Barriers and facilitators of chronic breathlessness digital self-management interventions in people living with lung cancer and chronic obstructive pulmonary disease- a systematic review and narrative synthesis

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Abstract

Background

Recent research highlighted the expansion of telehealth has accelerated and will continue unabated. Patients with advanced chronic respiratory diseases experience breathlessness, often to a debilitating extent. This review aims to identify the barriers and facilitators to self-management, digital health intervention implementation, focusing on managing pain and breathlessness, in community-dwelling adults living with lung cancer and/or Chronic Obstructive Pulmonary Disease.

Methods

A systematic review of the literature following PRISMA guidelines, searching Medline, Embase, Cochrane Library and CINAHL databases, with two searches performed in June 2021 and April 2022. Study quality was assessed using the Mixed Methods Appraisal Tool (MMAT) and the PARIHS framework was employed to extract key data. The findings were summarised via narrative synthesis and interventions classified according to the World Health Organization framework for digital health interventions.

Results

Twenty-four included studies indicate the current literature is highly heterogeneous in terms of both quality and study types. Barriers and facilitators towards intervention implementation were found. Ease of use, a good degree of intervention accessibility and financial savings over standard care were among the strongest facilitators. Advanced patient age, lack of technological skills or trust, variability of patient needs and unused data appeared as some of the main barriers.

Discussion

Involving all stakeholders during the early stages of planning, particularly patients and healthcare practitioners is very likely to increase chances of intervention implementation success. Interventions also should not increase burden on healthcare practitioners and implementing interventions locally appears to be more effective.

Conclusions

New knowledge is provided via a list of barriers and facilitators towards self-management interventions implementation. Earlier disease staging, younger target populations and advanced healthcare settings are likely to be the strongest facilitators towards implementation success, while healthcare practitioners will need additional support. Given the current fragmented state of the literature on this topic, future studies should focus on longer-term effectiveness and adherence of digital health interventions in chronic breathlessness, conducted both qualitatively and quantitatively.

Table of contents

Abstract 2
Table of contents 3
List of Tables and Figures 5
Acknowledgements 6
Author's declaration 6
1. Introduction 7
1.1 Overview of the topic and research background 7
1.1.1 Current implementation challenges and why this review is needed. 7
1.1.2 Evolution of the definition of breathlessness 10
1.2 Epidemiology of lung cancer and COPD 11
1.2.1 Lung cancer 11
1.2.2 Chronic obstructive pulmonary disease 12
1.2.3 Burden of breathlessness on patients 13
1.3 The issue of chronic breathlessness 17
1.3.1 Behavioural changes and approaches within Implementation Science 19
2. Current evidence and review question 22
2.1 Self-management interventions and relevance of digital health interventions 22
2.2 Focus on the use of self-management digital health interventions supporting people living with LC and COPD. 25
2.2.1 World Health Organization definitions and importance of novel palliative care measures 25
2.3 Research question of this systematic review 26
3. Methods 27
3.1 Systematic search of the literature 27
3.1.1 Use of WHO Digital Health Interventions classifications 28
3.1.2 Definition of key terms related to Digital Health Interventions 30
3.2 Population, exposure, outcome 31
3.2.1 Population 31
3.2.2 Intervention(s), exposure(s) 31
3.3.3 Main outcome(s) 31
3.3.4 Additional outcome(s) 32
3.3.5 Data extraction and study heterogeneity 33
3.3.6 Data management 36
3.4 Risk of bias (quality) assessment 42

3.5 Definition of mixed-methods studies 43
4. Results 44
4.1 Results of the search strategy 45
4.2 Populations and design types 52
4.2.1 Objectives of included studies 53
4.2.2 Quality of the studies 53
4.3.3 Results according to PARIHS constructs 56
4.4 Barriers and facilitators to interventions uptake 71
5. Discussion 72
5.1 Suggestions to address current knowledge gap 72
5.1.1 Characteristics of the innovation 72
5.1.2 People's ability to change 76
5.1.3 People's motivation 78
5.1.4 Inner context 80
5.1.5 Outer context 84
5.1.6 Applicability of current findings to cardiovascular disorders 87
5.2 Strengths and limitations of the review 88
5.2.1 Methodological and available literature considerations 90
5.2.2 Publication bias 90
5.2.3 Possible issues with the use of digital health interventions synonyms and definitions 91
5.2.4 Limitations regarding target populations in studies, possible lack of generalisability of findings 92
5.2.5 Reliability of findings and 'maturity' of research field. 92
5.3 Summary of main findings 93
5.3.1 Implications for practice 93
6. Conclusions 97
6.1 Contributions of this review 97
6.2 Facilitators towards implementation 98
6.3 Barriers towards implementation 98
6.4 Novelty compared to existing literature 98
6.5 Challenges and opportunities for future research 99
References 101
Appendix A - Summary of results, findings and search strategies 117
Embase and Medline search strategies 142
Appendix B – PARIHS extraction tables 150
Appendix C – Example of data extraction form 168

List of abbreviations

BCW: Behaviour change wheel

CIS: Critical Interpretive Synthesis

COM-B: Capability, Opportunity, Motivation, Behaviour

COPD: Chronic obstructive pulmonary disease

DHI: Digital health interventions

HCP: Healthcare provider

Inter-rater reliability (IRR)

LC: Lung cancer

mHealth: mobile health

NICE: National Institute for Clinical Excellence

NIH: National Institutes of Health

NSCLC: Non-small cell lung cancer

PARIHS: Promoting Action on Research Implementation in Health Services

PEO: Population, Exposure, Outcome

PICO: Population, Intervention, Comparator, Outcome

SDG: Sustainable Development Goals

SLC: Small cell lung cancer

WHO: World health organization

List of Tables and Figures

Figure 1: Classification of digital health interventions v1.0

Figure 2: The facilitation role and process

Figure 3: PRISMA flow diagram of study retrieval and selection

Table 1: Definitions of digital health interventions

Table 2: Studies identified via literature search

Table 3: PARIHS framework constructs considered for data extraction

Table 4: PARIHS framework constructs and their specific aims

Table 5: List of included studies

Table 6: Quality assessment summary

Table 7: Barriers and facilitators to intervention adoption

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Author's declaration

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or diagram(s) have been copied from academic papers, books, the internet or any other sources these are clearly identified by the use of quotation marks and the reference(s) is fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS, the University of Hull or the University of York regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct, and state that this piece of work is my own and does not contain any unacknowledged work from any other sources

1. Introduction

1.1 Overview of the topic and research background

This thesis reports the results and finding of a systematic review, focusing on the barriers and facilitators towards implementation of self-management digital interventions towards chronic breathlessness, in people living with lung cancer and/or chronic obstructive pulmonary disease (COPD). The introduction in chapter 1 focuses on current implementation challenges and the need for this review, together with an overview of the epidemiology of lung cancer and COPD. The burden of disease in patients is further described, together with the issue of chronic breathlessness.

Current evidence and the review questions are explored in chapter 2, giving the reader a view on self-management digital health interventions and their relevance, leading to the research question of this review. The methods are then described in chapter 3, providing a detailed view of how the systematic search was conducted and what criteria were chosen to include and analyse the literature. The results are then outlined in chapter 4, focusing on the populations and design types, quality of the literature and objectives of the studies, presented according to several constructs taken from the PARIHS framework, a model that *"proposes three elements (evidence, context and facilitation) that are related to successful [intervention] implementation"* (Ward et al, 2017).

The discussion in chapter 5 reports suggestions to address the current knowledge gap, strengths and limitations and a summary providing the key findings of this review. The conclusions in chapter 6 provide suggestions and advice on what future research should be performed, to reduce our current gap in the knowledge within this field.

1.1.1 Current implementation challenges and why this review is needed.

Healthcare systems worldwide have been experiencing profound changes in the way they operate and treat patients, due to numerous ongoing trends such as increase in healthcare costs and population ageing (Bauchner, 2019; Han et al, 2019; Tong et al, 2021). Available

data supports the notion that, in addition to a marked increase in the rate of global population growth since the 1950s, the percentage of older people worldwide is also increasing (Sadigov, 2022). This phenomenon is more pronounced in high-income countries, where population growth has generally stalled, but the share of older people keeps increasing. However, developing countries such as China are being affected as well (Khan, 2019). While living longer thanks to medical advances is an indication of human success, this ageing shift brings new challenges. As people live longer, they are also at higher risk of disease, often in terms of chronic illnesses and multimorbidity. This situation has forced many healthcare services to re-evaluate their approaches on how to treat their patients sustainably, by recommending more flexible standards and thus changing our current approach towards treatment with new interventions and *"…incorporating new definitions of excellence and acceptability.*" (Braithwaite et al, 2018; Patrício et al, 2020). Applying new interventions is therefore a desirable approach to change established treatment methods that may no longer be the most suitable.

The UK Medical Research Council recently published an updated version of a framework, named 'MRC Framework for Developing and Evaluating Complex Interventions', aimed at developing and evaluating complex interventions. Starting from a set of core elements (such as context, economic considerations, and others), the authors then encourage stakeholders to further assess the 'Feasibility', 'Evaluation' and 'Implementation' aspects of said intervention, to then decide whether a new intervention needs to be developed, or an existing one can be chosen and implemented (Skivington et al, 2021). To achieve solid evidence-based decision making, it is not encouraged to implement any interventions without the appropriate evidence. Should however no suitable evidence be available at the time of planning or implementation, an approach that may allow a development of an effective, low-risk interventions should be considered, particularly when aiming to address an urgent need and targeting the behaviour of both patients and HCPs. This framework is relevant to digital health intervention (DHI) implementation, including in chronic breathlessness, as it provides a set of questions and criteria to evaluate whether each phase of implementing a complex intervention is complete, or a revision of the process is needed.

An example of implementing novel interventions is provided by a systematic review by Reedy and colleagues, which aimed to *"…synthesise the published literature regarding health professionals', patients' and families' views on the use of opioids for chronic breathlessness, identifying issues which influence implementation in clinical practice"* (Reedy et al, 2021a). After analysing 22 studies, the authors concluded that implementation in clinical practice is strongly influenced by the knowledge, views and attitudes of all those involved in the treatment process (patients, their carers and medical personnel). Their results highlight the intrinsic complexity of promoting a novel intervention including opioids within a healthcare setting, where factors such as the choice of medication, mutual trust between the patient and the clinician and external regulatory approaches influence implementation.

An ongoing trend towards personalised medicine offers a relevant example of the difficulties in designing, testing and implementing new interventions aimed at increasing the quality of care administered to patients. For instance, in the UK's National Health Service (NHS) several initiatives were established over the past decade, including some where a shift from population-based interventions to patient-centred care was attempted. Examples include an intervention in a Musculoskeletal Physiotherapy department to increase remote patient participation and a further intervention to improve management of multimorbidity in general practice (Newson et al, 2022; Salisbury et al, 2019). For this to happen, different fundamental factors need to be in place, such as solid evidence-based decision making, the appropriate technological tools and an approach that allows increased awareness and Lung cancer and Chronic Obstructive Pulmonary Disease (COPD), and their association with breathlessness.

Recent studies highlighted the sudden and widespread increase in telehealth activity, with some suggesting the expansion of telemedicine has been accelerated and will continue unabated, thanks to consumer acceptance and technology maturation, but also dependent on government support and regulatory frameworks (Barney et al, 2020; Contreras et al, 2020; Ohannessian et al, 2020; Palmer et al, 2021; Spaulding et al, 2021).
Patients with advanced chronic respiratory diseases experience breathlessness, often to a debilitating extent. Previous research indicates that its intensity cannot be predicted by the

severity of lung pathology, and patients themselves may inadvertently exacerbate the problem. This could happen, for instance, when patients reduce physical activity to avoid being breathless, which however worsens breathlessness due to lack of exercise (Spathis et al, 2017). Given the complexity of managing breathlessness, it is essential to incentivise the use of self-management interventions, to provide patients and carers with increased control over their condition. Educational tools to manage breathlessness are available in the literature, one such example being the 'Breathing, Thinking, Functional'. The aim of this clinical model is to aid breathlessness self-management, via a non-pharmacological approach, by conceptualising behavioural responses to breathlessness. This should lead to an interruption of self-sustaining cycles of deteriorating symptoms in patients, often promoted by the negative effects of being breathless (Spathis et al, 2021).

Breathlessness, or dyspnoea, is a very common symptom in lung cancer patients, with a reported average prevalence of 70.5% when reaching the final stages of disease (Kathiresan et al, 2010). Patients experience shortness of breath, which can vary from very mild to debilitating, further classifiable into predictable and unpredictable (Linde et al, 2018). Existing research assessing the nature of distress associated with dyspnoea is available. In a 2018 study, the authors used semi-structured interviews and found that the unpredictability of episodic breathlessness seems to strongly impact anxiety in those patients, with a sharper effect compared to chronic breathlessness (Stowe et al, 2018). This finding indicates that breathlessness should not be viewed as a single, continuous, and predictable phenomenon, but instead as a complex symptom which can present itself with varying degrees of intensity and predictability. While breathlessness presents itself as a heterogeneous symptom, feelings of panic and anxiety have been described by patients in previous reports, alongside loss of independence, and fear of dying (Gallo-Silver et al, 2000; Gardiner et al, 2009; Zhao et al, 2008), thus requiring a more specific definition of the symptom.

1.1.2 Evolution of the definition of breathlessness

An early definition of 'breathlessness' was provided by the American Thoracic Society in the late 1990s, which was then re-confirmed in 2012 as *"a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity"* (Parshall et

al, 2012). In addition to a general definition, breathlessness has also been described as episodic or chronic. In 2014, Simon and colleagues published the results of an international Delphi panel study, providing the definition of episodic breathlessness. Their findings can be summarised as *"a form of breathlessness characterized by a severe worsening of breathlessness intensity or unpleasantness beyond usual fluctuations in the patient's perception"* (Simon et al, 2014). Following the results of an additional Delphi panel published in 2017, Johnson and colleagues described it as *"breathlessness that persists despite optimal treatment of the underlying pathophysiology and that results in disability"* (Johnson et al, 2017b). Both COPD and lung cancer patients are frequently required to spend extended periods of time in hospital, further reducing their quality of life. While it is not possible to directly quantify breathlessness as it's a subjective experience, it tends to increase in severity in both COPD and lung cancer patients, as their disease progress (Hui et al, 2020). Providing alternative resources to manage breathlessness, to be used independently at home, may reduce the burden on hospitals and patients themselves. For these reasons, the two populations were identified as distinctly relevant to this study. The following section will elucidate the epidemiology of both COPD and lung cancer.

1.2 Epidemiology of lung cancer and COPD

1.2.1 Lung cancer

1.2.1.1 Definition of Lung Cancer (LC)

As provided by the United States' National Cancer Institute (NCI-NIH), the basic definition of lung cancer is: *'Cancer that forms in tissues of the lung, usually in the cells lining air passages. The two main types are small cell lung cancer and non-small cell lung cancer. These types are diagnosed based on how the cells look under a microscope.'* (https://www.cancer.gov/publications/dictionaries/cancer-terms/def/lung-cancer, accessed 15 March 2023).

Lung cancer is divided into small cell lung cancer (SLC) and non-small cell lung cancer (NSCLC), with the latter being more common. NSCLC is further divided into:

1. Adenocarcinoma
2. Squamous cell carcinoma
3. Large cell carcinoma

1.2.1.2 Incidence of lung cancer

A 2011 study by Charles Dela Cruz and colleagues reported that in the United States, lung cancer is the second most common type in both men and women, and that the estimated cases of lung cancer cases worldwide has increased by 51% since 1985 (Dela Cruz et al, 2011). The age-specific incidence of lung cancer seems to have dropped in both genders, when considering data from the 30- to 54-year-old population (Jemal et al, 2018; Siegel et al, 2015). Additionally, despite death rates showing a general decline in the past three decades, LC is the most common oncological cause of death worldwide (Ridge et al, 2013).

1.2.2 Chronic obstructive pulmonary disease

1.2.2.1 Definition of Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease refers to a group of diseases causing breathing issues and airflow blockage, and is often, but not always, present in lung cancer patients as a comorbidity. It has been nonetheless documented that patients with COPD are at increased risk of developing lung cancer (Skillrud et al, 1986; Tockman et al, 1987).

A 2004 definition from the UK National Institute for Clinical Excellence (NICE) refers to COPD as “characterised by airflow obstruction. The airflow obstruction is usually progressive, not fully reversible and does not change markedly over several months. The disease is predominantly caused by smoking.” (Devereux, 2006). Graham Devereux, author of the 2006 study ‘ABC of chronic obstructive pulmonary disease, Definition, epidemiology, and risk factors’ provides a useful overview of COPD and definitions of conditions related to airflow obstruction. The author highlights that while asthma is associated with airflow

obstruction, it is not considered COPD. Other diseases such as cystic fibrosis, bronchiectasis and obliterative bronchiolitis, which sometimes cause similar symptoms, should not be confused with, or included in the COPD definition (Devereux, 2006). COPD should also be viewed as a heterogenous group of diseases, with differing causes and physiological effects.

In addition to the definition of COPD, Stephen Rennard and Bradley Drummond identified an issue with the definition of *early* COPD, highlighting the complexity of this condition. The authors provide a thorough and extensive analysis on how to recognise and define early COPD, based on its natural history, diagnosis, and prevention. They conclude that while smoking is not the only risk factor for COPD, policies aimed at reducing cigarette smoking will have a profound effect on COPD prevention (Rennard et al, 2015). For the purposes of this research, the general definition of COPD patients will be considered, without focusing on disease staging.

1.2.2.2 Incidence of COPD

A 2016 article published in Thorax reported that an estimated 1.2 million people in the UK, or 2% of the population, have diagnosed COPD (Snell et al, 2016). While these results are specific to one country, it is conceivable that a 2% incidence can be extrapolated to much of the global population. This is also for COPD is generally associated with long-term exposure to harmful substances (cigarette smoke, silica dust, coal dust among others), including a genetic predisposition. Given the shared aetiology of lung cancer and COPD, it expected that numerous studies will analyse the two conditions simultaneously (Durham et al, 2015).

1.2.3 Burden of breathlessness on patients

Both lung cancer and COPD patients are highly likely to suffer from dyspnoea on a long-term basis, whether they are affected by unpredictable episodes or chronic issues with breathing. The intensity and severity of these breathlessness episodes also tend to increase with the progression of the disease.

Existing studies question the interchangeability of the terms ‘breathlessness’ and ‘dyspnoea’ (or dyspnoea), citing possible issues for non-native English speakers and translation of the name into different languages (Morélot-Panzini et al, 2017). Studies including the terms ‘breathlessness’, ‘dyspnea’ and ‘dyspnoea’ were considered in the systematic review, not excluding additional possible definitions, as reported in the methods.
In a qualitative study using face-to-face interviews, Simon and colleagues asked patients with chronic heart failure, COPD, lung cancer or motor neuron disease to describe their strategies to self-manage episodic breathlessness. The results reported that patients employed various techniques to manage the symptom, both pharmaceutical and non-pharmaceutical (e.g.: adjustment of physical activity, psychological strategies). Some of these techniques were learned through pulmonary rehabilitation programs and other methods were developed by the patients themselves. The authors note that not all recommended strategies are necessarily helpful for the patients, therefore suggesting that self-management approaches should be tailored to each patient (Simon et al, 2016).

Estimates from 2015 reported that nearly a quarter of the global burden of disease, worldwide, is associated with people aged 60 years or older, with regional differences between low-middle income and high-income countries (Prince et al, 2015).
As populations continue to age, particularly in high-income countries (Balachandran et al, 2020), it is important to identify what implementations may help reduce the burden of lung cancer and COPD disease on patients and healthcare systems, while providing accessible solutions to patients who may be less familiar with digital technology. Symptoms such as fatigue, pain, dyspnoea, and worry are common across both cancer and non-cancer patients (Moens et al, 2014), suggesting that identifying parallels and potential solutions between conditions may help reduce the current burden of research waste (Macleod et al, 2014).
This review contributes to the reduction of research waste by summarising the current knowledge and providing clear statements on what barriers and facilitators have so far been identified, and providing advice that will hopefully guide future research on both patients and HCPs.

1.2.3.4 Effect of disease on patients and healthcare practitioners

One likely issue that will be encountered when trying to implement self-management interventions, particularly mobile health-based (mHealth) ones, is the heterogeneity of the population. mHealth is a relatively broadly defined, and derives from the earlier concepts of telemedicine and telehealth (Doarn et al, 2014). In this case, mHealth is defined as a subset of such disciplines, and describes the use of portable devices, particularly smartphones, as a means to deliver healthcare interventions (Cameron et al, 2017).

As previously reported, COPD is a collection of more specific diseases, caused by a multitude of factors. While patients tend to be older, possibly because of chronic multimorbidity, lifestyle choices over time will also influence a person's health. In a systematic review by Russell and colleagues, the authors report the views of patients and healthcare professionals, looking at barriers and facilitators to self-management of COPD (Russell et al, 2018). In summary, their findings reported that while patients can adapt to COPD, their needs are substantial and support from family and the healthcare system can help. They also conclude that COPD patients are not a homogeneous group and 'no one intervention will prove effective for all' (Russell et al, 2018). This view of heterogeneity is also shared by more recent studies such as those by Yadav et al conducted on a Nepalese cohort (Yadav et al, 2020) and a qualitative study by Wortz and colleagues, focusing on the availability of evidence regarding the optimal content and methods for delivering self-management support (Wortz et al, 2012). Relevant to this second study, the authors performed a series of interviews, administered to COPD patients, as part of a randomised controlled trial. The focus of their question was the development of cognitive-behavioural interventions for self-management support. The authors conclude that self-management support must consider and address 'patients' fears associated with the uncertainty, progression, and suffering of their disease, their expectations about overcoming or replacing losses, their needs for improved health literacy and their desire for improved care' (Wortz et al, 2012).

While this review focuses on COPD and lung cancer patients, after an initial analysis of the literature, it was apparent that it is not possible, or at least not advisable, to extrapolate results on patient studies without considering the available literature focusing on healthcare

practitioners. For instance, a published study on the views in managing breathless patients provides a view of the issue, albeit not focusing on telehealth, that involve not only the patient but also their caregivers and their medical teams (Reedy et al, 2021b). Frequently, General Practitioners are the main caregivers of chronic disease patients, and it is appropriate to consider whether the implementation of a telehealth intervention would be feasible, from an HCP perspective (Nguyen et al, 2019; Radhakrishnan et al, 2015; Segar et al, 2013).

In a 2017 study by Catherine McCabe and colleagues, the authors review evidence from three studies, to 'evaluate the effectiveness of interventions delivered by computer and by mobile technology versus face-to-face or hard copy/digital documentary-delivered interventions, or both, in facilitating, supporting, and sustaining self-management among people with COPD' (McCabe et al, 2017). The authors report that limited evidence is available from the three included studies on whether mHealth measures are safe and effective. They also aimed to assess whether any patient improvement could be sustained over time, however this conclusion could not also be reached due to insufficient data and generally poor-quality evidence (McCabe et al, 2017). The lack of knowledge on whether DHIs can be implemented and then maintained is a key element that needs to be further investigated, to gain evidence on their medium and long-term effectiveness.

Further evidence on DHIs has also been accumulating outside of the COPD domain, and within chronic pain. In a 2019 study, Ledel Solem and colleagues argue that evidence regarding how eHealth interventions can support daily needs of patients with chronic pain is lacking. Using qualitative thematic analysis on twenty patients plus five of their partners, the authors conclude that including the end user is essential when developing eHealth interventions (Ledel Solem et al, 2019)

Given the general lack of consistency in the literature and multitude of approaches towards self-management, the reader will be introduced to some specific examples that provide an overview of the current stages and characteristics of intervention implementations and

participation on behalf of the patient (Pickup et al, 2018; Pokorska-Bocci et al, 2014). To further elucidate the need to increase our knowledge on these issues, chronic breathlessness will be described in the following paragraphs.

1.3 The issue of chronic breathlessness

Chronic breathlessness is a common symptom in respiratory diseases, such as Chronic Obstructive Pulmonary Disease and Lung Cancer. Symptoms of breathlessness tend to exacerbate over time and negatively affect the quality of life of patients, both physically and psychologically (Johnson et al, 2017a). Managing chronic breathlessness is often complex, as its trajectory is seldom predictable, with its severity and symptoms varying widely among patients. While non-pharmacological interventions exist, previous research on the use of both pharmacological and non-pharmacological strategies to treat breathlessness provides examples of the challenges in implementing new interventions within healthcare systems (Klaic et al, 2022).

