms and to guide appropriate action. Lastly, the opportunity for DHT to create a comprehensive set of meaningful, objective indicators was discussed. Patients suggested that data from DHT could better validate the urgency of their status to HCPs and, subsequently, streamline their access to healthcare services.

Using qualitative methodology, this study sought to gain an in-depth understanding of COPD patient perceptions regarding the potential benefits that DHT may have in the self-management and treatment of their disease. The rigorous approach employed in data collection and the use of NVivo12 software to support analysis offers strength to the findings. However, although heterogeneous, due to the relatively small sample size, the perceptions expressed may have limited generalisability. For example, although a sample of convenience was recruited, this cohort are well-educated, largely ex-smokers with a significant proportion having exposure to various technologies. These sample characteristics should not be ignored when considering the generalisability of the findings and future studies should include larger representative samples that might afford better understanding of the influence of factors such as digital

literacy, education and age. That said, we did have a wide age range in our sample of convenience (46–89 years) and did not observe any marked effect of age in patient perceptions. Furthermore, because this research focuses on the potential benefits COPD patients perceive for the use of DHT, future research is needed to investigate patient perceptions of the barriers and facilitators for the use of these technologies. Understanding HCP perspectives will also be very important for determining the clinical impact DHT may have on routine care in COPD.

### Conclusion

DHT is seen as an innovative solution for the provision of an integrated, patient-centred care model for the management of COPD. The findings of this study are encouraging, as they suggest that COPD patients are receptive to the role DHT can have in the management of their disease, with benefits being highlighted on several fronts. Patients perceive DHT enhancing their self-management by cultivating self-efficacy and engagement, empowering them to partake in collaborative discussions during consultations and supporting HCPs to foster preventative care-provision practices. These findings are important as they highlight that patients have unmet needs in several domains of self-management that are often not prioritised in COPD digital health studies where the aims and objectives are pre-determined. Therefore, the findings can be used to inform patient-centred COPD digital interventions for researchers and clinicians who wish to develop study aims that align with the needs and preferences of patients. However, the findings should be viewed as a stepping stone and should not be seen as a replacement for gaining a deeper appreciation for the needs of patients in the development stages of digital health interventions in COPD. Lastly, the findings are timely, as digital health in COPD has yet to demonstrate any significant improvements for patient outcomes, nor has it become part of routine care.

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