Both types of interventions must be explored, given the multi-faceted components of breathlessness. Psychological trauma is also likely to arise in patients suffering from dyspnoea, as both chronic and acute episodes can be akin to asphyxiation. Repeated exposure to such traumatic events is known to cause long-term psychological damage such as PTSD (Post-traumatic stress disorder) (Başoğlu et al, 1994). For this reason, providing both pharmacological and non-pharmacological resources to breathless patients is extremely important, to reduce not only the risk of physical symptom exacerbation and direct effects on the patient, but also the psychological consequences that could derive from prolonged exposure to breathlessness episodes (Başoğlu, 2017).

There is currently a gap in the knowledge regarding implementation barriers and facilitators in chronic breathlessness, particularly in the case of self-management interventions. This limits our ability to plan and apply interventions aimed at improving patients' health outcomes and supporting healthcare systems, in terms of reduced hospitalisations and

financial burden, among others. Existing evidence on non-pharmacological interventions to address chronic breathlessness indicates that a lack of clarity on implementation roles within the healthcare setting led to limited patient access to dedicated equipment in hospitals. The authors describe that implementation of this intervention likely requires "*… service- and clinician-level interventions to ensure it is routinely recommended as a first-line intervention for chronic breathlessness…",* (Luckett et al, 2022).

Existing evidence highlights the need for additional knowledge on barriers and facilitators in breathlessness interventions. A systematic review indicated that DHIs can provide positive impacts on education, information sharing and decision-making, however it also reported that most reviews were deemed of low quality, and the authors' findings need to be interpreted with caution (Finucane et al, 2021). Similarly, recent publications indicate that while the enablers and barriers to intervention uptake in an older oncological population are similar to those found in other populations, more studies are necessary to better understand the unique needs of older patients (Hasnan et al, 2022). This conclusion is further reinforced by another finding that robust study designs are generally lacking within palliative care, limiting our current knowledge on how to optimise telehealth design (Hancock et al, 2019).

Non-pharmacological interventions are a powerful example of interventions that can be sustained by COPD patients, over prolonged periods of time. A study from Luckett and colleagues reports that after teaching patients self-management strategies to treat breathlessness, the authors conclude that psychological coping is likely the largest barrier towards maintaining the intervention, concluding that additional research is necessary to understand the role of psychological attitude and cognitive decline in this population (Luckett et al, 2021). A systematic review from Hutchinson and colleagues also reported that psychological coping and help-seeking behaviour of patients influence how engaged a patient may be towards the intervention, coupled with the clinician's responsiveness (Hutchinson et al, 2018). These examples of digital health interventions indicate that technology can potentially support the delivery of self-management programmes, helping address patient-level issues such as psychological or physical issues caused by a disease.

According to a 2020 editorial by Payne and colleagues, the widespread availability of smartphones/computers, connected medical devices and internet access in general will allow an increasingly growing presence of digital health interventions worldwide, in particular within palliative care (Payne et al, 2020). The authors argue that digital interventions provide greater access and control to patients, who are for instance able to record and report changes in their symptoms, pain, and general wellbeing. Additionally, automated data collection and transmission can be easily performed via wearable devices, with the potential to integrate such data in the patient's health record. However, data grows in terms of amount and complexity, there is an increased risk of healthcare professionals spending too much time looking at this data, and not being able to dedicate enough attention to the patient. Medical treatments are based on ongoing relationships between HCPs and patients, who are most likely to benefit from both new options brought in by DHIs, and increased time spent with their healthcare practitioner. For these reasons, it is arguable that optimal planning and implementation of digital health interventions should be central in improving patients' quality of life and HCPs work-life balance.

1.3.1 Behavioural changes and approaches within Implementation Science

Patient and clinician behaviours must be considered when planning the implementation of a new intervention, to increase chances of intervention success. Routine or habitual behaviours in healthcare have already been studied and defined, and they are known to make implementation of new processes more challenging (Potthoff et al, 2022). Applying evidence into clinical practice is normally a complex process, which may take years with no guarantee of success (Grimshaw et al, 2012). However, increasing evidence is available on how behavioural change can be implemented in professional settings. A systematic review performed in 2015 by Mark Johnson and Carl May looked at the effectiveness of behaviour change interventions in healthcare settings. They conclude that different types of interventions, such as persuasive and educational, and which focus on collective action, should be applied in complex work environments, as they may be more likely to be successful in reaching the desired behavioural change (Johnson et al, 2015). Behaviour change is therefore a core component that needs to be considered throughout the planning and implementation of interventions aimed at chronic diseases.

Implementing behavioural changes is complex, and various approaches have been suggested in the literature. A meta-analysis from Albarracín and colleagues focused on HIV patients and analysed information regarding the effectiveness of different existing preventive strategies. The authors found that effectiveness increased when interventions included attitudinal arguments, educational information and behavioural skills training, whereas those that focused on inducing fear of HIV were the least successful (Albarracín et al, 2005). They conclude that various factors need to be considered when planning a preventive intervention, such as gender, age group, ethnicity and risk group, for the intervention to be effective.
Such interventions consist of numerous components, not all equally effective, which need to be identified before implementation. A study from Davidson and colleagues identifies components as being part of the procedures to deliver the content, separate from the content itself (Davidson et al, 2003).

Further, a study from Michie and colleagues argues that implementing evidence-based practice improvement depends on behaviour change, and that while many frameworks to classify behaviour change interventions exist, none are comprehensive and conceptually coherent (Michie et al, 2011). The authors thus propose a behavioural framework involving three conditions: capability, opportunity and motivation (termed the COM-B system), which is part of the 'behaviour change wheel' (BCW). The COM-B represents the central hub of this framework, where the three sources of behaviour (change) originate. As one moves away from the centre of this wheel, and therefore from the person whose behaviour is being analysed, further concepts classified as 'intervention functions' and 'policy categories' are also described. As the authors report, the BCW approach is based on the question: *"What conditions internal to individuals and in their social and physical environment need to be in place for a specified behavioural target to be achieved?"* (Michie et al, 2011). While a detailed analysis of the reasons for behaviour change is outside of the scope of this review, planning an intervention should include an analysis of what influences behaviour change in each stakeholder, to increase chances of intervention uptake and adherence.

Additional work from the authors proposed a method to reliably characterise interventions in terms of behaviour change techniques (BCT), which are defined as *"an observable,*

replicable and irreducible component of an intervention, designed to alter or redirect causal processes that regulate behaviour; that is, a technique proposed to be to be an 'active ingredient' (e.g. feedback, self-monitoring, reinforcement)" (Michie et al, 2013). After gathering a Delphi panel including experts from various disciplines, the authors developed a 'taxonomy' which aims to systematically specify BCTs. This approach is needed to identify and categorise the 'active ingredient(s)' of an intervention, and under which conditions they are effective (Michie et al, 2013). All the concepts and considerations regarding behavioural changes will be taken into consideration in this review, to analyse current knowledge on barriers and facilitators in breathlessness management and provide recommendations for future interventions in specific diseases.

2. Current evidence and review question

2.1 Self-management interventions and relevance of digital health interventions

The concept of self-management intervention is already well-established in healthcare systems around the world, particularly in regions where populations need to cover large distances to reach the nearest healthcare facility. Before planning a new DHI, it is useful to consider existing examples, and learn from both the advantages and disadvantages of remote patient support. To illustrate the known pros and cons of self-management interventions, without yet focusing on breathlessness in COPD and lung cancer, it is helpful to explore existing programmes being offered in healthcare systems. Cardiovascular diseases are an example of medical issue where self-managed support interventions are already available, developed according to different needs and frameworks, to tackle the inherent complexity of this class of illness (Cruz-Martínez et al, 2020). There is, however, another approach to remote interventions that does not necessarily try to address the complexity of a disease, but rather support patients living in rural areas, who could be hours away from the next clinic. While Europe has its share of remote, hard-to-reach populations, the region has been described as the *"most developed and urbanized continent at the global scale"* (Salvati et al, 2018). Instead, other regions such as the United States and Australia provide useful examples of countries where their population can be either located within reach of advanced, specialist medical facilities or rely on entirely remote, virtual assistance from healthcare professionals (Lally et al, 2018; Nelson et al, 2021; Smith, 2017).

With its extensive land surface but extremely sparse population, Australia has been relying on remote medical consultations, and school education, for generations (Bursell et al, 2013; Symes, 2012). In their 2013 study, Bursell and colleagues briefly discuss the need to re-evaluate healthcare in the country, to provide a new system of healthcare that focuses on the improvement of health outcomes via mobile device-based healthcare, or mHealth. The authors argue that despite the support of the Australian Government, current healthcare initiatives are not being used to their full potential, and remote, under-resourced areas

would be the biggest beneficiaries of mHealth initiatives. Analysing their comments, several weaknesses in this policy can also be deduced. Given the increasing complexity of wireless devices and generated data, a suitable infrastructure must be developed, including reliable high-speed broadband coverage and data servers, which can only be completed with government support.

A related study published in 2021 by Le and colleague, aimed to explore patient satisfaction of telehealth in Australia. After receiving questionnaire responses by 13 patients, they reported full satisfaction with the 'specialist and the privacy' and in most cases, the quality of the communication and length of consultations were satisfactory. Additionally, the respondents reported a total combined financial saving of nearly AUD 17,000 in travel costs, and avoided 937km in travel (Le et al, 2021). The authors conclude that *"improved access to healthcare, decreased costs, reduced inconvenience, and improved management of chronic and complex conditions"* contributed to the success of the intervention, and promote the use of telehealth interventions in remote patients with chronic diseases.

While the authors note the limited sample size and that practitioners can only provide medical advice within the state where they are licensed, other limitations can be deduced. Not being able to ever see a doctor in person may lead to alienation on behalf of the patient, especially if older and not close to family. Issues regarding lack of IT equipment or knowledge are very frequent in the older population, and this could lead to a double barrier in terms of distance from healthcare practice and inability to join telehealth intervention. Additionally, it is conceivable that relying exclusively on remote consultations may deny the opportunity for carers to accompany the patient, who may have a more complete or objective view of the illness in the case of older or impaired patients, and provide a positive contribution to the visit (Brown et al, 1998), or in the case of moderate technological literacy (Timm et al, 2020; Tsai et al, 2014).

Additional research was also conducted on the economic effects of different models of care implemented in urban and rural areas. To provide a more 'tangible' view on how these interventions can compare financially, Snoswell and colleagues performed a return-on-investment analysis (ROI), using a telehealth orthopaedic fracture clinic as reference. In

particular, the authors 'explore the economic impacts of 3 different models of care: telehealth using videoconferencing (rural site to metropolitan partner), patient travel (rural site to metropolitan partner), and employing a virtual health practitioner at a rural site' (Snoswell et al, 2020). By analysing retrospective activity data for three years, the authors conclude that employing a virtual health practitioner, instead of subsidizing patient travel, the rural health care providers can increase their ROI. The authors also offer specific advice on the number of patients needed to reach a financial break-even point, highlighting the potential economic benefits on the local community if such programs are implemented elsewhere. The authors are also careful to note they are not suggesting to transfer all Australian patients to a virtual care model, but integrating telehealth interventions has the potential to greatly benefit local communities and the healthcare system at large (Snoswell et al, 2020).

However, the authors acknowledge the lack of generalisability of their findings, as they only refer to an orthopaedic clinic, based in the state of Queensland. They also indicate their results can only be applied to a service experiencing high and regular activity; it would not be possible to extrapolate the results in a low-activity setting. Overall, while they demonstrate the strength of economic models, their results are not definitive and more specific studies need to be performed in different areas of healthcare. Further research on how DHIs can be financially viable is essential to establish whether implementing a new intervention is economically sustainable, in addition to being safe and effective, whether they focus on COPD/LC patients or other populations.

2.2 Focus on the use of self-management digital health interventions supporting people living with LC and COPD.

To understand barriers and facilitators affecting the implementation, uptake and experience of digital health interventions addressing self-management of pain and breathlessness in patients with lung cancer and chronic obstructive pulmonary disease will be studied.

As healthcare costs increase worldwide, self-management could be seen as an effective tool for patients to participate in their own treatment (Grady et al, 2014). In this context, self-management will be intended as starting after any medical consultations and therefore will not directly include telemedicine. A central issue is raised by the fact that patients with advanced chronic respiratory disease regularly experience breathlessness, often to a debilitating extent. Previous research indicates that its severity cannot be predicted by the severity of lung pathology, and the patient may accidentally exacerbate the problem (Hancock et al, 2019). Given the complexity of managing breathlessness, it is essential to incentivise the use of self-management interventions, to allow patients and carers increased control over their condition. Further reinforcing the need for self-management symptom management was the COVID-19 pandemic, which imposed unprecedented limitations in terms of movement and medical care, in virtually every discipline (Budak et al, 2021; Ellison et al, 2021; Kemp et al, 2021). The following paragraph will describe the definitions of telehealth used in this review.

2.2.1 World Health Organization definitions and importance of novel palliative care measures

Following the WHO's classification of digital health interventions (DHIs), this study will focus on how telehealth is being used to support health system needs for healthcare providers, and how implementation science could be employed to improve current telehealth interventions. In this study, telehealth is defined as those healthcare services that include remote clinical and non-clinical interventions, which also include telemedicine interventions (https://www.who.int/reproductivehealth/publications/mhealth/classification-digital-health-interventions/en/ (Accessed 20 Jun 2021)). (Tuckson et al, 2017)

Digital health interventions include videoconferencing, electronic health records and phone consultations, more recently supported by the rapid ongoing development of Artificial Intelligence (Jiang et al, 2017). Despite this array of choices, it appears many available techniques are not being implemented in advance care due to significant obstacles (Hancock et al, 2019).

The need for increased global attention towards stronger palliative care policies and implementation strategies has been already highlighted, recently through the issuance of the Montreal Declaration, calling for the inclusion of hospices and palliative care in the Sustainable Development Goals (SDGs) (Powell et al, 2015). While tools to identify people who may benefit from palliative care exist, published analyses report ethical challenges and prognostic issues, and recommend more evidence is needed to confirm the benefits of such approaches for patients and their families (Gómez-Batiste et al, 2017). As the WHO defines several Health Systems Challenges (such as Information, Availability, Quality), the results of this study may help healthcare providers to implement existing digital self-managements interventions for pain and breathlessness and allow them to be sustainable in the long term, which leads to the research question of this review.

2.3 Research question of this systematic review

The current project intends to build on existing knowledge, regarding the clinical application of digital health intervention measures in palliative care. A systematic review by Sophie Hancock and colleagues already concluded that despite the growing offering of telehealth interventions in the UK, there is still a lack of robust study design and evaluations of such interventions, and the benefit of telehealth in palliative care is still unclear (Hancock et al, 2019).

Additionally, a systematic review by Anne Finucane and colleagues attempted to produce a synthesis and analysis to appraise the evidence provided by systematic reviews on DHIs in palliative care. The authors chose to include systematic reviews that aimed to critically appraise existing research on topic, thereby performing a systematic review of systematic reviews. They conclude that overall, DHIs are increasingly being implemented and are

generally safe and generate positive effects on many terminally ill patients, however the overall quality of existing studies is low, and no firm conclusions regarding the impact of DHIs on quality of life and physical/psychological symptoms could be drawn (Finucane et al, 2021). This indicates a gap in the knowledge that needs to be addressed, to effectively plan an intervention likely to positively improve a patient's quality of life.

The aim of this systematic review is to synthesize and appraise evidence from existing literature on the barriers and facilitators to digital health interventions implementation, with a particular focus on the management of pain and breathlessness in palliative care, for patients with lung cancer and COPD, specifically community-dwelling adults living with lung cancer and/or COPD. The final objective of this review is to provide recommendations for the delivery of clinical care, policy, and guidance for future researchers.

3. Methods

3.1 Systematic search of the literature

The search strategy is included in the Appendix, registered on PROSPERO on 18 May 2021 and updated on 5 October 2021, to reflect some minor changes in the focus of the thesis (Registration: CRD42021255112).

The search was conducted according to the PRISMA reporting guidelines in two sessions, the first in June 2021 and the second in April 2022, and the following databases were searched: MEDLINE and Embase via OVID, CINAHL via EBSCOhost and The Cochrane Library via https://www.cochranelibrary.com/. Any relevant qualitative, observational quantitative or mixed methods primary research was included. Systematic reviews were also included. Exclusion criteria: case reports, opinion pieces, front-matter content. Due to resource and time limitations, no other types of content or databases were searched during this review.

No limits on geographic location were imposed, however only research published from 2010 onwards was included for further analysis. This specific threshold was decided in conjunction with my supervisor while preparing the search strategy, for several reasons. A focus on interventions implemented in recent years was desired, supported by contemporary technology. This way, it was possible to exclude unsuitable studies during the early stages of study selection, which involved reading hundreds of abstracts and full-text manuscripts. Besides logistical constraints, however, the aim was to obtain studies that would be comparable to each other in terms of content, technology, and aim. Therefore, a cut-off of 2010 was deemed as appropriate, as smartphones had by then already been adopted by a significant fraction of the general population (White, 2010).

Types of study to be included

Any qualitative, observational quantitative or mixed methods primary research where data of interest can be extracted. Systematic reviews will also be included.

Types of study to be excluded

Case reports, opinion pieces, front-matter content, non-primary research.

3.1.1 Use of WHO Digital Health Interventions classifications

In particular, this search will focus on the following WHO classifications for Digital Health Interventions, specifically those found within the 'Clients category' (World Health, 2018):

1.1 Targeted client communication
1.3 Client to client communication
1.4 Personal health tracking
1.5 Citizen based reporting
1.6 On-demand information services to clients

Figure 1: Classification of digital health interventions v1.0.

Source: World Health Organization. (2018). Classification of digital health interventions v1.0: a shared language to describe the uses of digital technology for health. World Health Organization. https://apps.who.int/iris/handle/10665/260480. License: CC BY-NC-SA 3.0 IGO

These classifications were devised by the WHO to categorise the various digital and mobile technology approaches are being employed to support heath system needs. Additionally, each category represents a *"unit of a digital health intervention, which is a discrete functionality of the digital technology to achieve health sector objectives*" (https://apps.who.int/iris/bitstream/handle/10665/260480/WHO-RHR-18.06-eng.pdf - accessed 15 September 2022). A decision to focus on some of the 'Clients category' classification was due to the review focusing on patients self-managing breathlessness, being clients targeted by the interventions. Only those categories which reflected self-management interventions being included in the review were then considered. While telehealth interventions include telemedicine interventions, specific telemedicine

interventions will not be analysed directly in this review, as they include live support provided by HCPs, and not self-management.

3.1.2 Definition of key terms related to Digital Health Interventions

Table 1. Definitions of Digital health interventions.

Telemedicine	The use of information and communication technologies such as computers, the internet, mobile phones, to improve patient outcomes by increasing access to care and medical information (e.g. remote consultations between doctor and patient) (https://apps.who.int/iris/rest/bitstreams/1346306/retrieve - accessed 21 November 2022)
Telehealth	The delivery and facilitation of health and health-related services including medical care, provider and patient education, health information services and self-care via telecommunications and digital communication technologies (https://catalyst.nejm.org/doi/full/10.1056/CAT.18.0268 - accessed 21 November 2022). While an ongoing debate exists regarding the flexibility of the word 'telehealth' (Doarn et al, 2014), we will use the previous statement as definition. Examples are healthcare education, wearable devices, remote communication. The definition of telehealth is broader than telemedicine.
Digital health interventions	Health services delivered electronically through formal or informal care. Digital health interventions are digital functionalities to address several Health System Challenges (need or problem to be addressed).

Where 'Digital health interventions' is the broadest definition of the three, and it will be used as the main definition throughout this review.

As per the WHO criteria, the study will focus on:

- Acceptability
- Utilization
- Efficiency
- Accountability

3.2 Population, exposure, outcome

The following PEO list (Population, Exposure, Outcome) summarizes the core aspects of the search strategy and its content. In this case, a 'Comparator' element was not relevant, and therefore a PEO strategy was followed, instead of a PICO (Population, Intervention, Comparator, Outcome) (Brockmeier et al, 2019).

3.2.1 Population

Community-dwelling adults living with lung cancer and/or COPD.

3.2.2 Intervention(s), exposure(s)

Given the increasing costs faced by healthcare services worldwide, and the ongoing pandemic, self-management could be seen as an effective tool for patients to participate in their own treatment (9). Self-management will be intended as starting after any medical consultations and therefore will not include telemedicine. While telehealth interventions include telemedicine (defined here as live-supported interventions), specific telemedicine interventions will not be analysed in this review.

3.3.3 Main outcome(s)

What are the possible outcomes of different digital health interventions measures?

In particular:

1. Whether lung cancer and COPD patients and/or healthcare professionals indicate the existence of barriers and facilitators of digital self-management interventions for dyspnoea and pain;
2. Uptake of any existing measures;
3. Adherence and long-term sustainability of existing interventions.

3.3.4 Additional outcome(s)

1. Is there evidence that existing DHI measures are being or not being implemented due to barriers and facilitators?
2. Evidence about how digital self-management interventions are being integrated into primary, secondary, and palliative care services.

After an initial screening of all databases, the search yielded a total of 3111 studies. Duplicates removal was performed automatically at first, using the 'Remove duplicates' function within Endnote, and then manually by AR, to eliminate any possible remaining duplicates not identified by software. After manual screening, the list of candidate studies was uploaded on Rayyan. A total of 1163 studies remained after de-duplication. The search strategy was kept broad to avoid missing relevant studies.

Following the second search round conducted on 18 April 2022, a total of 2751 references were retrieved. After automatic deduplication in Endnote and removal of studies published before 2005, 1746 studies remained for manual screening. A total of 14 studies were selected for full-text screening, one of which was included in the study during this second round of selection.

Table 2: Studies identified via literature search

Embase	1671
Medline	813
Cochrane database	304 (28 reviews; 275 trials)
CINAHL via EBSCOhost	323
Total before de-duplication	3111
Total after de-duplication	1163
Studies included for full-text screening	108
Total studies included during first round	23
Total after de-duplication at second round	1746
Studies included for full-text screening at second round	14
Additional studies included	1
Total studies included and analysed	24

The titles and abstracts of those studies were screened by AR, and 108 studies were included for full-text screening. Twenty-five studies were included in the final list for data extraction. One additional study was removed after discussion with KB. A final twenty-four studies were included in the study for final analysis.

3.3.5 Data extraction and study heterogeneity

The primary reviewer (AR) screened the titles and abstracts of located studies using the inclusion/exclusion criteria. A second reviewer (KB, another postgraduate researcher) reviewed a random sample of five titles and abstracts, plus full texts extracted by the first reviewer, against the inclusion criteria.

Correlation between reviewers' decisions to include or exclude studies were checked for all studies checked by both reviewers, with the proportion assessed by both increased until discrepancies are minimised. An initial screening of five titles and abstracts was carried out as a pilot step. Any disagreements were resolved by discussion, or by referral to a third

reviewer (MP), if necessary. Multiple reports from the same study were collated, and authors contacted if necessary for clarification. As the data is publicly available, studies were not anonymised. The review was conducted according to PRISMA reporting guidelines.

Inter-rater reliability (IRR) has been cited as an important feature of a systematic review, to increase transparency a replicability of the study (Belur et al, 2021; Yawn et al, 2005). IRR has been defined as *"the extent to which two or more raters (or observers, coders, examiners) agree"* (Lange, 2011). A common way of reporting IRR is to employ kappa statistic (or kappa coefficient), where a coefficient of 1 indicates perfect agreement, a value of 0 indicates agreement equivalent to chance (Viera et al, 2005). It would be therefore natural to consider employing IRR at any stage of the systematic review two or more people are involved in replicating the same task, such as data extraction. Despite the use of standardized methods and forms, a certain degree of subjectivity, or bias, is always present when taking decisions (Hansen et al, 2014). Calculating IRR by means of k-statistic provides a numerical tool to represent the level of (dis)agreement between choices made by different individuals on the same subject. A low level of agreement is going to suggest that some issues may have present at such stage, and it may be necessary to review the procedures or inclusion criteria for such step. While IRR is a useful tool to allow the reader to assess reliability, it may not always be appropriate.

In the case of this systematic review, the included studies show a high degree of heterogeneity, both in terms of approach and quality. Most authors trying to study barriers and facilitators in breathlessness tend to employ a mixed-methods approach, combining qualitative and quantitative methods of research. This viewpoint allows the researcher to analyse tangible aspects of an intervention (for instance, time spent using an app) and intangible ones (e.g.: patients expressing their feelings in terms of usability of said app).

Meta-analyses are a statistical approach to aggregate and provide numerical evidence regarding the effect of any given intervention, particularly in evidence-based medicine. This approach is not required in every systematic review, and should only be employed when appropriate, with the reader being informed when a meta-analytic approach is not chosen (Haidich, 2010; Rudnicka et al, 2012). Performing a meta-analysis is however not

recommended when dealing with very heterogeneous studies (for instance in terms of quality and methods), as it may artificially introduce biased, unreliable results (Kicinski et al, 2015). For this reason, no meta-analysis was performed, and a narrative review was conducted instead.

After further discussion, it was also decided to proceed without applying k-statistic to the data extraction and analysis steps, as it would not be able to reflect choices made on the more subjective items of the literature search results. Differences in data extraction and quality assessment choices were nonetheless discussed and clarified by consensus or adjudication where necessary.

A data extraction form was produced individually for each study (example in Appendix C). Each form was standardized and adapted to report the necessary information. For each study, the following categories of information were extracted:

- Title, abstract, digital object identifier (doi), general information on the study type
- Quality appraisal and methodological characteristics
- PARIHS constructs
- Analysis of the results and authors' discussion
- WHO Digital Health Interventions (DHI) categories classification

3.3.5.1 Narrative synthesis

A narrative synthesis is a method used to synthesize the results of a systematic review, by using a narrative, rather than statistical approach, to summarize the findings. It is important to note that a narrative synthesis does not exclude performing a meta-analysis, and the two can co-exist in a study. In this case, however, only a narrative synthesis was performed. The main scope of a narrative synthesis is to provide an overview of the effectiveness of an intervention studied in a systematic review, and to provide recommendations according to its findings (Rodgers et al, 2009).

The option of employing the critical interpretive synthesis (CIS) approach was also considered while planning the systematic review. This method combines elements of systematic reviews (quantitative) with qualitative methods developed from meta-ethnography (Flemming, 2010). An existing study notes the importance of using such an approach when reviewing qualitative and quantitative studies, however also criticizes the high level of flexibility offered by CIS itself, which decreases trust and applicability of this method (Depraetere et al, 2021). A 2006 publication, which is also the origin of the critical interpretive synthesis method, stresses the benefits of employing CIS when analysing literature focusing on healthcare access by socio-economically disadvantaged people, which provides an interpretive tool not found within standard systematic reviews (Dixon-Woods et al, 2006). Despite the available literature on this second topic, we decided to proceed with the use of narrative synthesis.

3.3.6 Data management

The review was managed via EndNote and Rayyan review software.

The primary reviewer (AR) extracted data and details from all the included studies using a specifically adapted data collection form. A second reviewer (KB) independently checked the data extraction from a random selection of five studies.

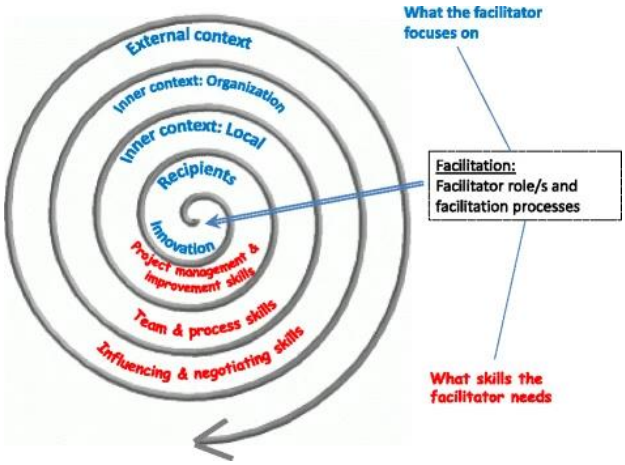
Second reviewer KB screened and commented on five data extraction forms chosen at random by AR. After discussion, one study was excluded as its outcome did not match our inclusion criteria (Apps et al, 2013). For qualitative data, original raw data such as original quotes were extracted when relevant. The extraction form was piloted on the first three publications included for analysis, and adjustments were made with the consensus of all reviewers.

Before data extraction commenced, two initial candidate forms were considered for the data extraction process. The first was the 'Data collection form for intervention reviews for RCTs and non-RCTs' provided by Cochrane (https://training.cochrane.org/data-collection-form-rcts, accessed 27 March 2023), and the second 'Appendix 8.1 JBI Mixed Methods Data

Extraction Form following a Convergent Integrated Approach' (https://jbi-global-wiki.refined.site/space/MANUAL/4689368/Appendix+8.1+JBI+Mixed+Methods+Data+Extraction+Form+following+a+Convergent+Integrated+Approach, accessed 27 March 2023). After discussion with KB and MP, it was decided not to proceed with the use of the two forms. The format offered by the Cochrane template was more suitable for RCT and RCT-like types of studies, whereas the JBI version proved to be simplistic and not very easily adaptable to this review. A third form, provided by MP was chosen and adapted. The original template was modified to include the necessary extraction fields.

After additional discussion with MP, it was decided to use the PARIHS framework (Promoting Action on Research Implementation in Health Services) as a reference for data extraction (Rycroft-Malone, 2004). This framework was conceived in the late 1990s and developed through the years, as a way of implementing research into practice. It was chosen for this review given its focus on 'successful implementation (SI) as a function (f) of the nature and type of evidence (E) (including research, clinical experience, patient experience, and local information), the qualities of the context (C) of implementation (including culture, leadership, and evaluation), and the way the implementation process is facilitated (F) (internal and/or external person acting as a facilitator to enable the process of implementation); SI = f(E,C,F)' (Bergström et al, 2020).

Figure 2: The facilitation role and process. (Harvey, 2016).



Implementation Science **volume 11**, Article number: 33 (2015)

Its main scope is to analyse interactions among three elements of knowledge translation:

1. Evidence (E)
2. Context (C)
3. Facilitation (F)

According to PARIHS, the quality of evidence is just as important as the context where evidence is being introduced, to achieve successful implementation (SI). Therefore, this framework is expressed as SI = *f*(E,C,F).

Where 'Evidence' can be provided by research, HCP expertise, the target population, or local and governmental environments. 'Context' refers to the setting where the intervention is being implemented and 'Facilitation' describes the type of support that stakeholders require to increase chances of implementation success.

This framework further relies on the following key points:

1. Implementation is an organisational issue and not just individual
2. Implementation needs to be supported by strong evidence
3. Planning of implementation strategies is needed, as well as their management and education of stakeholders
4. Before implementing any changes, criteria to evaluate the impact of the intervention need to be identified

(Source: https://www.nccmt.ca/knowledge-repositories/search/85, accessed 3 October 2022)

To achieve higher implementation success chances, previous studies argue PARIHS should be first used as a preliminary measure of evidence and context, then use the resulting data to choose the most appropriate facilitation approach (Kitson et al, 2008).
The use of an existing framework to enquire in a new area was deemed to be a suitable strategy to extract data in a consistent, structured fashion. The five headers used to extract the data are listed in Table 3 below.

Table 3. PARIHS framework constructs considered for data extraction

1. Characteristics of the innovation
2. People's ability to change
3. People's motivation
4. Inner context
5. Outer context

Focusing on these five elements of the PARIHS framework allowed to consistently report key aspects of each study, particularly about the characteristics of the implementation. These should also allow to represent the various challenges and approaches that exist in healthcare, when trying to implement an intervention (Harvey et al, 2016).

Table 4. PARIHS framework constructs and their specific aims

Construct	Specific aims (what information is the construct trying to provide)
Characteristics of the innovation	1. Who is likely to be affected by the intervention; 2. What the underlying evidence for the proposed innovation or evidence is; 3. Whether it fits with current practice 4. What people think about it 5. What is the perceived relative advantage 6. What scope there is to try out the intervention
People's ability to change	1. To carry out changes, do patients: a. Have the necessary skills? b. Understand how to change their routine? c. Have the authority to carry out changes? And under a team's perspective: 2. To carry out changes, do teams: a. Have the necessary skills? b. Understand how to change their routine? c. Have the authority to carry out changes? d. Have resources available to support implementation?

People's motivation	1. Whether patients a. Feel the need to change current practice b. Perceive a difference with the new intervention c. Are aware of any support from the intervention leaders 2. Whether teams in the healthcare system: a. Feel the need to change practice b. Perceive a difference with the new intervention c. Are aware of any support from the intervention leaders
Inner context	1. Do formal and informal leaders support implementation? 2. Does the work culture support innovation and change? 3. What are people's recent experiences of change? 4. What is in place to support learning and evaluation?
Outer context	1. Do proposed changes align with strategic priorities of the health system? a. Does the health system provide incentives to support change? 2. Are there inter-organizational networks that support the change?

3.4 Risk of bias (quality) assessment

Two researchers (AR, KB) independently assessed the quality of included studies using the Mixed Methods Appraisal Tool (MMAT) Version 2018 tool (Hong QN et al, 2018) for both qualitative and quantitative research. The MMAT tool was chosen after discussion with the two supervisors, as on a practical level, it was deemed suitable for the analysis of mixed methods studies included in this systematic review. When this study was registered on PROSPERO, we initially mentioned the use of the CASP tool to assess quality (Purssell, 2020). While CASP provides various checklists for different study types, the MMAT is described by the authors as allowing *"the critical appraisal of quantitative, qualitative, and mixed methods studies and was developed to address the challenges of critical appraisal in systematic mixed studies review"* (Hong et al, 2018) and provides a more straightforward checklist to appraise the various studies included in this search.

Previous publications already suggested that systematic reviews represent one of the highest levels of research evidence, when rigorously performed (Bunn et al, 2015; Yuan et al, 2009). As it is possible for systematic reviews to include various types of study designs, a flexible approach towards the analysis of heterogeneous data is required. In their 2018 study named 'A Conceptual Framework for Critical Appraisal in Systematic Mixed Studies Reviews', Hong and colleagues provide a conceptual framework to facilitate quality appraisal, from which the MMAT tool derives (Hong et al, 2019). The team met once to agree on the quality of the studies and a third reviewer would be involved to adjudicate if necessary.

During data extraction and quality assessment, it was noted that different techniques and methods are employed in the literature, to assess barriers and facilitators in lung cancer and COPD patients. This is expected and necessary to obtain a complete overview of the issue, however it increased the complexity of the data extraction and quality assessment process. The included studies can be broadly categorized under 'Qualitative, quantitative, and mixed methods' formats, each then classified according to a more specific category, such as quantitative randomized or case study.

One of the first challenges when compiling the data extraction form was regarding consistency, or lack thereof. While there is no standard way on how manuscripts are written or their data is presented, despite the existence of numerous guidelines such as PRISMA, STROBE and CONSORT (Moher et al, 2001; Moher et al, 2015; von Elm et al, 2007), it was sometimes difficult to accurately obtain the required information. Most scientific publications are written in English, however few authors are native English speakers (Drubin et al, 2012) or received formal writing training (Salita, 2015). Irrespective of the authors' native language, it was necessary to carefully read both the formally and informally collected data in each manuscript, to be able to deduce and report the effects of the studied implementation and conclusions.

Likewise, using the MMAT tool has sometimes been challenging. Overall, the methodological quality criteria have proven to be a useful tool to consistently rate the quality of the twenty-six analysed studies. Simultaneously, some of the criteria descriptions were too vague to be interpreted and applied unambiguously during the quality appraisal.

3.5 Definition of mixed-methods studies

Mixed-methods studies can be briefly described as those which simultaneously combine both qualitative and quantitative research approaches, to understand and corroborate a research question (Curry et al, 2015). Despite its relatively straightforward definition, this type of study needs to be carefully planned and executed, and varying methodological approaches may introduce additional bias and confusion. This type of approach is however fundamental in medical research, as psychological and social dynamics (such as behavioural change or patient interviews) need to be studied alongside more quantitative, directly measurable parameters, such as disease severity scores or biomarker values. Mixed-methods studies allow a pragmatic, realistic approach towards understanding the various issues caused by disease such as COPD and LC, which are virtually always accompanied by related symptoms and comorbidities, a strategy recently described in medical literature (Kishino et al, 2022). The modus operandi offered by mixed-methods studies allows to analyse both objective parameters, such as disease staging and subjective parameters such as psychological distress caused by shortness of breath.

4. Results

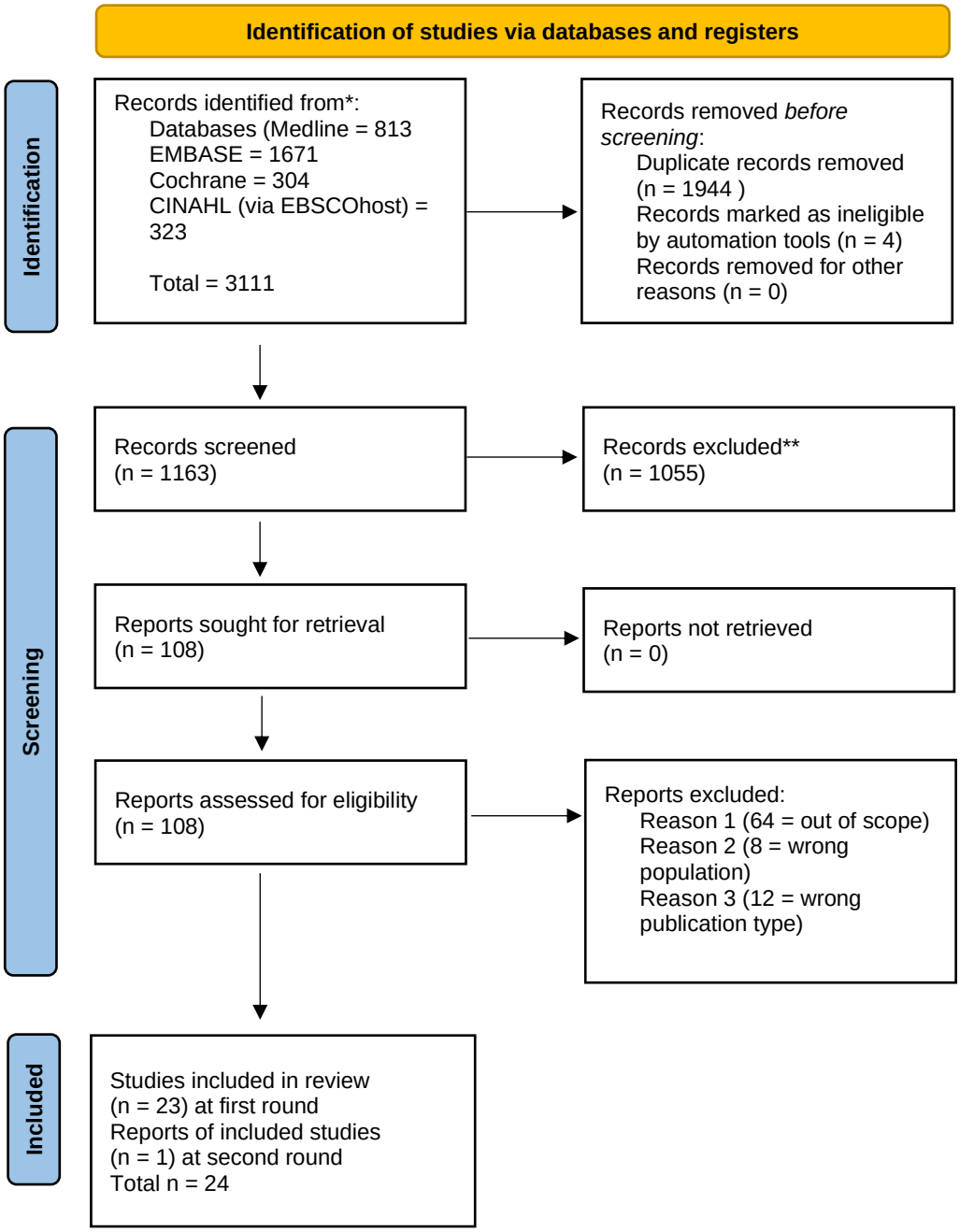
The initial literature search was conducted on 1 June 2021 and the following databases were searched: MEDLINE and Embase via OVID, CINAHL via EBSCOhost and The Cochrane Library via https://www.cochranelibrary.com/. Following this search, 23 studies were included for analysis. A second search was performed on 18 April 2022, to retrieve any relevant publications that may have been published in the meantime, which resulted in the addition of one study, for a total of 24.

A total of 24 studies were included in the systematic search, which were identified in the literature as described in the methods section. A further study that matched the inclusion criteria was identified and included in the final analysis after the second round of literature search. As indicated in the PRISMA diagram, studies were excluded for several reasons, including wrong population, wrong study type or wrong focus of the study.

(Alwashmi et al, 2020; Broese et al, 2021; Brown-Johnson et al, 2015; Brunton et al, 2015; Chau et al, 2012; Fitzsimmons et al, 2016; Granger et al, 2018; Henshall & Davey, 2020a; Jiang et al, 2022; Knox et al, 2021; Knox et al, 2020; Lewis et al, 2021; Maguire et al, 2015; Marklund et al, 2021; Nyberg et al, 2019; Obro et al, 2021; Rassouli et al, 2018; Rubio et al, 2017; Simmich et al, 2021; Tang et al, 2018; Taylor et al, 2015; Timmerman et al, 2017; van der Weegen et al, 2013; Voncken-Brewster et al, 2015).

4.1 Results of the search strategy

Figure 3: PRISMA flow diagram of study retrieval and selection



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.
From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Table 5. List of included studies

Study name	**Population (Country/ies)**	**Design type**	**Objective of study**
Henshall et al 2020	Lung cancer patients (survivors) and carers, plus HCPs (n=27). (UK)	1) qualitative focus groups 2) prototype app development and usability study	To identify • exercise interventions that improve symptoms • facilitators and barriers to exercise • behavioural change techniques to inform iEXHALE's development
Rassouli et al 2018	34 COPD patients. (Germany, Austria, Switzerland)	Observational – pilot study	to measure the feasibility and effects of a digitalized PR program (Kaia COPD) delivered on a smartphone on HRQoL
Knox et al 2020	11 COPD patients (UK)	Technology acceptance model / survey, semi-structured focus group	Conceptualise experiences of the usability and acceptability of a self-management app
Alwashmi et al 2020	30 HCPs: 10	Semi-structured interviews	explore the potential features of an mHealth intervention

	nurses, 10 pharmacists and 10 physicians; 10 COPD patients. (Canada)		for COPD management with healthcare providers (HCPs) and patients with COPD
Timmerman et al 2017	22 Non-small lung cancer patients and 22 HCPs. (Netherlands)	Two-stage mixed methods	Primary: evaluate feasibility of a telehealthcare application when used in clinical practice. Secondary: identify factors for adoption and implementation
Knox et al 2021	25 COPD and related HCPs (UK)	Technology acceptance model / survey, semi-structured focus group	COPD app in question aims to allow people with COPD to track and manage their condition. Study aims to look at barriers and facilitators in implementing intervention.
Taylor et al 2015	84 HCPs + 21 managers working with COPD and CHF patients. (UK)	Semi-structured interviews	Explore the usage and acceptance of telehealth among frontline staff working in community nursing settings in England
Marklund et al 2021	16 COPD patients (Sweden)	Qualitative study, interviews	Explore and describe the experiences of an eHealth tool over time and factors that might affect usage.
Rubio et al 2017	62 COPD patients in three phases. (UK)	Observational, semi-structured interviews	Comparing five different breathing monitors
Tang et al 2017	10 Lung cancer. (Hong Kong)	Mixed method design, feasibility study	Using tablets for self-reported symptom assessment

Nyberg et al 2019	83 COPD, HCPs and their relatives. (Sweden)	Controlled pragmatic controlled trial	Evaluate the feasibility of the COPD Web and its study design and study procedures and to increase the understanding of the potential effect of the tool in order to provide guidance for a future large scale trial.
Granger et al 2018	37 Lung cancer. (Australia)	Prospective case series	Determine feasibility of delivering this intervention for patients undergoing surgery for lung cancer
Simmich et al 2021	9 COPD + 9 control. (Australia)	Pilot randomized trial	Evaluate the feasibility of a co-designed mobile game by examining the usage of the game, subjective measures of game engagement, and adherence to wearing activity trackers. The secondary aim of this study is to estimate the effect of the game on daily steps and daily moderate-to-vigorous physical activity (MVPA)
Obro et al 2020	774 COPD from multiple studies. (Denmark)	Scoping review	Provide a literature-overview and identify any existing gaps in knowledge of mHealth in combination with health-coaching interventions for improving self-management in patients with chronic diseases.
Voncken-Brewster 2015	1325 COPD. (Netherlands)	Questionnaire, randomized	Test the effectiveness of a web-based, computer-tailored COPD self-management intervention on physical activity and smoking behavior

Broese et al 2021	1845 COPD from various studies. (Netherlands)	Systematic review	To describe the characteristics of palliative care interventions for patients with COPD and their informal caregivers and review the available evidence on effectiveness and implementation outcomes.
Maguire et al 2014	16 Lung cancer patients and 13 HCPs. (UK)	Mixed methods	explore the use of mobile technology in the remote monitoring and reporting of radiotherapy-related toxicity in people with lung cancer
Van der Weegen et al 2013	15 COPD pats + 16HCPs. (Netherlands)	Observational, user-centered design process	Report on the user-centered design process in which the user requirements for a monitoring and feedback tool were investigated
Brown-Johnson et al 2014	8 HCPs, connected to LC pats (USA)	Observational, interviews	To test the feasibility and usability of mHealth TLC
Chau et al 2010	45 COPD (Hong Kong)	Mixed, Single-centre randomized trial plus interviews	(1) to examine user satisfaction with the telecare service and (2) to examine the effects of the telecare service on health-related quality of life (HRQL), lung function, and hospital service utilization in older people with COPD
Fitzsimmons et al 2016	23 COPD, 3 HCPs. (Canada)	Qualitative, interview and questionnaire based.	Explore the experiences of patients with COPD who had received either a Telehealth-supported or a specialist nursing intervention

Lewis et al 2021	14 CRD pats (broader than COPD), 4 HCPs. (UK)	Mixed-methods, normalization process theory	Provide an evaluation of two web-based platforms for remote pulmonary rehabilitation
Brunton et al 2015	Meta-synthesis, 10 studies included, COPD. (UK)	Qualitative meta-synthesis	1. Systematically search the literature to identify relevant qualitative studies that explored user experience of telehealth in COPD 2. Conduct a meta-synthesis to identify shared themes in user experience across studies and gain new insights from synthesising the data 3. Discuss how findings can contribute to the design of new or the refinement of existing telehealth technologies and services
Jiang et al 2022	52 COPD patients and 23 HCPs. (China)	Qualitative descriptive study, semi-structured interviews	Explore perceptions and experiences of older patients and healthcare providers, in managing COPD via telehealth.

Note for Table 5: All included studies aimed to evaluate barriers and facilitators of mHealth intervention, focusing on patients, their carers and HCPs, either separately or in conjunction. The types of included interventions can be divided into the following general categories:

- *Physical exercise management*
- *Disease parameters self-tracking and managing, including monitoring and reporting*
- *Breathing techniques self-management/pulmonary rehabilitation*
- *Acceptance and usability/user satisfaction of a website or application design*
- *Acceptance and usability/user satisfaction of monitoring device*
- *Literature overview of existing intervention*

More detailed key findings for each study are reported in Table 1A in Appendix A, including patient population, what barriers and facilitators were identified and the relevant WHO classification where applicable. Most studies were published in Europe (16), North America (3), Australia (2), with some more recent exceptions being published in Asia (3). In terms of study design types, the literature was found to be very heterogeneous, with both qualitative and quantitative approaches available across studies. Another initial observation can be made in terms of population sizes, where, generally, most studies are conducted with fairly low numbers of patients and/or healthcare practitioners (HCP), including some randomized trials. The difficulty of recruiting and especially retaining COPD and lung cancer patients must be noted, given the unpredictable course of both diseases and the generally higher average age of the subjects. A further initial observation can be made regarding the quality of the included studies, which is very heterogeneous. A more in-depth analysis of each component will be provided in the discussion.

4.2 Populations and design types

For studies to be included, at least 50% of their population needed to be either COPD or lung cancer patients or their HCPs, in case of heterogeneous cohorts. This decision was taken to avoid excluding potentially relevant studies which analysed mixed populations. In some cases, such as in the Henshall et al 2020 and Nyberg et al 2019 publications, both patients and their HCPs were included in each study. Including HCPs was an explicit target of this search, to obtain the broadest possible view on barriers and facilitators in breathlessness, and to potentially avoid not being able to obtain enough data. While performing the initial literature screening, it was apparent that the number of suitable studies may have been relatively low, due to a general paucity of data on this topic. This, however, did not entail changing the inclusion criteria or unnecessarily broadening the research question, as ultimately a suitable number of studies was found.

4.2.1 Objectives of included studies

All included studies aimed to evaluate barriers and facilitators of mHealth intervention, focusing on patients, their carers and HCPs, either separately or in conjunction. The types of included interventions can be divided into the following general categories:

- Physical exercise management
- Disease parameters self-tracking and managing, including monitoring and reporting
- Breathing techniques self-management/pulmonary rehabilitation
- Acceptance and usability/user satisfaction of a website or application design
- Acceptance and usability/user satisfaction of monitoring device
- Literature overview of existing interventions

4.2.2 Quality of the studies

The quality of the studies included in this review was assessed via the MMAT assessment tool (Hong et al, 2018) (see section '*Risk of bias (quality) assessment'*). This tool is meant to be used when appraising the quality of empirical studies, however, not to provide a numerical score on the quality of each study, and its authors instead advise to present the ratings of each study in a more detailed way, to provide better information on the quality of the included studies. Given the heterogeneity in quality found during the assessment phase, studies will not be weighted equally when considering their results. A more detailed reporting of the quality of each study is available on Table 6 below, which summarizes the findings reported in the individual extraction forms, also providing a rating of 'low, moderate or high' quality. These ratings do not derive from the MMAT tool itself, which does not explicitly provide guidance on how to give a specific rating to a study, but encourages the user to be transparent in how the results were interpreted and used (http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/71030694/FAQ, accessed 12 September 2022). For the purpose of this review, 'low' quality studies are those with the most important shortcomings, such as wrong population, failure to reach stated aim or methodological limitations. Studies rated as 'moderate' were generally able to answer the stated aim, but reported minor issues. 'High' quality studies were able to provide stronger results, supported by data and only minor limitations. In general, the results of this review

are primarily based on moderate and high-quality studies, however studies rated 'low' were not ignored when providing results and recommendations.

Table 6. Quality assessment summary

Study	Quality assessment summary (MMAT)	Main reasons for rating
Henshall et al	Low – adequate approach but unclear results interpretation possible	Small, very few responses from HCPs, lack of generalizability, moderate patient attrition, potentially applicable to other diseases
Rassouli et al	Moderate – non-randomised pilot study	Sample not representative, but low risk of nonresponse bias, appropriate stats analysis, and measurements. Trial expected to follow.
Knox et al	Low – Correct approach but unclear results interpretation	Clear research question, unclear if interpretation supported by data
Alwashmi et al	High – approach and interpretation appear adequate, semi-structured interviews with stakeholders	Interpretation substantiated by data, patients, HCPs and pharmacists included
Timmerman et al	High – Adequate approach and interpretation	Unclear how respondents were selected, but selection criteria provided. Methods and interpretation of data appear appropriate
Knox et al (2)	Moderate – unclear sampling choice and lack of comparator arm	Generally appropriate methods and choice of population, measurements and unclear risk of nonresponse bias.
Jiang et al	Low – Approach suitable but methodological issues	Research question clear, lack of information, questionnaires not validated, population recruitment and data analysis unclear
Broese et al	High – Clear research question and methods, incomplete outcome data.	Appropriate methods and analyses, no major issues identified. Incomplete outcome data is main weakness, but addressed by authors.

Taylor et al	High – Appropriate research question and methods	No major weaknesses identified
Lewis et al	Low – most aspects appropriate, sample size extremely limited	Methods and approaches appropriate, sample size of four cannot provide solid conclusions on qualitative data
Marklund et al	Moderate – methods appropriate	No major limitations, except sampled population only female
Rubio et al	High – general approach appropriate	Risk of nonresponse bias is high and sample low, however advanced disease staging makes recruitment difficult
Tang et al	Low – Feasibility study	Cross-sectional design, low number of patients, question not very clinically relevant
Nyberg et al	Moderate – feasible approach with some limitations, pilot trial	Design and methods appropriate, shorter follow-up than expected and population not randomised
Granger et al	Moderate – feasible approach with limitations, feasibility study	Short follow-up, unclear how confounders accounted for, low intervention uptake
Simmich et al	Moderate – important limitations, pilot trial	Clear research question, few details about randomisation, very low response rate
Obro et al	Moderate – Questions and methods appropriate	Scoping review very appropriate, study bias seems relatively high, unclear if analyses appropriate
Voncken-Brewster et al	Moderate – RCT but results not completely reliable	Approach and methods reliable, lack of power, inability to evaluate selection bias and collect additional data, results not all suitable.
Brown-Johnson et al	Low – Clear question but important issues	Methods not fully described, unclear data analysis, conclusions generally not very strong
Van der Weegen et al	Moderate – Clear questions and methods	Conclusions appear vague and unclear if data supports them

Maguire et al	Moderate – Clear questions and methods	Limitations stated, sample size much smaller than planned, no randomisation appears employed, low response rate, findings unlikely generalisable
Brunton et al	Moderate – Clear questions and methods	Results not conclusive, further studies needed, some assumptions made
Fitzsimmons et al	Moderate – Feasibility study and pilot trial	Approach and analyses suitable, data supports findings, small sample size reduces generalisability and strength
Chau et al	Moderate – Suitable approach, conclusions mixed	Conclusions appear to minimise issues found during study, data presentation inconsistent, short duration

4.3.3 Results according to PARIHS constructs

During the data extraction process, a separate document was created for each of the PARIHS categories used in this research. Each category allows to further delve into specific features of each intervention, and results from all the studies were tabulated accordingly. Using different categories also helps define the concept of 'context', a term that can be defined in numerous ways. Related to PARIHS, context is comprised of four main elements, specifically receptive context,
organizational culture, leadership, and evaluation (Helfrich et al, 2010). These four elements are then reflected within the five categories below, which will report the results in line with the PARIHS criteria.

4.3.3.1 Characteristics of the innovation

This section aims to describe the core elements and features of each study. Data for this section was extrapolated by analysing the findings of each study, to provide a description of the intervention being reported. An overview of the type of intervention is essential, before extracting more specific details according to the other PARIHS constructs. The extracted data for this section is available in Table 1B, Appendix B. The main aim of this section is to provide information regarding:

1.Who is likely to be affected by the intervention;
2. What the underlying evidence for the proposed innovation or evidence is;
3. Whether it fits with current practice
4. What people think about it
5. What is the perceived relative advantage
6. What scope there is to try the intervention out

While analysing the original texts, it became apparent that not all the sections above could be accurately completed. It was not possible to always extract data from each point, and in some cases, not limited to this section, information had to be inferred indirectly from what was available in terms of details, data and descriptions reported in each study.

Table 1B in Appendix B reports a summary of the main characteristics identified for each study.

4.3.3.2 Main themes within 'characteristics of the innovation'

An initial analysis of the findings of each manuscript reveals a very high degree of heterogeneity, particularly regarding the reported perceived strengths of an intervention and feedback from the population. One common theme found across many studies, is that existing literature highlighted the benefits of self-management, such as in diabetes (Moskowitz et al, 2013) or dyspnoea (Henshall et al, 2019). Pulmonary rehabilitation has positive effects on all the stages of COPD disease progression (mild, moderate or severe) and patient mortality, as it allows the patient to increase control of their breathing, improve muscle strength and increase physical activity (Jácome et al, 2016). Simultaneously, self-management may also help in reducing the burden on healthcare systems, by reducing the amount of time spent either in hospital or during practitioners' visits. This second aspect was also highlighted in some of the included studies, where they agreed that COPD and lung cancer patients are populations that although represent a relatively small percentage of all diseases, require a disproportionate amount of healthcare resources. For instance, in the Lewis et al 2021 study, the authors indicate that existing evidence suggests providing home pulmonary rehabilitation is feasible and just as effective as face-to-face delivery, when

performed as a trial. While trials represent a more controlled environment compared to real-world care, and are not immune to limitations and issues, they are widely seen as a reliable source of information across medical disciplines and drug approvals (Del Paggio et al, 2019). In this case, patients found the intervention acceptable, and HCPs adapted their workload to improve online delivery as part of ongoing service provision. The authors note that further trials are necessary to improve online education delivery, and therefore adherence.

A different observation reported in the analysed publications relates to the lack of coherence between evaluations of telehealth programs and existing frameworks for complex interventions, such as those provided by the Medical Research Council in the United Kingdom. The study conducted by Brunton et al indicated that users' voices are often ignored, and interventions are frequently designed without their input (Brunton et al, 2015). The authors argue that users, especially patients, need to be involved in all processes of technology and service development. The overall conclusion of their study is that future research needs to include potential users at an earlier stage of service development, and not simply towards the end or after commercialisation.

A further issue identified in the studies is the ubiquity of healthcare apps, which are however seldom effective or consistent, also because of a lack of patient involvement during development. This issue is linked to additional concerns, reported in the following paragraph.

One study performed by Timmerman and colleagues aimed at evaluating the feasibility of a telehealthcare application when used in clinical practice on non-small lung cancer patients (Timmerman et al, 2017). Patients and their HCPs built their query on the premise that acceptability and clinical safety of an intervention must be evaluated together with its context, to ensure successful adoption and use in everyday care. This question stems from the issue that not all interventions, even if successfully implemented, are necessarily useful or cost-effective (Morrell et al, 2016). In their study, Timmerman and colleagues find that patients are generally positive about the intervention, which provided ambulant monitoring and web-based exercise, however they were not sure about the overall usefulness.

Differently, HCPs indicated they found the approach interesting, and they would be willing to keep using it in the future. This is in contrast with the findings of Taylor et al (Taylor et al, 2015). In their study on COPD and chronic heart failure (CHF) patients, they focus on the role of frontline acceptance towards an intervention, which is not always considered in research. The premise is that new technology is necessary to support patients, however the current situation in the healthcare system is overwhelming, with HCPs frequently overworked (West et al, 2018). According to their findings, HCPs did not report a perceived benefit, however the authors also indicate more research is needed. Throughout the study, it was difficult to gauge the level of interest towards the intervention, as HCPs displayed a range of reactions from engaged to sceptic. Some indicated that DHIs could help them free up some capacity, whereas others expressed doubts regarding the evidence towards telehealth effectiveness. The authors concluded that if an intervention is hindered by barriers, clinicians can quickly lose interest in tasks that can normally be delivered in person, likely due to existing high levels of workload and reluctance to change their practice or introduce further complexity in their routine.

An approach raised by Simmich et al relates to the use of gamification as an emerging strategy to improve engagement with digital technology, including within healthcare. The authors tested an app co-designed by clinicians and patients, and aimed to evaluate whether users would remain engaged with the program and their adherence to wearing activity trackers. While the central question of the study is very important, especially as it tries to address the issue of lack of patient/consumer engagement during early phases of intervention planning, the sample size was very limited and the results inconclusive. The authors observed that the app is potentially useful, but they cannot provide firm recommendations. Additionally, they report moderate use of the game on behalf of the users, and patients tended to show high adherence in terms of tracking device wearing (above 80%), however only a moderate improvement on physical activity engagement was reported. While these initial results provide a useful overview of the possible impact of gamification within digital healthcare, only larger follow-up trials will be able to provide more solid conclusions on whether this approach is worth pursuing in COPD.

Some issues with DHI programmes implementation and adherence appear to be identical across disease spectrum, age of population and geographical location. A study conducted in China aimed to explore how older patients and their HCPs perceived telehealth interventions tailored at managing breathlessness and their disease in general (Jiang et al, 2022). Old age, lack of formal education and widespread misinformation present on the internet strongly hindered the adoption and trust towards telehealth interventions on behalf of patients, despite HCPs generally being in favour and supportive of mHealth programmes. While healthcare practitioners saw a strong incentive in reducing patients' travel time and costs, especially for vulnerable populations in the middle of a pandemic, the lack of traditional Chinese practices and in-person visits were identified as major barriers. Fraud and the perceived inability to receive an accurate diagnosis are themes that, interestingly, do not seem to have been raised in previous studies. Specific verbatim comments were also reported in the study, indicating both positive and negative aspects of the intervention, For instance, a user indicated that "*COPD is really my concern…I gasp even getting dressed. I often search to see if there is any good solution or 'wonder drugs'. I also asked the COPD patients in WeChat group what medicines work".* On the other hand, some patients indicated they wanted to avoid frequent exposure to negative disease-related news: "*I don't want to go online because a lot of people there say that COPD is a disease that can't be cured…negative views like that make me feel uncomfortable".*

The authors' conclusions are however limited by important shortcomings, such as a very small sample size and questionnaire not being validated. Additionally, some of the patients' responses reported in the text don't appear to be relevant to the question. Finally, it is unclear how people were recruited, where the intervention took place and when the interview was performed. Overall, while many of the authors' findings mirror those available in the literature, this study is not able to provide conclusive evidence on the main characteristics of the analysed intervention.

Lack of training has also emerged as an issue in terms of implementation uptake and adherence. Obro and colleagues conducted a scoping review of the literature, to identify gaps in knowledge of mHealth and health-coaching self-management interventions which targeted patients with chronic conditions. The authors found that coaching terminology is

still unclear, and that education was only specified by a minority of the included studies. Patients also reported higher satisfaction with physical interactions, compared to mHealth interventions. Overall, their results recommend that future interventions prioritise human contact and approaches that favour personalised care, as also highlighted in other healthcare disciplines such as oncology, cardiology, and nursing (Grandori et al, 2018), (Hoffmann, 2018), (Spanakis et al, 2020). A correction note from Obro and was taken into account when analysing the results (Faurholt Obro et al, 2021). In this case a study initially deemed of low quality by the authors was recognised as carefully designed, and another study should have not been included in the review, as out of scope. The correction didn't affect the overall assessment of this study, which was classed as 'moderate' in the MMAT quality assessment summary, mainly due to relatively high bias.

4.3.3.3 People's ability to change

The extracted data for this section is available in Table 3B, Appendix B. This section aims to answer the following questions:

1. To carry out changes, do patients:
    e. Have the necessary skills?
    f. Understand how to change their routine?
    g. Have the authority to carry out changes?

And under a team's perspective:

1. To carry out changes, do teams:
    h. Have the necessary skills?
    i. Understand how to change their routine?
    j. Have the authority to carry out changes?
    k. Have resources available to support implementation?

Regarding patients' abilities to carry out changes, an initial overview of the results suggests that most studies reported mixed levels of skillsets, being shown across different

populations. In a few studies, a specific question regarding patients' abilities to implement change was not asked, however it was possible to generally extract meaningful data on this point.

In cases where the population is reported as not having sufficient skills to carry out change, this was mostly observed in conjunction with lower literacy levels, both general and health-related, and most frequently, with advanced age. These two factors appear to be generally consistent across geographies, as similar comments were reported by HCPs and patients themselves in studies performed in both Western countries and Asia. This is unfortunately foreseeable to be a persistent issue in COPD treatment, as most late-stage disease patients are older, and therefore less likely to have been exposed to recent technology.

In particular, two issues were commonly raised by the patients, related to: 1. A lack of technological skills or knowledge, and 2. An issue with the software or equipment, where sufficient skills were present.

A different and notable issue reported in a minority of studies was that patients, including older ones, would be mostly satisfied with the intervention, however they found the app or software too simplistic (Henshall et al, 2020b). This view is in contrast with the majority of people who reported being overwhelmed by the new system. In this case, recipients of the interventions reported being satisfied, at time enthusiastic about the implementation, however then lamented the fact that very little, if any, customization was possible within the program. In cases where the app was deemed too simple, patients also reported a lack of flexibility and interactivity, which contributed to a decrease in adherence levels. While this observation is important to plan future studies, in terms of early patient and HCP involvement, it is also true that some of the apps presented to the patients were released in test version and may not necessarily reflect what the final product was intended to be. Nonetheless, it is important to note that early development of an intervention should involve users from the initial stages, to avoid wasting resources and to increase chances of developing an effective digital intervention (Moore et al, 2019).
Despite numerous patients being only somewhat or not satisfied with the proposed intervention, others provided more positive feedback in terms of necessary skills and

understanding on how to change their routine. Specifically, a study on lung cancer patients performed in Hong Kong aimed to evaluate how newly diagnosed patients would respond to a tablet-assisted, self-reported symptom assessment intervention (Tang et al, 2018). This, in contrast to some other studies (though not all), focuses on early-stage patients, rather than late-stage disease. A relatively small sample size of 10 people was included, and dyspnoea was listed among the observed symptoms, therefore this study can be viewed as a proof-of-concept approach. The authors report a moderate level of acceptance and satisfaction among the patients, reporting that *"lung cancer patients found the assessment enjoyable and time-saving"*. Also, *"clear presentation allowed independent completion of the assessment"* and *"the self-reporting approach reduced the time pressure associated with responding to each item during face-to-face assessment".*
In addition to the above points, the use of a single device, and touch-screen interface were also beneficial in terms of convenience and ease of use.

A third domain that was possible to explore in this section was the opinions of HCPs. Like previous sections, only the minority of studies included healthcare providers in their evaluations, and therefore data is relatively scant, due to several reasons. Most of the included studies only focused on a patient's perspective, which could lead to an incomplete view of the issue. Since an intervention needs to be implemented by a healthcare facility, it would be appropriate to investigate the views and opinions of involved practitioners.

Healthcare providers seem to occasionally disagree with patients, especially in terms of clinical utility of proposed interventions. The first issue was related to the amount of additional time they would need to invest throughout the life cycle of the intervention. This issue represents one of the biggest concerns raised by HCPs, who, in most cases, are already struggling to maintain a healthy work schedule in their current roles. Many worried about the increase in duties and time needed to follow-up with the implementation, and that additional responsibilities would be difficult to manage. In multiple cases, it was unclear how tasks would be assigned and shared, and whether there was enough expertise in the team to run the program. No study reported a unanimous view on whether the intervention would be feasible or not, in some cases also because not enough HCPs responses were collected to reach definitive conclusions.

4.3.3.4 People's motivation

The extracted data for this section is available in Table 2B, Appendix B. This section aims to answer the following questions:

1. Whether patients
    d. Feel the need to change current practice
    e. Perceive a difference with the new intervention
    f. Are aware of any support from the intervention leaders

2. Whether teams in the healthcare system:
    g. Feel the need to change practice
    h. Perceive a difference with the new intervention
    i. Are aware of any support from the intervention leaders

This section, in line with the previous ones, also consists of very heterogeneous results. In most cases, only some of the questions above were explored by the studies, leaving gaps in the knowledge which should be explored in future studies.
In terms of patients' views, many of the reasons to either support or reject the utility of an innovation, and whether change is perceived as necessary, are the same as those reported in previous PARIHS sections. Advanced age appears to be one of the main barriers, with a perception that new technology may not bring any meaningful improvements in the patient's life. This view limits the enthusiasm and willingness to approach a new type of digital intervention, both from the patient's and HCP's sides, who may not show any interest towards a proposed program. This type of concern was reported both in terms of a general 'worry' on behalf of the patients or HCP before the intervention even took place, and also based on the success of an intervention. By assuming that a digital intervention is out of reach due to its technological content, it can be argued that one is already diminishing, or even eliminating, the potential value of such intervention.
In some cases, patients' views changed positively after taking part in the program. Despite mixed feedback, multiple studies reported an improvement in perception after testing the intervention, where patients indicated they would be in favour of joining further programs

and showing a stronger appreciation towards the need of changing current practice. This was more often the case when they perceived the intervention as useful, and when the patients became more aware of their symptoms and felt more in control of their disease. Simultaneously however, some patients felt that knowing more about their illness made them increasingly worried and disheartened by possible future issues they might face. Additionally, older age and lower IT familiarity contributed negatively towards the feeling of usefulness.

Two specific outliers among the included studies are worthy of further analysis. In the study of Granger and colleagues (Granger et al, 2018), a group of lung cancer patients undergoing surgery indicated that without professional support, they would have had issues in changing their physical activity and behaviour, mostly due to fears that exercise would increase symptom burden. Despite the limited size of this study, and the lack of a control group, the authors indicate that physiotherapists were successfully able to deliver a personalized approach to the patients, thereby increasing the success rate of the program. The authors cite the customised approach as the fundamental element for the positive achievement. However, the authors also recognise the following limitations. Healthcare professionals such as nurses, physiotherapists and oncologists only have limited time to routinely structure and deliver detailed messages to their patients during consultations. This is chiefly due to lack of time, which in many cases prevents a personalized approach towards treatment. It was the authors' opinion that current services for HCPs would need to be improved and adapted, to effectively deliver the recommended approach. This mirrors previous findings of this review, where time constraints and excessive workload prevented change. No direct feedback from the participants was available in this study, which perhaps could have clarified some of the specific issues they encountered. Additionally, as a feasibility study, the conclusions should be interpreted carefully. Nonetheless, the authors are able to show their results are in contrast with existing literature, and observe no decline in physical activity after surgery. They are also able to, cautiously, conclude their intervention is feasible in the post-operative, but not pre-operative setting. This finding could be useful for future studies, where the delivery timing of an intervention administration should also be studied.

The second study is Broese and colleagues' systematic review (Broese et al, 2021). The authors observed that, irrespective of the implemented intervention, patients were generally motivated to change current practice. In particular, the authors observed a preference towards low-tech, non-pharmacological interventions, such as a hand-held fan and breathing techniques, which the patients indicated as preferable when managing their breathlessness. This specific results is derived from an early systematic review published in 2013 by Bausewein and colleagues (Bausewein et al, 2013). A warning needs to be made regarding this review, however. At the time of writing this paragraph (September 2022), the Bausewein et al publication is listed as 'Withdrawn' from the Cochrane Library website. The reason cited on the Cochrane website is that *"This review is now out of date although it is correct as of the date of publication [Issue 2, 2008]. The authors are developing a new protocol which will replace this review."* Furthermore, the withdrawal notice indicates that: *"At September 2020, these replacement titles were deregistered (Multi-dimensional interventions) or the protocols withdrawn (Cognitive-emotional interventions; Multi-dimensional interventions; Respiratory interventions) as they did not meet Cochrane standards or expectations.".*

While the withdrawal was performed due to outdated results, and not misleading ones, it is unfortunate that no more recent findings on this topic are available at the time of writing. Therefore, the authors' original observation that non-pharmacological interventions may be in some cases preferable may still be valid, however more conclusive and recent evidence must be provided, in order to adequately assess whether certain pharmacological and otherwise non-drug-based interventions can be seen as barriers or facilitators.

4.3.3.5 Inner context

The extracted data for this section is available in Table 4B, Appendix B. This domain focuses on the environment present at the time of study related to the healthcare facility where the intervention is taking place, according to the specific queries:

1. Do formal and informal leaders support implementation?
2. Does the work culture support innovation and change?
3. What are people's recent experiences of change?
4. What is in place to support learning and evaluation?

The questions above are at aimed at both the individuals affected by the interventions, and for teams involved in their implementation.

In contrast to the section 'Characteristics of the innovation', much less data was available regarding inner contexts, that is, relevant to the healthcare facility or settings where the intervention was being implemented. Unfortunately, in the majority of cases, it was not possible to extrapolate meaningful data regarding existing views within healthcare and patient environments. From a first look at the data grouped in the 'Inner context' document, only very few studies explicitly tried to answer some or all the points reported above. In some cases, it was necessary to indirectly infer the responses, likely leading to additional bias in terms of results interpretation. Overall, the three main reasons for the lack of data regarding this section can be reported as: 1. not being the focus of the study, 2. such details not being reported, or 3. not being clear from the published data.

From the literature included in this review, it appears that in most cases, HCPs and healthcare providers tend to initiate and support an intervention only if previous studies reported either a positive or null result, thus providing a basis of knowledge to establish said intervention. By starting with existing available data, funders, HCPs and other involved stakeholders are more likely to allocate resources, financial or otherwise, to test the implementation and possibly its long-term adoption. Related to some of the issues identified in the Characteristics of the intervention section, staff is usually overwhelmed

during normal hospital routine work, and are often reluctant, understandably, in taking on additional work or responsibilities. This second point therefore reinforces the necessity of high-quality data available in the literature about whether formal and informal leaders and whether the current work culture encourage and support a new intervention, more so where a healthcare setting is already working at full capacity.

Following the latest paragraph, it was indeed noted that the presence of knowledgeable people on topics relevant to the intervention, allows for a smoother implementation of the innovation. This point, as obvious as it may appear, should be strongly supported by future attempts at implementing a new intervention. In this case, it is not known whether such individuals gained their knowledge independently and prior to the implementation of the intervention, or they were given relevant ad-hoc training.

An additional reported barrier, which follows a lack of implementation support, was indicated as a lack of continuous resourcing. This is of course a barrier to implementation, but it can be more specifically seen as a barrier to longer-term adoption. Should a project be only supported through the first initial phases, but not actively past those, it is likely that said intervention is going to fail, either due to lack of infrastructure, or simply due to lack of interest from the relevant parties. Allowing a project to start, but not continue (assuming the project was deemed useful and worthy of being promoted further), only represents an additional unnecessary waste of resources, an issue that has been the focus of studies for numerous years now (Harris et al, 2017; Yu et al, 2018).

4.3.3.6 Outer context

The extracted data for this section is available in Table 5B, Appendix B. This section aims to answer the following questions:

1. Do proposed changes align with strategic priorities of the health system?
    a. Does the health system provide incentives to support change?
2. Are there inter-organizational networks that support the change?

Similarly to the 'Inner context' section, not all studies reported results regarding what approaches are being taken by local healthcare systems, however the available data allows to provide a more detailed picture of the current situation.

Several studies reported that their local healthcare system shows the intention to support digital health interventions (Fitzsimmons et al, 2016; Knox et al, 2021; Lewis et al, 2021; Maguire et al, 2014; Nyberg et al, 2019; Voncken-Brewster et al, 2015). This attitude is however not homogeneous across studies, and it is not always clear whether healthcare settings are looking to increase the number of telehealth programmes for their patients, and whether tangible incentives are effectively provided. A lack of continuous support appears to be the first obstacle towards further implementation, much like one of the main issues reported in the inner context section, as reported below.

The systematic review performed by Broese and colleagues provides a useful overview of several types of interventions being applied across different countries (mostly represented by Western Europe, North America and Oceania). While virtually all included studies in this review focus on COPD patients and/or breathlessness, the nature of these interventions is very heterogeneous, focusing both on patients alone and together with their HCPs. The overall theme of their findings indicates that a lack of continuous resourcing was a barrier to implementation in many of the included studies (not all included studies reported barriers and facilitators in their results), however a more detailed view of the issue can be extrapolated from the authors' results.

Key facilitators reported in three or more studies included the following examples:

- *"The innovation was perceived as helpful for patients, which motivated professionals to refer patients"*
- *"Consistent staffing by knowledgeable people aware of the program goals contributed to a smooth implementation of the innovation"*
- *"The timing of the assessment meant that actions overlapped with existing discharge planning"*

Conversely, several barriers were also identified:

- *"Referrers were not aware that the service existed, which hampered referral of patients to the innovation"*
- *"Due to the unpredictable disease trajectory of COPD, referrers found it challenging to determine whether a patient was at the end of life, and thus eligible for referral to the innovation"*
- *"Staff were unable to dedicate adequate time to the improvement efforts"*
- *"Patients experienced difficulty travelling to ambulatory services"*

All the points above overlap with previous observations, where lack of time, issues with travel arrangements and no knowledge the intervention existed are some of the most common, and difficult to address, barriers towards implementation. Simultaneously, the authors' findings confirm that knowledgeable staff, adequate timing of intervention administration and perceived usefulness on behalf of the patients encourage further implementation of the intervention.

An additional observation regarding the unpredictability of COPD should be made. Multimorbidity and a long-term trajectory of lung function decrease have already been identified as frequent features in COPD patients, including a largely irreversible pathology of the disease (Buttery et al, 2021). For these reasons, it is interesting to note that even experienced HCPs may find it challenging to accurately predict what is likely to happen to a COPD patient, and thus deciding whether a digital health intervention would be beneficial at all. This is not a way to criticize the work of healthcare professionals or suggest shortcomings in current diagnostic systems, but simply highlights additional obstacles in implementing novel interventions, that do not appear obvious at first.

Despite this negative observation, however, efforts made by healthcare settings during the COVID pandemic, to increase remote delivery of services, were generally met with positive results, in terms of adherence, engagement and completion (Lewis et al, 2021).

4.4 Barriers and facilitators to interventions uptake

This section illustrates what barriers and facilitators are identified from the analysis of each study results, regarding the uptake of an intervention. In general, the concept of 'uptake' focuses only on whether an intervention is adopted, and no consideration is given as to whether an intervention is then sustained afterwards. By analysing the data and results reported in the included studies, overlapping trends were identified, in terms of both barriers and facilitators experienced by the subjects. However, these are not the same for all cohorts, and a relatively high degree of heterogeneity among such trends and findings exists. A summarised overview of the results is provided in Table 7.

Table 7. Barriers and facilitators to intervention adoption

Facilitators to adoption	Barriers to adoption
- Ease of use, good degree of accessibility; - Financial savings over standard care; - Reduced travel to healthcare facility and continuous support/accessibility; - Personalized content; - Personal interest/high level of engagement.	- Advanced age; - Lack of technological skills or trust; - Variability of patient needs and lack of customised functions; - Lack of personal interaction with HCPs; or interest towards intervention from patients; - Loss of data or data not being used by HCPs.

5. Discussion

The aim of this systematic review is to synthesize and appraise evidence from existing literature on the barriers and facilitators to digital health interventions implementation, with a particular focus on the management of pain and breathlessness in palliative care, for patients with lung cancer and COPD, specifically community-dwelling adults living with lung cancer and/or COPD. The final objective of this review is to provide recommendations for the delivery of clinical care, policy, and guidance for future researchers.

5.1 Suggestions to address current knowledge gap

This section provides an overview of the findings gathered by systematically reviewing the available literature. Following the structure of the PARIHS framework used in the Results section, each paragraph will analyse key results, presented according to end-user relevance (i.e. patients and carers, HCPS, DHI designers and managers). Presenting the discussion following the relevant PARIHS constructs was chosen to directly guide the reader towards the most appropriate section, highlighting the information pertinent to their role. A complete overview of the findings for each study is reported in Table 2A in Appendix A.

5.1.1 Characteristics of the innovation

Data input and user interface

5.1.1.1 Relevance to patients and carers

Measuring breathing rates is usually intrusive, especially when monitoring needs to happen continuously. In the study published by Rubio et al, the authors compared five breathing monitors suitable for home use, and therefore self-management of breathlessness. The authors were specifically trying to answer if existing commercial devices would help breathless COPD patients improve their conditions. Overall, the study was not conclusive, and it is unfortunately unclear from the results what the patients thought of the intervention. An important finding however, which can be seen as a facilitator for this type of intervention, was that generally, patients could easily report their symptoms through a

touchscreen system, rather than a traditional paper-based method. This could encourage future uses of digital interventions to allow reporting and tracking of a patient's symptoms, possibly reducing the risk of data loss and inaccuracies. Another observation of this study indicated that the specific use of a touchscreen, rather than keyboard and mouse inputs, were easier for older patients, who commonly find typing difficult. Simultaneously, the study reports lack of competence and reliability as barriers, a finding that is in line with other studies included in this review.
This finding could be extrapolated and potentially applied to related settings, where patients with limited technical knowledge or advanced age would still be able to take part in a self-management intervention, and reliably manage to track and input their personal data in the device.

5.1.1.2 Relevance to HCPs

Healthcare practitioners are also likely to benefit from a user-friendly interface, that allows patients to adequately input the necessary data. Data loss and security is a particularly acute issue in healthcare settings (Singh et al, 2021). However, the Singh et al study reports findings outside of the scope of this review, which focuses only on the input, retention and use of patient details.

Issues with data retention and usability have already been discussed in this review, as such limitations were identified in some of the included studies. In some cases, HCPs reported that data would not always be reliable, or they simply did not have enough time to follow up with the intervention. This is obviously a significant issue for the entire intervention, as unreliable data leads to undesirable consequences.

Should an HCP not be aware the quality of the data is suboptimal, this could result in misdiagnosis of the patient. While not a clear-cut conclusion, as doctors may quickly become aware of a discrepancy between the available data and their own judgement towards a patient's illness progression, there is simply no reason to rely on compromised data for any length of time. If patients are unable to accurately input the required information, then an HCP will obtain either incomplete or misleading information. The most

likely reaction from a provider's point of view is to stop recommending the intervention altogether, in response to uncertainty of treatment effectiveness and their expectation to manage both the patient's medical needs and expectations (Kushida et al, 2021).

Alternatively, it is also plausible that HCPs may not notice issues with the data, until it is too late to begin the collection process again. This could happen in case the HCP is only able to verify the patient's data at irregular intervals, or with delay compared to the initial input. This situation could lead to doctors prescribing treatment based on wrong information, for an undetermined amount of time.

To avoid the possible scenarios above, it is therefore necessary that data input is optimized and made secure even before the intervention takes place, and specifically, this should be tested and decided at the design phase, a procedure recommended when planning to use a cloud-based service to share sensitive personal details (Thilakanathan et al, 2016). A possible solution would be to include patient representatives, HCPs and relevant stakeholders early in the process, where different data input, retention and distribution methods are tested and approved. Lack of early stakeholder involvement in the design of health apps has already been mentioned in this review, as one of the findings extrapolated from the included studies. Therefore, the notion that patients and HCPs should be involved as early as possible by digital intervention designers, should be reinforced and normalised as part of the development process. Existing research explored the relationship between respiratory patients and staff involvement, towards the development of an intervention to reduce short-acting beta agonist use in asthma treatment. In their study, Crowther and colleagues outline the five pillars which formed the intervention and conclude a co-designed process can be successfully delivered to asthma patients and their HCPs (Crowther et al, 2022). This co-design process is also currently being explored in other disciplines such as psychiatry, where a tailored approach towards a target population (in this case, paediatric patients from minority groups) indicates that "*Without co-design collaboration the intervention would have been inaccessible, unengaging, difficult to deliver and thus ineffective"* (Porche et al, 2022).

5.1.1.3 Relevance to Digital Health Interventions designers and managers

Co-design is directly applicable to DHI designers and managers, in addition to HCPs and their patients, encompassing all stakeholders included in the intervention. Designers and managers would benefit from early input from end users (patients and HCPs). This would allow for an intervention to be designed for a specific population, focusing on the features they would benefit the most from, for the needs of a chronic respiratory disease patient are seldom the same as another one presenting with an acute communicable disease. Designers could then decide on whether no existing data input interface fits the needs of the intervention, and whether a new one needs to be developed. In turn, this would allow managers to budget accordingly and what kind of expertise is required to develop the intervention.

Timing of intervention administration

5.1.1.4 Relevance to patients and carers

A salient perspective raised by a study focusing on lung cancer, published by Granger and colleagues, focuses on the timing of administration of an intervention, rather than the characteristics of the interventions itself. The authors aimed to study the feasibility and effectiveness of a self-management intervention to increase physical activity levels in people undergoing surgery to treat lung cancer. After an 8-week follow-up, the authors concluded that the programme was feasible in the post-operative setting, but not pre-operative. The authors however acknowledge important limitations such as relatively low adherence in terms of device wearing (50%), lack of a control group, single-centre setting, a 27% drop-out rate, and a lack of measurements for exercise adherence. Given the declared limitations, the conclusions of this study need to be interpreted carefully and ideally followed up by a randomized trial, however it would be inappropriate not to consider the timing of an intervention a key parameter when planning the implementation of self-management programmes in chronic disease populations.

5.1.1.5 Relevance to HCPs

Despite the study limitations, the timing of intervention administration is also particularly relevant to HCPs, particularly when they are at risk of excessive workload. While the best approach to treat diseases is almost always 'as early as possible', in this case, the study findings are slightly counterintuitive (Chen et al, 2016). By noting that the intervention appeared to be more effective in the post-operative setting, an HCP could delay the programme initiation, and instead have the chance to discuss it with the patient in advance. This would allow additional time for the HCP, and the patient, to ask questions and potentially tailor the programme accordingly.

5.1.1.6 Relevance to Digital Health Interventions (DHIs) designers and managers

Similarly, DHI designers and managers will benefit from the optimal timing of an intervention. Like most projects, numerous variables need to be planned and accounted for, such as time, financial budget, human resources, among others. Following the example of the Granger and colleagues' findings, should an intervention be planned for delivery before surgery, it would not only be potentially ineffective for the patient, but also wasteful. As discussed previously in this review, some of the key barriers towards implementations are low adherence from patients, lack of HCP time and unreliable support from relevant stakeholders. It is therefore safe to assume that initiating an intervention at the wrong time would essentially prevent making any changes to the plan later, increasing chances of project failure. A failed intervention will likely discourage further continuation within the team or even implementation elsewhere, reducing the chance to obtain additional resources. Managers and designers are possibly going to benefit from appropriate intervention timing just as much as patients, as they may be able to structure a successful program that could be replicated elsewhere (Muuraiskangas et al, 2016).

5.1.2 People's ability to change

5.1.2.1 Relevance to patients and carers

The most frequent issues reported by patients were related to a general lack of knowledge on how to use smartphones and other electronic equipment. In these instances, patients

would frequently lose interest towards the intervention, as the demands of reading small text, using unfamiliar devices or simply not being able to fully understand all the requirements of the programme, made adherence too burdensome and inconvenient. It is possible that some older patients managed to become more accustomed with their devices after an initial introductory period, in which case satisfaction towards the intervention, but not necessarily successful adherence and implementation, followed. Despite this promising observation, where older and sicker patients may still be able to benefit from a novel digital intervention despite their initial lack of necessary skills, it is not possible in this review to provide conclusive evidence this is indeed an avenue to be explored. Most of the studies only included a small number of patients, and results are frequently unclear due to high levels of attrition. Therefore, it appears that offering some training to older patients, and the opportunity to familiarize themselves with new technology, may increase chances of intervention adoption and success, however this aspect will require larger and longer-term studies, preferably within a randomized controlled trial-type of environment.

5.1.2.2 Relevance to HCPs

Patient training appears to be the most effective tool to increase intervention success. Healthcare practitioners are the most likely stakeholders who will administer training to patients. HCPs would then find themselves in a 'train the trainer' situation, where support from their managers will be needed. To avoid increasing their workload, HCPs should be provided with detailed information regarding the DHI, and what devices the patients will be expected to use. This type of information would be discussed during the consultation session and should be accessible for the end-user. HCPs could be provided with printed material, intended for use by the patient. Such material should contain instructions and guidance on how to use the digital device, which the patient would read before the start of the intervention. Once the patient is given access to the device, a website or digital copy of the instructions, together with important contact details, could also be included. HCPs would need to be trained by their managers prior to explaining their patient how to proceed with the intervention.

5.1.2.3 Relevance to DHI designers and managers

Designers and managers of the intervention will need to plan ahead and include HCPs in their patient-focused training programme. Such material will need to be tailored to the intervention, and possibly developed with HCPs and patients or their representatives. An existing example of training material is reported in a publication by Riggs and colleagues. The authors developed tailored material for a cohort of seriously ill, multimorbid patients, and their carers. This material was intended to train this cohort for remote, at-home supervision of Transcranial direct current stimulation (tDCS). In their study, the authors indicate that priority was given to making the content accessible, and therefore they developed the material in a series of steps, describing the assembly and operation of the device. Additionally, they found it appropriate to structure the content at fifth-grade reading level, given the older population (Riggs et al, 2017).

5.1.3 People's motivation

5.1.3.1 Relevance to patients and carers

Advanced age and low technological skills were the key barriers identified in this section, where a general lack of enthusiasm and willingness to participate in the intervention was reported by the patients, and to an extent by HCPs. Simultaneously, some patients reported positively changing their attitude towards the intervention after trying it, which can be identified as a facilitator. In this case, it can be argued that positive engagement *after* the intervention has started, or even concluded, may not be classed as a facilitator towards 'implementation'. However, as implementation refers to the whole life cycle of a project, it is worth noting that positive feedback from previous patients might encourage further patients to join future sessions of a DHI.

5.1.3.2 Relevance to HCPs

Healthcare professionals are most likely those who will communicate directly with the patient and tasked with the responsibility to enrol them. As discussed in the results section, it is not only the patient that could be sceptical towards an intervention, but HCPs themselves, especially when treating older people. Unless the intervention is obviously

unsuitable for the patient, healthcare practitioners should consider encouraging them irrespective of their age and educational background.

When trying to include a patient in a DHI, the process should be approached case-by-case. The findings of this review recommend encouraging patients to attend the intervention, without any obligations to continue. Healthcare professionals would need to justify their proposal to join, especially if the patient is not convinced the intervention will benefit them, with a realistic view of the intervention's contribution and limitations needs to be provided, encouraging the patient to 'try it out'. An appropriate approach may be providing the patient with the potential gains brought by the DHI, and the resulting possible improvements in their health outcome. Mentioning satisfaction reported by previous patients will probably increase chances of attendance, while not guaranteeing complete adherence, however the patient can then decide whether the intervention really benefits them, based on personal experience. Ultimately, a patient should be allowed to take a final decision without pressure, and only join if they conclude it is in their best interest.

5.1.3.3 Relevance to DHI designers and managers

Managers and designers should always focus the development of an intervention on the target population. In this case, it is being argued that older people may benefit from digital interventions similarly to younger and more technologically advanced patients, who can however be left out due to underlying personal limitations of scepticism. In particular, the strengths of the intervention should be highlighted at enrolment stage, with the aim to increase patient motivation to join. Since HCPs are most likely those who will perform patient enrolment and education, and older patients form most COPD/LC cohorts, designers and managers should include a motivational component for patient, in the implementation structure (Bajwa et al, 2019). In this case, an existing study from a cohort of heart failure patients could serve as a relevant example.

Ercole Vellone and colleagues performed a randomised controlled trial, with a sample of 510 heart failure patients, evaluated whether motivational interviews (MI) would improve, as primary endpoints, self-care maintenance, self-care management and self-care confidence three months after enrolment (Vellone et al, 2020). Additionally, they also

observed whether patients showed changes in self-care over one year, and if patient self-care improved if informal caregivers were involved. In their discussion, the authors argue that MI was effective in improving health-related outcomes, both in terms of self-care maintenance after three months, but also self-care management. Furthermore, confidence and illness management also improved throughout the intervention. At 1-year follow-up, the authors could also conclude that informal caregivers positively influenced patient outcome over time, particularly regarding the effectiveness of MI towards self-care management. Overall, the authors argue that MI is an inexpensive tool to effectively improve HF patients' outcomes. Simultaneously, the authors also acknowledge that stakeholders performing MI, most often nurses, need to be specifically trained and evaluated, before being allowed to perform the intervention. While the latter is potentially a barrier to implementation, appropriate personnel training should always be planned and structured accordingly by DHI designers and managers during early stages, but will ultimately decrease the risk of error and reduce the amount of resources needed to run the programme over time (Edwards et al, 2015; Fukui et al, 2011; Lee et al, 2016).

5.1.4 Inner context

This section of the review was more difficult to develop compared to the 'Characteristics of the Innovation' topic, as little data is available from the included studies. However, despite the general lack of information regarding this domain, it is still possible to draw results relevant to the original research question.

<u>Shared decision-making</u>

In shared decision-making (SDM), physicians contribute with their knowledge and experience on medical evidence, while patients provide their opinion on their primary needs and how they want to be treated (Bomhof-Roordink et al, 2019). Incentivising SDM in healthcare settings has been discussed for many years, with researchers providing their advice on how to encourage HCPs in using this approach with their patients (Stiggelbout et al, 2012). However, there is no consensus on whether SDM improves patient outcome, as indicated by existing research. Lack of reliable data is a reason why a 2018 Cochrane review

cannot recommend SDM as a tool to improve treatment effectiveness, whereas other studies argue that SDM should certainly be scaled up in healthcare settings, and its poor implementation worsens patient-related outcomes, quality indicators, and increases healthcare utilisation (Hughes et al, 2018; Légaré et al, 2018; Légaré et al, 2014).

5.1.4.1 Relevance to patients and carers

As this review focuses on self-management interventions, it should be argued that SDM be considered a central approach towards treating breathlessness in COPD and LC patients, for the following reasons.

With this approach, health decisions are taken by both the clinician and patient, after discussing the options available to them, including benefits and drawbacks. Patients who understand the intervention are more likely going to actively participate to the best of their ability, instead of simply accepting instructions given to them by their HCPs or carers. As doctors explain the features and limitations of a DHI, patients begin to share ownership of the programme and their illness, with the opportunity to take informed decisions throughout the treatment. In addition, they may also discuss their experience with their doctor, potentially providing useful information to help treatment. Therefore, where possible, it is arguable that patients will benefit from taking decisions regarding the intervention together with the HCP, and where not possible, a patient's carer should be included in the shared decision-making process and given the chance to discuss the features of the intervention, especially during the initial stages of implementation.

5.1.4.2 Relevance to HCPs

An important finding suggests that a minimum number of stakeholders should be trained and supported with resources, throughout the planning of the intervention. This refers specifically to HCPs and managers, who will be involved in the intervention on a regular basis and are responsible for its management, unlike patients.

Existing studies already provide an articulated view of this process, which can provide the right framework to reach decisions within a team of people. This approach is particularly useful in circumstances where the available evidence is unable to support a clear decision that would allow to reach a superior outcome. By involving all parties, expectations regarding the benefits and limitations of an intervention can be managed as a team, where each member can bring additional evidence and knowledge that are potentially available to them (Müller-Engelmann et al, 2013). This approach is also feasible within teams where a 'hierarchy' of decision-making process exists, including the above-mentioned 'need-to-know' information sharing approach.

Asking teams to share responsibility for sharing decisions can however increase their workload, which has already been identified as one of the major barriers towards intervention implementation. It is therefore necessary to consider incentives that can be provided to HCPs and other decision-makers in the intervention. As PARIHS does not focus on the provision of incentives, this aspect should be planned without the use of the framework's tools (Bergström et al, 2020). Such incentives may be provided in different ways, via financial benefits, additional time off or reducing workload from other duties, among other examples, and can be tailored according to the recipient. An overview of 33 studies published in 2014 by Renee Misfeldt and colleagues provides a useful starting point that could be applied when designing incentives for HCPs (Misfeldt et al, 2014). Their study focused on the identification of financial and non-financial incentives to improve health workforce outcomes, with the aim of supporting evidence-based recruitment and retention strategies. Their findings report that evidence is generally mixed, in terms of clinical and social support on outcomes. However, some important points were reported in the study. The authors suggest that financial incentives, both in terms of direct retribution or indirect bonus packages, is the most common approach towards incentivising healthcare professionals. They also report however that financial incentives are effective in recruiting, but not retaining, HCPs in rural and remote settings. While the authors acknowledge that evidence in support of non-financial incentives is mixed, and their findings in general need to be read with some caution, they argue that providing incentives such as family-friendly policies, self-scheduling, child support and professional autonomy do increase job

satisfaction and reduce personnel turnover (Misfeldt et al, 2014), therefore encouraging HCP participation and shared decision-making.

5.1.4.3 Relevance to Digital Health Interventions (DHIs) designers and managers

Designers and managers are also likely to benefit from similar approaches recommended for HCPs. As managers' responsibilities are likely to cover both the technical aspects of an intervention and its people, is also important to note that stakeholders should be involved in the intervention only as needed, as different roles may only require occasional or non-supervisory tasks. For instance, it would not be necessary for an HCP to know the intervention at the level of detail required instead by managers or designers. Tailoring stakeholder training to only deliver the information they will need for their role should be prioritised, to avoid unnecessarily burden the individual. With that in mind, it is important that a selective approach towards knowledge does not exclude individuals and teams from taking decisions relevant to the intervention. Authors Anand and Hassan published an article in 2019, describing the concept of 'Knowledge hiding' in organisations, essentially framed as the opposite of 'Knowledge sharing' (Anand et al, 2019). The authors argue that knowledge hiding can be intentional, unintentional, or a mixture of both, and it's present at the individual and organisational level. In their study, they recommend that managers implement measures to prevent the formation of a siloed culture among employees. Examples of suggested measures include financial and non-financial rewards, facilitating a positive work environment and designing roles that promote teamwork. These general recommendations should be considered by managers of an intervention, to support the concept of shared decision-making and keep the stakeholders engaged.

While the above recommendations are based on the findings of this review and existing additional literature, not necessarily related to the population being considered here, there is a need for further studies aimed at how teams can work together to effectively implement an intervention. This is of importance, given the little objective data that could be gathered via this review. In this regard, it could be appropriate to explore existing studies and interventions focusing on the concept of shared decision making, and then apply those findings to an intervention focusing on COPD and LC patients.

5.1.5 Outer context

While a push for IT-based intervention has been ongoing for years across healthcare systems, a slow uptake of such interventions may also be identified as an issue in novel implementation.

5.1.5.1 Relevance to patients and carers

The main difference between delivering an in-person intervention, and an online-only one is the obvious lack of personal contact resulting from the second. This aspect brings both challenges and strengths, especially during pandemics and with weaker or immunocompromised patients. Not having to travel to a facility, or reducing exposure to additional illnesses, certainly contribute positively to a patient's treatment. However, as it was already noted in previous paragraphs, numerous patients still value personal contact with their healthcare providers, and in some cases, people are sceptical that a remote intervention can replace an in-person interaction.
As a potential solution towards low adherence, vouchers or a prize-based system could be considered for patients. In the first case, patients could be offered a cash-equivalent voucher to be spent in their local community (supermarkets, pharmacies, etc.) or online, should they choose to actively participate in the intervention. Likewise, a prize-like system could be devised for the same patients, based on their continued participation in the implementation. Previous studies indicate that both approaches are helpful in increasing adherence and effectiveness of an intervention (Petry et al, 2007). While it must be noted that the population under study in the Petry et al trial was formed of drug use disorder patients, either technique should not be excluded a priori when trying to increase participation in a reluctant cohort of COPD and LC patients.

5.1.5.2 Relevance to HCPs

A slow intervention uptake can be caused by several factors, and mostly influenced by the patient, healthcare facility, technology, or a combination of the three. An issue may arise when patients are asked or encouraged to use new technology they are not familiar with, and despite (or sometimes given the lack of) appropriate training, the desired result is not

achieved. While it may be in the local healthcare authority's interest to increase the uptake of digital interventions, it is possible the local population is not the ideal target for such innovation, as already indicated by patients who felt or confirmed they lacked the adequate skills to use digital devices. Seasonal pressure on hospitals may also strongly influence how effective an intervention is, especially if follow-up with patients is planned or desired. In interventions where patients are simply required to guide themselves through a program, but where progress is not tracked at regular meetings, it may happen that a patient doesn't follow the necessary instructions provided by a software. This was particularly evident in a case where HCPs indicated the following points:

- *"[Patients] only need to click on the section for it to go green, they don't have to watch the video"*

While this is only a single observation reported verbatim from an HCP interview, the issue is unlikely to be found in isolation. Relevant to the seasonal pressure experienced by hospitals, especially in winter for respiratory diseases, a lack of engagement on behalf of the patient, and a subsequent hospitalization due to a lack of efficacy from the telehealth intervention, reduces the effectiveness of the program, which may negatively impact further uptake within the affected facilities.
In this regard, a systematic review by Tobias Bonten and colleagues may provide a potential solution for HCPs who are trying to evaluate whether an intervention will work for their patients. In their study, the authors analyse existing eHealth evaluation approaches, aiming at assisting eHealth evaluators in finding the best approach to evaluate their DHI at a specific evaluation phase. They find seventy-five unique approaches that stakeholders could use when testing the feasibility of an intervention at each of its phases, and possibly help HCPs and designers better develop a tailored intervention (Bonten et al, 2020).

Furthermore, Greenhalgh and colleagues mention the NASSS (Nonadoption, Abandonment, and challenges to Scale-up, Spread, and Sustainability) framework as another potential solution towards technology-supported healthcare program. In their study, the authors combine a literature review and empirical case studies of technological implementation, to provide a framework to "*help predict and evaluate the success of a technology-supported*

health or social care program" (Greenhalgh et al, 2017). The authors conclude that after additional empirical testing, stakeholders could employ the NASSS framework to identify new or existing technologies that may (or may not) be suitable for the intended DHI, and identify the main challenges in the various domains of the intervention itself.

5.1.5.3 Relevance to DHI designers and managers

The findings above indicate that a nationwide IT strategy may not be a realistic solution to implementing software aimed at providing novel digital interventions. This result could be extrapolated to the management breathlessness in COPD and lung cancer, where no single programme or solution is ever going to be suitable for all patients. However, a modified approach could be considered in this case.

In addition to the voucher/prize scheme recommended earlier, another potential solution could be drawn by existing policies guiding Decentralised Clinical Trials (DCTs). Such an approach has been in use for numerous years now, but its application has expanded greatly during the pandemic. In short, DCT do not follow traditional clinical trials structures, and rely less on traditional research facilities for data collection. Digital health interventions are key enablers for DCTs, as one of the core aspects of this type of trial is the near- or complete absence of in-person visits to enrol, manage, treat and release patients throughout the trial's lifecycle (Van Norman, 2021). Both Canada and the European Union issued a series of guidelines to support DCT development, aiming at improving the accessibility, diversity, and retention of patients. Following an analysis across European regulators, no face-to-face interactions and the lack of physical examinations were cited as key barriers towards patient participation, in line with the findings of this review (de Jong et al, 2022). To reduce a patient's apprehension towards a digital intervention, the concept of a 'satellite' facility could be considered when planning the intervention. This concept was introduced in Canada, where the use of telehealth is being encouraged given the uneven population distribution. In a study by Sundquist and colleagues, the CRAFT framework (Canadian Remote Access Framework for clinical trials) for DCTs is proposed (Sundquist et al, 2021). The authors argue that providing 'satellite' centres for patients participating in a trial "*will improve research experience, regulatory compliance and patient safety"*. These centres are

represented by local community healthcare facilities, rather than main research facilities, where the trial may be based. This way, patient have the option to visit the nearest healthcare facility, rather than travelling further to a larger hospital. The authors provide specific advice on how to implement such a 'hub and spoke' system of care, and conclude after ongoing pilot studies, this approach will be helpful in ensuring successful trial conduct.

Parts of the CRAFT approach could be applied to COPD and LC patients, where local healthcare facilities or pharmacies may be included in the support network of a digital health intervention. A current example is ongoing in the United States, where the Walgreens pharmacy chain intends to use their nationwide presence to increase patient participation in clinical trials (https://news.walgreens.com/press-center/walgreens-launches-clinical-trial-business-to-address-industrywide-access-and-diversity-challenges-and-redefine-patient-experience.htm, accessed 3 October 2022). The company argues that most people live within a short distance of their stores, and therefore patients will not necessarily need to travel far to reach a main trial research centre.
The example above is not necessarily applicable to healthcare system outside the US, plus local laws, limitations and regulations need to be followed. However, the concept of providing patient support through existing local facilities should be explored by intervention managers.

5.1.6 Applicability of current findings to cardiovascular disorders

COPD and lung cancer patients are frequently multimorbid, exhibiting additional systemic manifestations ranging from musculoskeletal disorders, psychiatric issues, and cardiovascular disease (CVD) (Divo et al, 2020; Niksic et al, 2021). While the findings of this review originate from the needs and observations of COPD/LC patients and their HCPs, they can also be implemented in CVD populations, as in many cases, cardiovascular diseases are chronic, complex and tend to evolve over time (Dahlöf, 2010). Given millions of patients are affected by CVD worldwide, who also frequently experience respiratory issues, such patients may experience very similar barriers and facilitators, particularly those patients affected by *chronic* heart diseases, rather than *acute.*

Existing literature does report ongoing efforts to provide DHIs in patients suffering from Coronary Heart Disease, in particular when patients experience a case of emergency (Keikhosrokiani et al, 2018). In this two-country study, the authors highlight the importance of patient-centric design, while also seeking the opinion of healthcare practitioners to make any improvements to the intervention.

In a separate study, Lindsay Rosman and colleagues explore the effect of a self-management intervention for atrial fibrillation (AF), during the COVID-19 pandemic. After including 68 patients with AF in a single-centre pilot study, the authors analysed the effects of a 4-week virtual AF self-management program. In conclusion, the authors find that a virtual education program could improve adherence to existing guidelines for AF management, emotional wellbeing in patients and their knowledge of COVID-19 (Rosman et al, 2021). Similarly to the themes identified in this review, the authors conclude that their study *"…suggests that the technology-based programs may facilitate access to underserved populations by overcoming traditional barriers to nonattendance (e.g. inadequate transportation, lack of insurance, work obligations and caregiver responsibilities)"* (Rosman et al, 2021). While the authors acknowledge the intervention did not influence AF-related quality of life, and that future trials are needed to confirm the results, this generally reinforces the findings of this review and extends their applicability.

5.2 Strengths and limitations of the review

Most of the results of the 'people's ability to change' section cannot necessarily be extrapolated to the general population, given the low number of participants and the possibly positively skewed type of patients (i.e., the patients might have shown a higher degree of interest towards technology and/or the intervention, compared to the general population), the specific practical observations made by the authors should be noted for future studies on topic. It is possible that using contemporary and relatively affordable technology, such as tablets in this case, might be a cost-efficient and more straightforward solution towards the monitoring and self-reporting of disease symptoms. Previous studies employed the use of sensors and personal devices such as step-counters or more advanced

fitness technology products, however these were often found intrusive or inaccurate, from both patients and HCPs. This recommendation broadly follows that made in the 'Outer context' paragraph, where a consolidation of existing procedures, and the sourcing of commercially available hardware and software may increase the success chances of an intervention.

It is possible that some older patients managed to become more accustomed to their devices after an initial introductory period, in which case satisfaction towards the intervention, but not necessarily successful adherence and implementation, followed. Despite this promising observation, where older and sicker patients may still be able to benefit from a novel digital intervention despite their initial lack of necessary skills, it is not possible in this review to provide conclusive evidence this is indeed an avenue to be explored. Most of the studies only included a small number of patients, and results are frequently unclear due to high levels of attrition. Additionally, little data was available in terms of barriers to *adherence* following *adoption*, as most studies did not focus on the former, or their follow-up was not adequate to obtain meaningful results.

One of the most favoured study designs employed in the studies was the qualitative/interview. In this case, it is appropriate to approach the patient population with the use of questionnaires, both structured and unstructured, as they are essential to capture their views on what worked and what didn't (direct barriers and facilitators). Simultaneously, interview responses and their analyses also allow to understand what has not been said explicitly by the relevant parties, and they help identify further issues or strengths within an implementation process. In addition to interviews, controlled trials, case studies, literature reviews and pilot studies were also employed.

Despite these limitations, by systematically reviewing the literature it was possible to highlight the current status of our knowledge on this topic, and provide recommendations to future researchers.

5.2.1 Methodological and available literature considerations

A considerable difficulty encountered during the planning of this project was the lack of consistent literature describing how to perform a narrative synthesis, especially for people without prior expertise. Despite the relative abundance of texts describing the general aims and features of narrative syntheses, as also described above, it was not possible to locate documents clearly outlining the steps and requirements of such technique. After reading numerous sources, it appeared that the concept of narrative synthesis is still somewhat undefined, and, while guidance on how to perform one exists, no frameworks or agreements have been put in place (Lisy et al, 2016; Popay et al, 2006). It seems that the concept of 'narrative synthesis' broadly describes the end result of the analysis, without requiring researchers to follow a specific structure. This allows for considerable independence in terms of interpretation and implementation of this technique, which relies on implicit, rather than explicit guidance, rendering its scope generic and non-standardized. Another limitation was the inability to search additional databases or further review the search strategy to potentially include additional relevant studies. This was chiefly due to this review not being conducted as a team, and with only limited time and resources. Nonetheless, the results provided in this review should be able to guide future research via a single source of information.

5.2.2 Publication bias

Systematic reviews such as this one aim to summarise the evidence available in healthcare literature or other fields, with the aid of a structured approach. However, while internationally accepted reporting guidelines such as PRISMA and CONSORT exist, the definition of systematic review is still loose and variable according to author and topic (Bearman et al, 2012). All research publications are also affected by publication bias, which exists in several different forms, including improper use of statistical methods or incomplete reporting of findings (Ayorinde et al, 2020). For instance, a common form of publication bias is represented by the non-publication of negative and null results. When authors do not make their negative results available to the community, readers may simply assume that an intervention, or treatment, performs better than expected, since only 'positive' results are available to them. This phenomenon of positive bias is widespread across all research

disciplines, including health services research, and still appears to be a common issue among research groups, generating very significant amounts of waste in healthcare investment, depriving patients of appropriate treatments (Chan et al, 2014). In this review, numerous study types were included, ranging from small observational studies to systematic reviews. Policymakers and healthcare managers generally focus on systematic reviews when planning interventions implementation, as this type of literature is normally seen as the most robust, however far from perfect (Afshari et al, 2015). When producing this review, care was taken in identifying the most appropriate studies and extracting the data as accurately as possible, to allow objective interpretation of the results in line with a research waste reduction approach (Chan et al, 2014). However, given the very high heterogeneity of the included studies, it is not possible to exclude that a certain degree of publication bias affects this review.

Additionally, when interpreting the results, it was at time necessary to extrapolate findings based on what *was not mentioned* versus what was *explicitly mentioned*. As stated earlier, great care was placed when interpreting the results of this review, to avoid inappropriate speculation or distortion of facts. This approach is termed 'retroduction', and can be described as *"…inference to theorize and test hidden mechanisms"* (Jagosh, 2020). An in-depth analysis of the concept of retroduction is beyond the scope of this review, however the reader should be aware of this approach, which may allow better understanding of causal mechanisms that cannot be directly identified via empirical measurements.

5.2.3 Possible issues with the use of digital health interventions synonyms and definitions

Following the World Health Organization classification. 'Digital health interventions' is used in this review as the main definition to refer to all included interventions, except for some cases where more specific terms such as 'telehealth' or 'mHealth' were kept in the text, where necessary. A lack of agreement on how to define and name digital health interventions is an issue affecting the literature on this topic, which can lead to confusion how to classify and describe a given intervention. While this matter is widely known in the research community, it appears that no common approach towards defining and classifying DHIs is being taken by researchers worldwide.

5.2.4 Limitations regarding target populations in studies, possible lack of generalisability of findings

Many, though not all, of the populations included in this review tend to represent older patients with generally lower technological skills and worse disease prognosis. This is not unexpected, as COPD and lung cancer are chronic diseases often accompanied by other issues, such as cardiovascular disorders, which tend to accumulate and worsen later in life. This may limit the generalizability of these findings to such types of patients. It is possible that in the future, via a general trend towards increased automation in healthcare, and a more conscious approach towards addressing multimorbidity in respiratory diseases, some of the identified barriers, or facilitators, may become less relevant to DHI implementation (Bousquet et al, 2019; Fernández-Niño et al, 2020; Pepito et al, 2019; Van Wilder et al, 2022).

Out of the 24 studies included in this review, two did not explicitly mention 'breathlessness' in their research question, it was however decided to include them (Brown-Johnson et al, 2015; van der Weegen et al, 2013). In both studies, the authors focused on a user-centred design approach for digital interventions, relevant to COPD and lung cancer patients, plus their healthcare practitioners, while also matching the WHO classification categories chosen for this review. Given the relevant overlap in research questions, and the general difficulty in recruiting chronically breathless patients, it was possible to extract meaningful data regarding the usability of the apps in question and specific feedback provided by the users. The authors' observations were thus analysed and included in the findings of this review.

5.2.5 Reliability of findings and 'maturity' of research field.

As stated in previous paragraph, quality of evidence on this topic is heterogeneous, and the results are based on studies which greatly differ in terms of approaches and sample sizes. Overall, the majority of the included publications rely on limited numbers of patients, inherently reducing the solidity of the findings. This, however, does not compromise the results and recommendations of this review. By applying appropriate inclusion and exclusion criteria and combining a systematic review with a narrative synthesis approach, only those studies deemed of sufficient relevance and quality were considered. This

research topic appears to be evolving, and while studies are being undertaken to better understand how to address breathlessness in COPD and LC patients, current knowledge is still limited and needs to be expanded. While it is now understood that patients and their representatives need to be included during the early stages of planning an intervention, rather than simply at delivery, other aspects that apply to other stages of intervention implementation are less defined. In terms of 'maturity' of this research field, the review highlights we are currently at early stages of knowledge development, and changing approaches towards the management of breathlessness is likely to take years. Additionally, more evidence is needed to understand which type of intervention is best suited for a specific cohort of patients.

5.3 Summary of main findings

5.3.1 Implications for practice

Findings from the current literature indicate a growing trend across healthcare systems towards designing and implementing digital health interventions, not only for patients with chronic breathlessness but also for other diseases. From the findings of this review, no single approach can be recommended when treating COPD and LC patients, and that further steps are necessary to close current gaps. Healthcare organisations will need to consider several aspects before planning and implementing a new intervention, aspects which should be ideally addressed in the short term.

Lack of cooperation and end-user inclusion needs to be addressed at the very early stages of planning. The findings of this review suggest that HCPs and their patients are too often consulted in isolation, or after the intervention has been largely planned, and this has clear repercussion on the likelihood of success of the intervention. Lack of motivation, time and trust in the interventions are also major obstacles that need to be addressed early on by the healthcare provider, at a local level. It is unlikely that the same intervention will be suitable in a different setting or country, especially in in countries where healthcare systems are managed at a highly decentralised level, such as Italy and Germany. This however should not discourage consolidating existing fragmented digital systems still being used in healthcare systems worldwide, which can sometimes create incompatibilities between

neighbouring hospitals by relying on obsolete technology such as fax machines, hampering data entry and generating electronic health records (Takeshita et al, 2022). Further issues in implementing novel electronic management systems are also given by the generally high cost and complexity of procuring new software, and the need to make major alterations to current medication processes (Lindén-Lahti, 2022). However, it is very likely that further development in medical software and devices, compounded with an increase in technological literacy in the general population, may provide new and currently unavailable solutions to implement digital interventions more easily in the management of respiratory diseases. The association between low literacy levels and worse health outcomes is firmly established in scientific literature, and this is valid for all ages and socioeconomic status (Evangelista et al, 2010; Larsen et al, 2015; Quenzel et al, 2015).

This systematic review aimed to synthesize and appraise evidence from existing literature on the barriers and facilitators to digital health interventions implementation, with a particular focus on the management of pain and breathlessness in palliative care, for patients with lung cancer and COPD, specifically community-dwelling adults living with lung cancer and/or COPD.

Overall, the results of this review offer a very heterogeneous picture of the barriers and facilitators identified in the self-management of breathlessness. However, the following core findings can be extrapolated.

1. Advanced age and health/technological literacy are very important factors that may act as barriers, however this is not universally true.

Across populations, and irrespective of where the study took place, older and frailer people tended to engage less successfully with the intervention, due to lower technological skills or lack of trust towards a remote intervention. Numerous patients expressed their scepticism regards a partial or complete lack of personal interaction with their HCPs, however some studies highlighted that reduced travel to a healthcare facility and continuous support were seen as facilitators towards implementation. This was particularly evident in patients with limited mobility or lower incomes, and those who preferred to have facilitated access to

their HCPs via a remote connection. Based on these findings, it may be useful to focus on the characteristics of the innovation and its recipients (in this case, older and frailer patients), and ensure these domains are aligned with the intended targets. To facilitate this process, the reader can refer to the six points reported in the 'Characteristics of the innovation' paragraph, page 56.

2. Irrespective of age, additional knowledge about disease does not necessarily empower patients.

This aspect was gradually discovered during the data analysis phase of this review, and strongly focuses on how each patient may psychologically respond to their disease status. Only studies that employed a qualitative approach were able to report this type of finding, by directly asking their patients and/or HCPs. Patients who report being frustrated from knowing how their disease might evolve are less likely to benefit from the intervention. It is therefore recommended to design and plan a DHI by considering both its technological aspects, and also the potential reaction exhibited by the target population, that is, the psychological effect generated by increased patient participation. This type of issue could be tackled by referring to the 'Patient's ability to change' and 'People's motivation' sections, where both the target population and HCPs are the key stakeholders of a DHI.

3. Healthcare professionals need additional, continuous support during all stages of a DHI implementation.

This theme was approached by several studies in this review and showed one of the highest degrees of agreement and overlap, when comparing results from each individual study. Overall, HCPs are frequently too overwhelmed by current work requirements to effectively take on additional responsibilities. This issue is present throughout the lifecycle of an intervention and is likely one of the most significant barriers towards implementation. Recommendations such as incentives, implementing shared decision-making and appropriate stakeholder training have been made in this review, to tackle existing barriers and transform them into potential implementation facilitators. It is recommended that, in particular, DHI designers and managers incorporate stakeholder support from the early

stages of planning an intervention. In this case, HCPs are the recipients of the intervention, and DHI designers may be helped by looking at the features reported in the 'Inner context' and 'Outer context' paragraphs of this review.

4. Patients should be included in the decision-making process as much and as early as possible.

This concept has already gained traction in healthcare settings, and it is actively being discussed under the notion of 'patient-centric healthcare approach'. While this postulation is generic, it focuses attention on the importance of considering patients as active decision-makers during the treatment process (Breen et al, 2009). Patients' views about how useful an intervention is may differ from HCPs', so their feedback on the user-friendliness of a proposed digital app or hardware needs to be included in the implementation. From the results, it was apparent that including patients only during later stages of planning an intervention may cause designers to overlook important details, or increase complexity when trying to address any necessary changes. Once more, both patients and HCPs are the recipients of the innovation, and are also affected by the 'People's ability to change' and 'People's motivation' criteria elucidated in PARIHS.

5. Data loss/use of patient data.

The issue on how data is entered, stored and used was raised in some of the included studies, focusing more on the 'user-friendliness' of data use and input, rather than their technical implications. In some cases, patients reported having difficulties using the digital interface, and in some limited cases, malfunctioning devices. Likewise, some HCPs reported not being able to use the data adequately, or not having time to perform the necessary analyses. The importance of having reliable, complete data needs to be considered at the beginning of an intervention design, starting with the idea that any collected data should be treated as confidential and lead to the identification of the patient, and also allow their HCP to compile an accurate diagnosis. The topic of health data recording and transfer is not new, and an in-depth analysis of this issue is beyond the scope of this study. However, some key themes should be mentioned. As data is generated, stored and transmitted, each step needs

to be compliant in terms of integrity and privacy towards the patient. Encryption and anonymisation are two fundamental requirements of data management, to avoid catastrophic data loss and potential identity theft, in addition to ensuring the data is stored safely for future reference (Zala et al, 2022). Therefore, to ensure that HCPs have access to reliable, stable early involvement of DHI managers and HCPs is strongly recommended, and ideally the inclusion of data specialists should be considered when designing how this part of the intervention should be implemented (Gold et al, 2007). In this case, both the Inner and Outer context sections of PARIHS provide relevant guidance to develop the intervention. Healthcare centres will need to manage their own data policies internally, for instance in terms of what equipment to use, who is responsible for its maintenance, and what rules employees need to follow. Simultaneously, it is likely that some services will need to be outsourced, such as hardware procurement, data storage or analysis. These aspects will be influenced by the current policies and environment present within the healthcare organization, and external factors, such as national policies for handling sensitive data and availability of funding for equipment maintenance and renewal.

6. Conclusions

6.1 Contributions of this review

The findings of this systematic review add to previous literature in several ways, highlighting the status of our knowledge, and its gaps, regarding the barriers and facilitators towards implementation of digital health interventions for chronic breathlessness. Patients are most likely to benefit from digital interventions to self-manage their symptoms, however several factors need to be considered prior to implementing an intervention. The target population, disease staging, and healthcare setting play decisive roles on whether an intervention is more likely to be successful, and it appears beneficial to tailor an intervention according to the local setting, rather than at a broad geographical level. Age and cultural differences also profoundly affect how patients perceive a DHI, indicating that existing solutions may need to be adapted over time, to adequately support their patient population and keep pace with technological advances. Early involvement of both patients and HCPs when designing the intervention is crucial to increase acceptance, relevance,

adherence and effectiveness, and therefore to maximise the investment required to launch and maintain a DHI.

6.2 Facilitators towards implementation

Facilitators broadly include user-friendliness, clinical utility, reduction of workload for HCPs and carers, increase in patient self-awareness and 'ownership' of the disease, reduction of healthcare costs and burden on both the patient and healthcare system.

6.3 Barriers towards implementation

Barriers that are likely to persist, when trying to design self-management interventions for chronic breathlessness are related to disease staging and patient health, as those who may benefit the most are most probably older and reached a more advanced disease staging, including possible comorbidities. Likewise, recruiting such patients is a major obstacle towards studying how DHIs may influence their self-management skills, as reflected by the literature gathered in this review. It was not possible in this review to identify specific and reproducible DHI techniques that could be applied in different settings or populations, given the lack of data and heterogeneity of results.

6.4 Novelty compared to existing literature

A list of barriers and facilitators towards DHI implementation in breathlessness was not previously available in a single place, underlining the additional knowledge brought by this review. This novel result will hopefully help palliative care researchers plan their future interventions or investigative activities, by providing a more focused view of what can increase intervention implementation rates. Age and culture appear to also affect DHI effectiveness, not universally but to a significant extent. In general, older people from a lower socioeconomic background reported more difficulty and scepticism towards joining DHIs, however this was not universally. A moderator towards the negative effect of age and education was found to be patient (and HCP) engagement, and early stakeholder engagement also fundamentally increases chances of intervention success. These findings combined should encourage stakeholders to include frailer patients and their HCPS in future

research, as they are likely to benefit from the intervention the most. Finally, local, community-focused interventions appear to be more feasible than broad regional or national ones, however current data cannot conclusively confirm this observation. Overall, intervention implementation success appears to be mostly influenced by the target population, disease staging and healthcare setting.

6.5 Challenges and opportunities for future research

With regards to implementing and ensuring adherence to digital health interventions, the challenges that remain are manyfold. Data strongly suggests that healthcare professionals are generally overwhelmed, and while most agree novel DHIs are likely to benefit their patients, measures and incentives to compensate for the lack of time and resources must be addressed early on to achieve successful implementation. In those situations where a lack of clinical utility is indicated, managers and designers need to consider whether the issue can be addressed before proceeding with implementation.

Future studies focusing on longer-term effectiveness and adherence of DHIs in chronic breathlessness are strongly encouraged, to reduce the current gaps in the knowledge on this topic. This will be achieved by performing different types of studies, both qualitative and quantitative.

Qualitative studies should aim at understanding the longer-term effects of an intervention, particularly on adherence and effectiveness. Adequate data regarding adherence and efficacy of an intervention can only be provided by increasing follow-up times, and ideally also the number of enrolled patients. A changing disease trajectory is likely to affect patient and HCP behaviour, and possible variations in how the intervention is perceived or used should be predicted before large-scale implementation. Future investigations should focus on extending the length of data collection, while trying to minimise patient attrition, and aiming at verifying whether an intervention is both possible to *implement* and *maintain,* together with investigating its benefits for the patient. Such studies should still rely on community-based populations and involve primary care physicians and nurses as far as possible, since gathering information on patient behaviour during their daily routines will

provide more realistic, and hopefully implementable data compared to controlled environments such as clinical trials. Numerous qualitative methodologies exist, such as Narrative Research and Grounded Theory Research, and the strongest advantage of this study design is to allow for flexibility and respond to the dynamics of disease evolution over time, while considering the various factors involved in a patient's response towards the intervention (Cristancho et al, 2018; Renjith et al, 2021).

Simultaneously, more quantitative research is needed to provide stronger 'measurable' results, to address identified issues such as what data should be collected and processed, what types of devices are likely to perform better, and how many patients could benefit from an intervention. These studies are not going to always mirror clinical trials settings, given the community-based nature of the patients, however they should be as structured and reproducible as possible. In this case, it would be appropriate to include a population that is as large and diverse as possible, to ensure generalisability of study results. A main goal of quantitative studies is to test and confirm existing hypotheses, done via a systematic collection and analysis of data. This approach should be considered when trying to obtain a more numerical interpretation of a given issue, for instance the percentage of medical students affected by disruption in their education (Harries et al, 2021). Quantitative studies could focus on the type and usability of any collected data, allowing future researchers to decide which parameters should be collected from patients, to design the most effective DHI. Importantly, both designs should be considered complementary to each other, and not in conflict. It could be appropriate to consider a mixed-method approach in either case, where elements of a qualitative study are integrated in quantitative research, and vice-versa (Moffatt et al, 2006).

Following additional availability of both qualitative and quantitative data, health economic modelling studies should then be performed, to potentially allow the expansion of suitable DHIs from small-scale, and reach levels of implementation at either regional or national scale.

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Appendix A - Summary of results, findings and search strategies

Table 1A. Summary of results

Study name	Population	Design type	Objective of study	Results	WHO classification
Henshall et al 2020	Lung cancer patients (survivors) and carers, plus HCPs (n=27)	1) qualitative focus groups 2) prototype app development and usability study	To identify • exercise interventions that improve symptoms • facilitators and barriers to exercise • behavioural change techniques to inform iEXHALE's development	Patients valued iEXHALE's self-management capabilities, but identified potential modifications including improved self-monitoring diaries and navigation	1.4 Personal health tracking 1.4.2 Self-monitoring of health or diagnostic data by client 1.4.3 Active data capture/documentation by client
Rassouli et al 2018	COPD patients	Observational – pilot study	to measure the feasibility and effects of a	Application provides statistically significant effect above minimum clinically	1.4 Personal health tracking

			digitalized PR program (Kaia COPD) delivered on a smartphone on HRQoL	important threshold of the Chronic Respiratory Disease Questionnaire in various domains (fatigue, mastery, emotional function) but not clinically relevant for dyspnea.	1.4.2 Self monitoring of health or diagnostic data by client 1.4.3 Active data capture/documentation by client
Knox et al 2020	COPD patients	Technology acceptance model / survey, semi-structured focus group	Conceptualise experiences of the usability and acceptability of a self-management app	Ease of use and perceived usefulness as main overarching resulting themes. Authors conclude COPD.Pal app usable and acceptable in people with COPD.	1.4 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client 1.4.3 Active data capture/documentation by client.
Alwashmi et al 2020	HCPs who work with COPD patients, some COPD patients too.	Semi-structured interviews	explore the potential features of an mHealth intervention for COPD management with healthcare providers (HCPs) and patients with COPD	Recommendations from HCPs categorised into patient interface and HCP interface.	Not applicable, no specific intervention described, but a hypothetical one.
Timmerman et al 2017	Non-small lung cancer patients and HCPs	Two-stage mixed methods	Primary: evaluate feasibility of a telehealthcare application when used in clinical	Application use varied according to module, weekly logins and adherence declined over time. Patients	1.4 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client

			practice. Secondary: identify factors for adoption and implementation	indicated perceived benefits by using the app.	1.4.3 Active data capture/documentation by client
Knox et al 2021	COPD and related HCPs	Technology acceptance model / survey, semi-structured focus group	COPD app in question aims to allow people with COPD to track and manage their condition. Study aims to look at barriers and facilitators in implementing intervention.	Users indicated they would use the app long-term, no statistical difference found between time points, for any of the variables measured.	1.4 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client 1.4.3 Active data capture/documentation by client.
Taylor et al 2014	HCPs working with COPD and CHF patients.	Semi-structured interviews	Explore the usage and acceptance of telehealth among frontline staff working in community nursing settings in England	Staff responses towards telehealth (in general) heterogeneous. Flexibility and reliability in technology deemed essential by HCPs, together with encouragement.	N/a as no specific intervention is analysed
Marklund et al 2021	COPD patients	Qualitative study, interviews	Explore and describe the experiences of an eHealth tool over time and factors	Patients' experiences after using the tool divided into three main categories, specifically: ambiguous impact, basic conditions for	1.4 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client

			that might affect usage.	usage and approaching capability. Responses from non/seldom users and regular users differed in terms of motivation and literacy.	1.4.3 Active data capture/documentation by client.
Rubio et al 2017	COPD patients	Observational, semi-structured interviews	Comparing five different breathing monitors	Two monitors deemed of acceptable accuracy compared to standard, some participants found them intrusive during exacerbation. Reduction in breathing rate observed in some, but not all, plus considerable variation observed.	1.4 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client
Tang et al 2017	Lung cancer	Mixed method design, feasibility study	Using tablets for self-reported symptom assessment	Authors find moderate acceptance of the assessment method. Patients indicated approach is user-friendly and helpful in identifying symptoms, plus increase awareness.	1.4 Personal health tracking 1.4.3 Active data capture/documentation by client.
Nyberg et al 2019	COPD, HCPs and their relatives	Controlled pragmatic controlled trial	Evaluate the feasibility of the COPD Web and its study design and study procedures and to increase the understanding of the potential effect of the tool in order	Most of the studied population was still using the app at 3 months, time spent was related to physical activity and exercises. Intervention group reported increased PA, conceptual knowledge and altered disease management	1.4 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client 1.4.3 Active data capture/documentation by client.

			to provide guidance for a future large scale trial.	strategies, compared to control.	
Granger et al 2018	Lung cancer	Prospective case series	Determine feasibility of delivering this intervention for patients undergoing surgery for lung cancer	Most patients commenced program after surgery. No change in physical activity levels or sedentary time pre- or post-operative surgery.	1.4 Personal health Tracking 1.4.2 Self monitoring of health
Simmich et al 2021	COPD	Pilot randomized trial	Evaluate the feasibility of a co-designed mobile game by examining the usage of the game, subjective measures of game engagement, and adherence to wearing activity trackers. The secondary aim of this study is to estimate the effect of the game on daily steps and daily moderate-to-	Participants used the game to record PA. Highest motivation found in the value and usefulness domains. Adhere to wearing Fitbit was high, usage of game positively correlated with changes in daily steps but not moderate-to-vigorous physical activity.	1.4 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client 1.4.3 Active data capture/ documentation by client

			vigorous physical activity (MVPA)		
Obro et al 2020	COPD	Scoping review	Provide a literature-overview and identify any existing gaps in knowledge of mHealth in combination with health-coaching interventions for improving self-management in patients with chronic diseases.	Patients prefer physical interactions to telecommunication. mHealth primarily used to facilitate telecommunication and to monitor disease aspects.	n/a
Voncken-Brewster 2015	COPD	Questionnaire, randomized	Test the effectiveness of a web-based, computer-tailored COPD self-management intervention on physical activity and smoking behavior	No significant treatment effect found on either outcome, application used by only 36% of the participants in experimental group.	1.4 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client
Broese et al 2021	COPD	Systematic review	To describe the characteristics of palliative care interventions for patients with COPD and their informal	Only 20% interventions evaluated in adequately controlled clinical trial. Results on effectiveness mixed and inconclusive. Acceptability of intervention	N/a

			caregivers and review the available evidence on effectiveness and implementation outcomes.	high, support and education on breathlessness valued by users.	
Maguire et al 2014	Lung cancer patients and HCPs	Mixed methods	explore the use of mobile technology in the remote monitoring and reporting of radiotherapy-related toxicity in people with lung cancer	Patients rarely report problems using the handset, authors observed clinical improvements in patient anxiety, drowsiness, self-care and self-efficacy. Important to reduce complexity of the system to promote its utility.	1.4 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client 1.4.3 Active data capture/documentation by client
Van der Weegen et al 2013	50% COPD pats + 16HCPs	Observational, user-centered design process	Report on the user-centered design process in which the user requirements for a monitoring and feedback tool were investigated	Tool generally meets requirements of the end-users. A combination of wearable sensor and app provide amount of activity and goals reached. Practice nurse can see results of all patients on secure webpage and discuss personalised goals with the patients.	1.4 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client 1.4.3 Active data capture/documentation by client
Brown-Johnson et al 2014	8 HCPs, connected to LC pats	Observational, interviews	To test the feasibility and usability of mHealth TLC	Users confirmed mHealth Tool for Lung Cancer to be believable, clinic-appropriate,	1.1Targeted client communication

				helpful in support of informed healthcare consumers. Concerns expressed about emotionally charged content and plans to use mHealth TLC in clinic settings as opposed to home.	1.1.1Transmit health event alerts to specific population groups 1.1.2 Transmit targeted health information to clients based on health status or demographics 1.4 Personal health tracking Self monitoring of health or diagnostic data by client
Chau et al 2010	45 COPD	Mixed, Single-centre randomized trial plus interviews	(1) to examine user satisfaction with the telecare service and (2) to examine the effects of the telecare service on health-related quality of life (HRQL), lung function, and hospital service utilization in older people with COPD	Overall, patients in intervention group expressed satisfaction with telecare service. Difficulties reported in reading screen of mobile phone, using the buttons. No significant differences in pulmonary function and number of emergency department visits and hospital re-admissions found between study groups.	1.1 Targeted client communication 1.1.1 Transmit health event alerts to specific population group(s)

Fitzsimmons et al 2016	23 COPD, 3 HCPs.	Qualitative, interview and questionnaire based.	Explore the experiences of patients with COPD who had received either a Telehealth-supported or a specialist nursing intervention	Seven themes emerged from patient interviews: patient demographics, information received by participants, installation of Telehealth technology, telehealth service functionality, visits, service withdrawal, service perception. Recipients of both services reported feeling safe from delivery of integrated, community-based service.	1.1 Targeted client communication 1.1.1 Transmit health event alerts to specific population group(s) 1.1.2 Transmit targeted health information to client(s) based on health status or demographics 1.4 Personal health Tracking 1.4.2 Self monitoring of health or diagnostic data by client
Lewis et al 2021	14 CRD pats (broader than COPD), 4 HCPs	Mixed-methods, normalization process theory	Provide an evaluation of two web-based platforms for remote pulmonary rehabilitation	Patient pulmonary inclusion made possible with digital support and a PR introduction session improved patient engagement and safety. Progression of exercise	1.1 Targeted client communication 1.1.1 Transmit health event alerts to specific population group(s)

				perceived as more successful online compared with face to face. Education sessions less successful, online-PR required significant staff time resources.	1.1.2 Transmit targeted health information to client(s) based on health status or demographics
Brunton et al 2015	Meta-synthesis, 10 studies included, COPD	Qualitative meta-synthesis	1. Systematically search the literature to identify relevant qualitative studies that explored user experience of telehealth in COPD 2. Conduct a meta-synthesis to identify shared themes in user experience across studies and gain new insights from synthesising the data 3. Discuss how findings can contribute to the design of new or the refinement of existing telehealth technologies and services	Main overarching themes identified: influence on moral dilemmas of help seeking, transforming interactions and reconfiguration of 'work' practices.	N/a

Jiang et al 2022	52 COPD patients and 23 HCPs	Qualitative descriptive study, semi-structured interviews	Explore perceptions and experiences of older patients and healthcare providers, in managing COPD via telehealth.	Four themes and 16 sub-themes identified. Main four: faced with vast amount of online health information, essential competencies and personality traits ensuring older patients' participation and sustained use, user experience with the use of technology, being in a complex social context.	1.1Targeted client communication 1.1.1Transmit health event alerts to specific population groups 1.1.2Transmit targeted health information to clients based on health status or demographics 1.1.3Transmit targeted alerts and reminders to clients 1.1.4Transmit diagnostics result, or availability of result, to clients

Table 2A. Summary of findings

Study name	**Population**	**Design type**	**Objective of study**	**Facilitators to intervention uptake**	**Barriers to intervention uptake**	**Facilitators to implementation adherence**	**Barriers to implementation adherence**	**WHO classification**
Henshall et al 2020	Lung cancer patients (survivors) and carers, plus HCPs	1) qualitative focus groups 2) prototype app development and usability study	To identify • exercise interventions that improve symptoms • facilitators and barriers to exercise • behavioural change techniques to inform iEXHALE's development	Specificity to LC survivors, relative accessibility	Advanced age, end of program, lack of usability, motivation to use app longer term, some users lack specific skills	Improvement seen by patient, interactivity, personal accountability and being provided a routine	Advanced age, app lacks complexity, flexibility, and interactivity	1.4 Personal health tracking 1.4.2 Self-monitoring of health or diagnostic data by client 1.4.3 Active data capture/documentation by client
Rassouli et al 2018	COPD patients	Observational – pilot study	to measure the feasibility and effects of a digitalized PR program (Kaia COPD)	Unclear from data presented – very small and unrepresenta	Unclear from data presented – very small and unrepresentative sample size	Unclear from data presented – very small and unrepresenta	Unclear from data presented – very small and unrepresenta	1.5 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client

			delivered on a smartphone on HRQoL	tive sample size		tive sample size	tive sample size	1.4.3 Active data capture/documentation by client
Knox et al 2021	COPD patients	Technology acceptance model / survey, semi-structured focus group	Conceptualise experiences of the usability and acceptability of a self-management app	Patients reportedly very positive, but few further details available	Patients reportedly very positive, but few further details available	Patients reportedly very positive, but few further details available	Patients reportedly very positive, but few further details available	1.5 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client 1.4.3 Active data capture/documentation by client.
Alwashmi et al 2020	HCPs who work with COPD patients, some COPD patients too.	Semi-structured interviews	explore the potential features of an mHealth intervention for COPD management with healthcare providers (HCPs) and patients with COPD	Current practice needs to be changed, mHealth interventions tend to be more affordable than usual care	Patient needs are very variable and one single intervention may not meet the correct one(s). Lack of access from carer, not tailored to patient's need.	Willingness from some patients to take ownership of disease control, incentive from HCP, rewarding patient/HCP would be bonus if applied	Unwillingness from some patients to take ownership of own illness, not all HCPs have time/resources to implement additional intervention	Not applicable, no specific intervention described, but a hypothetical one.
Timmerman et al 2017	Non-small lung cancer	Two-stage mixed methods	Primary: evaluate feasibility of a	Ease of use, active lifestyle promotion,	Loss of connection and loss of data from	Hypothetical: Next to tailoring, other	Not looked at in current study	1.4 Personal health tracking 1.4.2 Self monitoring of health or

	patients and HCPs		telehealthcare application when used in clinical practice. Secondary: identify factors for adoption and implementation	decreased anxiety, accessibility to specialized HCPs, physiotherapists generally favourable.	HCPs, HCPs do not see usefulness of program and hardly used the data.	motivational strat-egies have been reported by our patients and HCPs that might improve the use and adherence of the RMT service.		diagnostic data by client 1.4.3 Active data capture/documentation by client
Knox et al 2021	COPD and related HCPs	Technology acceptance model / survey, semi-structured focus group	COPD app in question aims to allow people with COPD to track and manage their condition. Study aims to look at barriers and facilitators in implementing intervention.	Ease of app use, flexibility, and app layout.	Patients wouldn't use the app if data not used by HCPs or themselves. Excess of available data could overwhelm patient and negate benefits	Hypothetical: not re-entering personal data each time patient visits doctor, but make it available to HCP via app.	Unclear.	1.5 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client 1.4.3 Active data capture/documentation by client.

Taylor et al 2014	HCPs working with COPD and CHF patients.	Semi-structured interviews	Explore the usage and acceptance of telehealth among frontline staff working in community nursing settings in England	(Selection): Simple referral process, dedicated role to manage implementation, equipment easy to use	(Selection): reservation about new tech, unreliable data, limited customizing options, lack of shared vision and rationale	N/a	N/a	N/a as no specific intervention is analyzed
Marklund et al 2021	COPD patients	Qualitative study, interviews	Explore and describe the experiences of an eHealth tool over time and factors that might affect usage.	Motivation, curiosity about disease information, sense of hope, increase of self-management	Lack of IT knowledge, low self-competence, heterogeneity of patient type.	N/a	N/a	1.5 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client 1.4.3 Active data capture/documentation by client.
Rubio et al 2017	COPD patients	Observational, semi-structured interviews	Comparing five different breathing monitors	Reliable data capture by device, lower intrusiveness compared to standard methods	Intrusiveness, adhesive patches not working, no feedback to patients by device	Data reliable to predict exacerbations in more ill (therefore more sedentary) patients	Heterogeneity among disease trajectories, many patients were advanced disease.	1.5 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client

Tang et al 2017	Lung cancer	Mixed method design, feasibility study	Using tablets for self-reported symptom assessment	Touchscreen interface,	Feasibility study, very low number of patients, perceived lack of competence and reliability	N/a	N/a	1.5 Personal health tracking 1.4.3 Active data capture/documentation by client.
Nyberg et al 2019	COPD, HCPs and their relatives	Controlled pragmatic controlled trial	Evaluate the feasibility of the COPD Web and its study design and study procedures and to increase the understanding of the potential effect of the tool in order to provide guidance for a future large scale trial.	Providing access to patients with COPD seems to effectively increase PA levels	Lack of rigorous inclusion/exclusion criteria, short monitoring of intervention, lack of knowledge and insight in their diagnosis, strenuous transportation and changing health have been identified as barriers for participation in pulmonary rehabilitation	Unclear	Intervention only followed-up for three months, pilot trial, final sample size not known a priori,	1.5 Personal health tracking 1.4.2 Self monitoring of health diagnostic data by client 1.4.3 Active data capture/documentation by client.

Granger et al 2018	Lung cancer	Prospective case series	Determine feasibility of delivering this intervention for patients undergoing surgery for lung cancer	Personal interest in self-managing physical activity	Little time between intervention offer and surgery, feasibility study.	Offer of intervention post-surgery, more time to initiate and develop adherence.	Eight week program too short, unclear if intervention administered as intended.	1.4 Personal health Tracking 1.4.2 Self monitoring of health
Simmich et al 2021	COPD	Pilot randomized trial	Evaluate the feasibility of a co-designed mobile game by examining the usage of the game, subjective measures of game engagement, and adherence to wearing activity trackers. The secondary aim of this study is to estimate the effect of the	High perceived value and usefulness, being involved in initial design stage.	Unclear	Wrist-worn device,	Hip, pocket or lanyard devices were obtrusive and annoying.	1.5 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client 1.4.3 Active data capture/ documentation by client

			game on daily steps and daily moderate-to-vigorous physical activity (MVPA)					
Obro et al 2020	COPD	Scoping review	Provide a literature-overview and identify any existing gaps in knowledge of mHealth in combination with health-coaching interventions for improving self-management in patients with chronic diseases.	"The papers all found that a critical element to developing self-management skills is patient engagement", "health-coaching as a significant method to engage patients"	"lack of training and education of the coaches since only 2 of 9 studies clearly defined specific education of the coaches", "No papers focused on mental illness."	n/a	n/a	n/a
Voncken-Brewster 2015	COPD	Questionnaire, randomized	Test the effectiveness of a web-based, computer-	Initial concern about technology use.	*Possible explanations for the lack of effect may be: (a) low exposure to the intervention, (b)*	N/a	N/a	1.5 Personal health tracking 1.4.2 Self monitoring of health

			tailored COPD self-management intervention on physical activity and smoking behavior		*that the intervention method was not sufficient for our target population, and (c) inadequate content of the intervention itself.*			or diagnostic data by client
Broese et al 2021	COPD	Systematic review	To describe the characteristics of palliative care interventions for patients with COPD and their informal caregivers and review the available evidence on effectiveness and implementation outcomes.	Innovation deemed useful by patients, HCPs encouraged by feedback, knowledgeable staff, timing of assessment if appropriate.	Referrers not aware service existed, unpredictability of COPD trajectory, staff had not enough time, patients couldn't travel to healthcare facility, wrong timing of assessment	Not openly described, but assumed same as uptake.	' *Most frequently named barriers to implementation were uncertainty about the timing of referral due to the unpredictable disease trajectory (referrers), time availability (providers) and accessibility (patients).'*	N/a

Maguire et al 2014	Lung cancer patients and HCPs	Mixed methods	explore the use of mobile technology in the remote monitoring and reporting of radiotherapy-related toxicity in people with lung cancer	real-time reporting of symptoms, the quick clinician response to alerts, and the reassurance that was evoked by the fact that clinicians were able to closely monitor patient symptoms	half of the clinicians were unsure of its clinical utility,	Unclear	Patients' views are opposite to those of HCPs (positive v negative)	1.5 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client 1.4.3 Active data capture/documentation by client
Van der Weegen et al 2013	50% COPD pats + 16HCPs	Observational, user-centered design process	Report on the user-centered design process in which the user requirements for a monitoring and	User-centered design	Usability, lack of agreement on requirements within the app, intrusive device, unpredictable COPD trajectory,	Unclear	Unclear	1.5 Personal health tracking 1.4.2 Self monitoring of health or diagnostic data by client 1.4.3 Active data capture/documentation by client

			feedback tool were investigated					
Brown-Johnson et al 2014	8 HCPs, connected to LC pats	Observational, interviews	To test the feasibility and usability of mHealth TLC	' Users found the avatar and office environment visuals believable within the context of the game and fully engaged with the narrative regardless of technical problems'	'Auditory content distracted players, highlighting the need for investment in high-quality voice and sound recording. Although important, the oncall coaching function had minimal utilization and poor performance'	n/a	n/a	1.1Targeted client communication 1.1.1Transmit health event alerts to specific population groups 1.1.3 Transmit targeted health information to clients based on health status or demographics 1.4 Personal health tracking Self monitoring of health or diagnostic data by client
Chau et al 2010	45 COPD	Mixed, Single-centre randomized trial plus interviews	(1) to examine user satisfaction with the telecare service and (2) to examine the effects of the telecare	Easy access to healthcare provider, better understanding of own's health	Text too small, lack of technological knowledge, uncomfortable device, lack of blood pressure monitor	n/a	n/a	1.1 Targeted client communication 1.1.1 Transmit health event alerts to specific population group(s)

			service on health-related quality of life (HRQL), lung function, and hospital service utilization in older people with COPD					
Fitzsimmons et al 2016	23 COPD, 3 HCPs.	Qualitative, interview and questionnaire based.	Explore the experiences of patients with COPD who had received either a Telehealth-supported or a specialist nursing intervention	Ease of use, perceived usefulness, confidence assistance would be available.	Concerns about technology after using device, issues with troubleshooting, equipment retained for too short period of time,	Ease of use, support from HCPs.	Lack of personal (perceived) competence, technical issues	1.1 Targeted client communication 1.1.1 Transmit health event alerts to specific population group(s) 1.1.2 Transmit targeted health information to client(s) based on health status or demographics 1.4 Personal health Tracking 1.4.2 Self monitoring of health or diagnostic data by client

Lewis et al 2021	14 CRD pats (broader than COPD), 4 HCPs	Mixed-methods, normalization process theory	Provide an evaluation of two web-based platforms for remote pulmonary rehabilitation	Inclusion of severely disabled/unable to travel, low number of agreed people.	No internet access, low confidence, technical issues during implementation phase	More comfortable do perform exercises at home, pace of intervention, no difference from in-person sessions	Significant amount of staff time, lack of personal engagement, self-isolation	1.1 Targeted client communication 1.1.1 Transmit health event alerts to specific population group(s) 1.1.2 Transmit targeted health information to client(s) based on health status or demographics
Brunton et al 2015	Meta-synthesis, 10 studies included, COPD	Qualitative meta-synthesis	1. Systematically search the literature to identify relevant qualitative studies that explored user experience of telehealth in COPD 2. Conduct a meta-synthesis to identify shared themes in	Type of intervention does not hinder adoption, involvement of partners/carers, flexibility, no travel required.	Inherent complexity, not following existing (local) frameworks, ignoring users' opinions during development, set up can be cumbersome	Patients feel supported, possibility of stronger continuity, reassurance, increased contact level.	HCPs generally less favourable than patients, perceived additional risk to patients, lack of personal contact (both patients and HCPs), additional workload for HCPs, may promote	N/a

			user experience across studies and gain new insights from synthesising the data 3. Discuss how findings can contribute to the design of new or the refinement of existing telehealth technologies and services				patient dependency	
Jiang et al 2022	52 COPD patients and 23 HCPs	Qualitative descriptive study, semi-structured interviews	Explore perceptions and experiences of older patients and healthcare providers, in managing COPD via telehealth.	HCP view telehealth as potentially beneficial for chronic patients,	Old age, content available online depicts diseases negatively, misinformation, lack of understanding, inability to read and write	No travel necessary, significantly lower cost, no need to visit hospitals during pandemic.	Scepticism about accuracy of remote diagnosis and follow-ups, lack of personal interaction, possible fraud and	1.1Targeted client communication 1.1.1Transmit health event alerts to specific population groups 1.1.2Transmit targeted health information to clients based on health status or demographics

							information leakage	1.1.3Transmit targeted alerts and reminders to clients 1.1.4Transmit diagnostics result, or availability of result, to clients

Embase and Medline search strategies

Final medline search corrected

Add to FavoritesEmail JumpstartSearch EditSearch Edit

Permanent

1. Dyspnea, Paroxysmal/ or Dyspnea/
2. breathless*.ti,ab,kw.
3. dyspn*.ti,ab,kw.
4. (short* adj3 breath*).ti,ab,kw.
5. dyspnoea.mp.
6. shortness of breath.mp.
7. or/1-6
8. copd.ti,ab,kw.
9. cobd.ti,ab,kw.
10. coad.ti,ab,kw.
11. (chronic$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).ti,ab,kw.
12. exp Pulmonary Disease, Chronic Obstructive/
13. chronic obstructive pulmonary disease.mp.
14. or/8-13
15. exp Lung Neoplasms/
16. exp Carcinoma, Non-Small-Cell Lung/
17. Adenocarcinoma of Lung/
18. (lung* adj3 cancer*).ti,ab,kw.
19. (tumor* adj3 pulmon*).ti,ab,kw.
20. (tumour* adj3 pulmon*).ti,ab,kw.
21. small cell lung cancer.mp. or exp Small Cell Lung Carcinoma/
22. (pulmon* adj3 cancer*).mp. or (living adj3 cancer*).ti,ab,kw. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
23. sclc.mp.
24. nsclc.mp.
25. ((lung or pulmonary) adj3 (oncolog* or malignan* or metasta* or cancer*)).mp.
26. or/15-25
27. exp Telemedicine/
28. eHealth.mp.

29. telehealth.mp.
30. mobile health.ti,ab,kw.
31. mhealth.mp.
32. Remote Consultation/
33. Mobile Applications/
34. ((digital adj (health or tool*)) or devic* or electron* or remot* or computer*).ti.
35. smartphone/
36. cell phone/
37. (app or apps).mp.
38. (android or ios).mp.
39. or/27-38
40. exp Self Care/
41. exp Self-Management/
42. (self* adj3 manag*).mp.
43. self-management.ti,ab,kw.
44. (self* adj3 direct*).ti,ab,kw.
45. exp Pain Management/
46. exp Patient Care Management/
47. or/40-46
48. (barrier* adj3 facilitat*).ti,ab,kw.
49. barrier*.mp.
50. facilitat*.mp.
51. (implement* or feasib* or sustainab* or acceptab* or constraint* or enabler* or usage*).ti,ab,kw.
52. obstacle*.ti,ab,kw.
53. or/48-52
54. 7 or (14 or 26) [dyspnea or COPD or LC]
55. 39 and 47 and 53 and 54 [with self management]
56. 39 and 53 and 54 [without self management]
57. 55 or 56

Final embase without conference abstract

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Permanent

1. exp dyspnea/
2. breathless*.ti,ab,kw.
3. dyspn*.ti,ab,kw.

4. (short* adj3 breath*).ti,ab,kw.
5. dyspnoea.mp.
6. shortness of breath.mp.
7. or/1-6
8. copd.ti,ab,kw.
9. cobd.ti,ab,kw.
10. coad.ti,ab,kw.
11. (chronic$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).ti,ab,kw.
12. exp chronic obstructive lung disease/
13. chronic obstructive pulmonary disease.mp.
14. or/8-13
15. exp lung tumor/
16. exp non small cell lung cancer/
17. lung adenocarcinoma/
18. (lung* adj3 cancer*).ti,ab,kw.
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20. (tumour* adj3 pulmon*).ti,ab,kw.
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37. (app or apps).mp.
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42. (self* adj3 manag*).mp.
43. self-management.ti,ab,kw.
44. (self* adj3 direct*).ti,ab,kw.
45. exp analgesia/
46. exp patient care/
47. or/40-46
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49. barrier*.mp.
50. facilitat*.mp.
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52. obstacle*.ti,ab,kw.
53. or/48-52
54. 7 or 14 or 26 [COPD or LC]
55. 39 and 47 and 53 and 54 [with self management]
56. 39 and 53 and 54 [without self management]
57. 55 or 56
58. limit 57 to conference abstract status
59. 57 not 58

Final search Embase

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Permanent

1. exp dyspnea/
2. breathless*.ti,ab,kw.
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14. or/8-13
15. exp lung tumor/
16. exp non small cell lung cancer/
17. lung adenocarcinoma/
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19. (tumor* adj3 pulmon*).ti,ab,kw.
20. (tumour* adj3 pulmon*).ti,ab,kw.
21. small cell lung cancer.mp. or exp small cell lung cancer/
22. (pulmon* adj3 cancer*).mp. or (living adj3 cancer*).ti,ab,kw.
23. sclc.mp.
24. nsclc.mp.
25. ((lung or pulmonary) adj3 (oncolog* or malignan* or metasta* or cancer*)).mp.
26. or/15-25
27. exp telemedicine/
28. eHealth.mp.
29. exp teleconsultation/
30. exp mobile application/
31. ((digital adj (health or tool*)) or devic* or electron* or remot* or computer*).ti.
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33. mobile health.ti,ab,kw.
34. mhealth.mp.
35. smartphone/
36. mobile phone/
37. (app or apps).mp.
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40. exp self care/
41. self-management.mp.
42. (self* adj3 manag*).mp.
43. self-management.ti,ab,kw.
44. (self* adj3 direct*).ti,ab,kw.
45. exp analgesia/
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47. or/40-46
48. (barrier* adj3 facilitat*).ti,ab,kw.
49. barrier*.mp.
50. facilitat*.mp.
51. (implement* or feasib* or sustainab* or acceptab* or constraint* or enabler* or usage*).ti,ab,kw.

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53. or/48-52
54. 7 or 14 or 26 [COPD or LC]
55. 39 and 47 and 53 and 54 [with self management]
56. 39 and 53 and 54 [without self management]
57. 55 or 56

Medline final

Add to FavoritesEmail JumpstartSearch EditSearch Edit

Permanent

1. Dyspnea, Paroxysmal/ or Dyspnea/
2. breathless*.ti,ab,kw.
3. dyspn*.ti,ab,kw.
4. (short* adj3 breath*).ti,ab,kw.
5. dyspnoea.mp.
6. shortness of breath.mp.
7. or/1-6
8. copd.ti,ab,kw.
9. cobd.ti,ab,kw.
10. coad.ti,ab,kw.
11. (chronic$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).ti,ab,kw.
12. exp Pulmonary Disease, Chronic Obstructive/
13. chronic obstructive pulmonary disease.mp.
14. or/8-13
15. exp Lung Neoplasms/
16. exp Carcinoma, Non-Small-Cell Lung/
17. Adenocarcinoma of Lung/
18. (lung* adj3 cancer*).ti,ab,kw.
19. (tumor* adj3 pulmon*).ti,ab,kw.
20. (tumour* adj3 pulmon*).ti,ab,kw.
21. small cell lung cancer.mp. or exp Small Cell Lung Carcinoma/
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53. or/48-52
54. 14 or 26 [COPD or LC]
55. 39 and 47 and 53 and 54 [with self management]
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57. 55 or 56
58. ("33375573" or "33741232").ui.
59. 57 and 58

Appendix B – PARIHS extraction tables

Table 1B. Characteristics of the innovation

Study	**Affected population**	**Reported perceived advantage/feedback from population**	**Overall summary**
Henshall et al 2020	Lung cancer patients (survivors) and carers, plus HCPs	Previous publications highlight benefits of self-management, they want to test if app usable	Users generally satisfied but app lacks complexity, flexibility, and interactivity
Rassouli et al 2018	COPD patients	Pulmonary rehab has positive effect on disease progression and mortality. Novel digital therapies previously found useful	Unclear from data what people think about this intervention, but pulm rehab remains underused in clinical routine.
Knox et al 2021	COPD patients	Healthcare apps are ubiquitous but rarely developed together with end users. Feasibility study to verify usability of COPD.pal app	Feasibility study, participants reportedly extremely positive about the app and TAM useful model to conceptualize how people discussed app.
Alwashmi et al 2020	HCPs who work with COPD patients, some COPD patients too.	HCPs see this mobile phone intervention as valuable, as mHealth to manage COPD relatively unexplored.	Getting perspective of HCPs and patients should help understand what's needed to implement mHealth interventions.
Timmerman et al 2017	Non-small lung cancer patients and HCPs	Acceptability and clinical safety of an intervention must be evaluated together with its context for successful adoption and use in everyday care.	Pats generally positive, but rated intervention low on usefulness. HCPs more positive and stated willingness to keep using the module.

Knox et al 2021	COPD and related HCPs	COPD pats are extensive NHS users but spend less than 1% of their time with HCPs. Is an app safe and do COPD pats engage?	Pilot study, conclusions not strong. App does not increase self-management knowledge and 61% pats found app useful. Patients generally willing to use app, but feedback must be improved.
Taylor et al 2014	COPD and CHF patients	The role of frontline staff acceptance features in these studies, but rarely central focus of research. New tech necessary but current situation overwhelming	No perceived advantage reported, more research needed. Other settings are seen at higher priority, difficult to gauge level of interest through this study.
Marklund et al 2021	COPD patients	Previous studies report self-management techniques help reduce negative consequences of the disease.	eHealth tools promising way to delivering health services. Few patients offered them. Users generally positive about IT tools on the COPD web. The view on information can influence whether to use an eHealth tool or not. Technical knowledge/support also necessary and potentially dealbreaker.
Rubio et al 2017	COPD	Breathing rate measures usually intrusive, home monitoring could help but unclear if existing devices that work well in fit people will function in breathless COPD.	Overall feedback was uneven, patients found it hard to speculate about self- or nurse-led monitoring of their breathing.

Tang et al 2017	Lung cancer	Lack of effective approaches to assess symptoms in clinical settings. Increasing use of electronic personal health records has been argued to be physician oriented. Explore patients' experiences of using self-assessment method	Overall, unclear from results what patients think of this intervention, but overall pats found reporting their symptoms positive. Authors report touchscreen better received than pen and paper. Maybe better for older people as they commonly find it difficult to use a mouse and hesitant to use a desktop pc. Perceived barriers: lack of competence and reliability
Nyberg et al 2019	COPD, HCPs and their relatives	Pilot trial to evaluate feasibility of COPD web before proceeding with larger trial	Pilot findings indicate access to this intervention seems to be an effective short term strategy to increase levels of PA and knowledge. Issues with lack of rigorous incl/excl criteria, short follow-up time and lack of randomization.
Granger et al 2018	Lung cancer	Less work focused on unsupervised/home-based interventions and those targeting overall physical activity levels. Program based on the international cancer phys activity guidelines, encourages self-mgmt and behavioural change techniques, low resource intensive.	Program was feasible in the post op setting but not pre-op. Participants did not have time to receive intervention pre-op. No data on cost-effectiveness. Unlikely offering this to all patients routinely is a good use of resources.

Simmich et al 2021	COPD	Gamification is an emerging strategy to improve engagement with digital technology, including within the context of healthcare. Previous knowledge indicates games incentivize people to move more.	Limited results, very small sample size. App is potentially useful but conclusions not firm. Usage of game moderate, patients reported moderate shortness of breath.
Obro et al 2020	COPD (50% of total population)	Scoping review conducted to systematically map the research, as well as to identify any existing gap in the knowledge	Lack of training and education of the coaches for mHealth interventions. Only 2 of 9 studies defined specific education of the coaches. Difficult to understand meaning of 'coaching'. Unclarity in coaching terminology, no papers focused on mental illness. Human contact should be prioritized in future research.
Voncken-Brewster 2015	COPD	Computer-tailored interventions known to be successful, but self-management not yet tested on supporting behaviour change in COPD	Section is rather incomplete from study, difficult to extract summary. While a trial, it is noted that 'not all the results are listed as reliable'.
Broese et al 2021	COPD	In previous SRs, most interventions designed for patients with cancer or focused on single intervention component. Results on effectiveness from multiple components still lacking.	Study found little high-quality evidence available on the effectiveness and implementation of palliative care interventions in COPD-care

Maguire et al 2014	Lung cancer	Promotion of self-care can give people with cancer greater confidence and sense of control, and enhance perceived well-being and quality of life	Lack of interventions that explore use of real-time technologies in the patient population; pats with LC perceived the intervention as positive, however very small sample size and low confidence in results. Physicians disagree with patients, half of HCPs couldn't see clinical utility.
Van der Weegen 2013	50% COPD pats + 16HCPs	"Professionals can be more successful at improving an active lifestyle by increasing patients' awareness through self-monitoring, goal setting, and discussing self-efficacy."	(Previous) "Self-reporting studies revealed that the use of pedometers is an effective approach to increase physical activity. It is however still unknown to what extent the observed changes are sustainable or whether it is possible to continue to accumulate benefits as a result of long-term adherence."
Brown-Johnson et al 2014	8 HCPs, connected to LC pats	mHealth TLC provides coached patient-provider communication techniques, opportunities for practiced stigma resistance, pat-specific health information	Eight users found it potentially useful for LC pats. Conclusions are: few testers, auditory content distracted players, elements of the game did not function properly. Health game overall allows individuals to experience first person virtual visits with clinician.
Chau et al 2010	45 COPD	Aging population, telecare may improve patients' self care and management of chronic illnesses	Feasibility study, unclear what people think about intervention. Single centre, limited by short duration of implementation

Fitzsimmons et al 2016	23 COPD, 3 HCPs.	How issues are addressed is still missing from the evaluation of Telehealth interventions	Intervention designed to assist pats to mng illness aiming to decrease readmission rates, with minimal increase in resources. Conclusions report patients overall satisfied and intervention acceptable alternative to traditional home nursing.
Lewis et al 2021	14 CRD pats (broader than COPD), 4 HCPs	Evidence suggests that providing home PR is feasible and comparably effective to face-to-face delivery when performed as part of a randomised controlled trial (RCT)	Pats found the evaluation acceptable, HCPs adapted their workloads and normalized the online delivery as part of ongoing service provision. Trials needed to improve online education delivery (elearning module)
Brunton et al 2015	Meta-synthesis, 10 studies included, COPD	Evaluations of telehealth do not routinely follow MRC framework for complex interventions, early phases (theoretical work and modelling how the intervention works). Users' voice is often ignored, but users need to be involved in all processes of technology and service development	Future studies need to include potential users at an earlier stage of telehealth/service development.
Jiang et al 2022	Qualitative descriptive study, semi-structured interviews	Rapid ageing of population, chronic disease management in older people becoming more challenging. Health inequality increasing, need point view of both patient and HCP. HCPs may want to introduce changes to reduce travel requirement for older people.	Telehealth appears advantageous, but lack of personal contact and traditional Chinese medicine techniques seen as limitations to diagnosis. Role of speech needs to be reinforced.

Table 2B. People's motivation

Study	**Need to change practice/see difference/support from leaders**	**(Teams) Need to change practice/see difference/support from leaders**	**Overall summary**
Henshall et al 2020	Not reported/Mixed but mostly positive/not reported	No apps aimed at lung cancer survivors/Not reported/Not reported	Mostly positive view but no conclusive data
Rassouli et al 2018	All three not reported	Not focus on all three	No data
Knox et al 2021	Not reported/Mostly, some details not reported/Not reported	Not reported on all three	No data
Alwashmi et al 2020	Yes/They see benefit of testing blood oxygen levels daily/Can't tell	Yes/They see benefit of pats taking ownership of checking blood oxygen levels/Among interviewed HCPs, no. Some see benefit of self-testing, to alleviate repeat hospital tests. Others concerned about technique used by pats	Patients enthusiastic, HCPs less so and worried about quality of results.
Timmerman et al 2017	Not clear/Yes, in general they find the intervention useful/Not clear	Not clear/Yes but concerned that a low level of adoption by referring physicians may hamper successful implementation/Unclear	Both positive, but HCPs concerned about possible low adoption levels
Knox et al 2021	Not reported/Mixed reports, authors received negative	Not reported on all three	Not enough data, coupled with tech issues.

	feedback and experienced technical issues/Not reported		
Taylor et al 2014	Not focus on all three	Yes/Mixed results, some scepticism due to current overload/Not reported	Existing overload among HCPs seems to be main issue, despite general optimism.
Marklund et al 2021	Not reported/Prior to administration not reported. Afterwards, mixed. Opinions are worse as IT literacy decreases. More confident patients reported more positive feedback/Not reported	Authors report that despite evidence, mHealth interventions severely underused/Not reported/Not reported	IT capabilities influence optimism towards intervention (the lower, the worse it gets); evidence favours mHealth interventions but still underused.
Rubio et al 2017	Possibly but not openly stated/Not reported/Not reported	Yes, intrusiveness of breathing rate measures/BR changes may be useful in identifying exacerbations at an early stage/Not reported	HCPs see a possible improvement given invasiveness of current breathing rate measurements
Tang et al 2017	Not reported/Prior to intervention, not reported. Following intervention yes (More aware about their symptoms)/Not reported	Authors see current monitoring methods as only physician-oriented/Enhance symptom assessment by including patients more/Not reported	Following intervention, pats more positive as aware of their symptoms. Unclear about HCPs (opinions more from the authors).
Nyberg et al 2019	Not reported on all three	Yes, only a limited proportion of patients with COPD get access to self-mgmt services/Lack of pt knowledge, transport issues, changing health are barriers for participation in pulmonary rehab, reducing support for self-	HCPs see benefit of intervention but lack of access major issue against self-mgmt strategies

		mgmt strategies/Not directly reported	
Granger et al 2018	Pats indicate that without professional support, they have difficulty exercising and changing their physical activity behaviour, which can be worsened by fear of exercise and symptom burden/Not reported/Not reported	Indicate presence of barriers in healthcare systems, towards PA, which is beneficial for lung cancer patients/Consent rate from patients indicate they would be interested in the intervention, and are able to participate when the intervention is delivered in the post-surgical setting/Not reported	Pats report issues in exercising without professional support, HCPs confirm presence of barriers in healthcare systems, despite interest shown by pats towards intervention delivered in post-surgical setting.
Simmich et al 2021	Not reported on all three	Not reported/Generally yes, but as a pilot study data not sufficient to draw conclusions/Not reported	Pilot study insufficient to draw conclusions
Obro et al 2020	Not reported on all three	Not reported on all three	No data
Voncken-Brewster 2015	Cannot tell on all three	Yes, personalizing health messages deemed useful in disease mgmt./Strategy likely more cost-effective than usual care/Can't tell	HCPs favour personalizing health messages as this could be more cost-effective than current care
Broese et al 2021	Yes, not specific to intervention but in general non-pharma measures are seen as positive in breathlessness/Not reported/Not reported	Yes, little known about COPD intervention, previous lit. indicates self-mgmt intervention are associated with QoL improvement/If statistically significant/Not reported	Pats would appreciate non-pharma intervention in breathlessness. HCPs would be ok if difference statistically significant

Maguire et al 2014	Not clear/Generally yes/Not reported	Generally yes/They think patients can increase control of their own disease/Appears to be	Pats see how intervention could make a difference. HCPs agree pats can increase control of their own disease
Van der Weegen 2013	Not clear/Seems not. There is considerable negative feedback/Not clear	Not clear/According to feedback, intervention not universally accepted/Not clear	Negative feedback from both pats and HCPs.
Brown-Johnson et al 2014	Not reported on all three	Play promotes motivation through the incorporation of voluntary engagement and pleasure and is a means of stress management/'If older people perceive enough personal utility, they are eager to participate in new digital technology/Not reported	HCPs agree play promotes motivation through voluntary engagement, older people need to perceive utility to participate in digital health tech.
Chau et al 2010	Not initially, but some feedback positive after trying intervention/Mixed, mostly positive but not all patients see a benefit or have issues with the technology/Can't tell	Not reported on all	Some patients see benefit after trying intervention but opinion not universal
Fitzsimmons et al 2016	Patients initially concerned about use of technology. After use, most patients positively received the intervention/No, it would be a significant change/Can't tell	HCPs are worried patients are too old and frightened by technology/Not reported/Not reported	Both patients and HCPs underwhelmed, HCPs concerned about age of patients and lack of tech familiarity
Lewis et al 2021	Patients unlikely to be familiar with IT/Not reported/Not reported	Unclear	Data insufficient to draw conclusions

Brunton et al 2015	N/a	From SR extract, users' voices often ignored in the process of such technology development	Unclear to draw conclusions
Jiang et al 2022	Not reported on all	HCPs may want to introduce interventions to reduce travel requirements and costs for older people/Unclear/Unclear	HCPs see a potential benefit in making it easier for older people to access intervention.

Table 3B. People's ability to change

Study	**Do people have the skills?/Understand how to change their routine?/Have the authority to carry out changes?**	**(Teams) Do people have the skills?/Understand how to change their routine?/Have the authority to carry out changes?/Resources available to support implementation?**	**Overall summary**
Henshall et al 2020	Mixed, some users happy but others found app too simplistic/Mixed, some pats do not use app or change routine/Not reported	Very few responses from HCPs, unclear/Unclear/Unclear	Mixed, but overall negative as app perceived simplistic or lack of change in routine. Not enough data from HCPs.
Rassouli et al 2018	Unclear on all	Not reported on all	N/a
Knox et al 2021	Mostly/Not focus/Not reported	Not reported on all	Patients mostly have skills to change but not enough data
Alwashmi et al 2020	Not all/Mixed/Can't tell	Not reported on all	Some pats able to change but overall no conclusive data
Timmerman et al 2017	Mixed, but generally yes. Issue is convenience sample favoured ppl interested in the intervention and with sufficient IT skills/Generally yes, they also reported issues/Not clear	Yes/Yes with reservations/Not clear/Not clear	People generally able to change, but convenience sample introduced bias towards interested pats with right skills.
Knox et al 2021	Unclear if asked or tested/Unclear/Not reported	Not reported on all	N/a
Taylor et al 2014	Not reported	Not reported	N/a

Marklund et al 2021	Most do not, low levels of literacy, high guilt and shame/Only some/Not reported	Not reported on all	Patients improved slightly after three months, but overall people unable to change due to important barriers such as illiteracy, shame, guilt, stress.
Rubio et al 2017	Unclear but pats report degrees of acceptability (few details provided)/Unclear/Not reported	Not reported on all	N/a
Tang et al 2017	Prior to study most do not/After delivery most thought intervention was clear/Not reported	Not reported	Administering intervention removed initial barriers and pats more satisfied
Nyberg et al 2019	Yes but unclear about skills/Unclear/Not reported	Not reported	Pats possibly able to change but overall unclear.
Granger et al 2018	Unclear/Mixed results, numerous patients (around 50%) didn't wear device	Not clear	Pats are maybe able to understand routine, but overall results unclear due to high attrition
Simmich et al 2021	Not reported	Not reported	N/a
Obro et al 2020	Not reported	Not reported	N/a
Voncken-Brewster 2015	Not focus/Inconclusive/Can't tell	Unclear on all	N/a
Broese et al 2021	Data very heterogenous, some features helpful/Mixed results/Not reported	Not enough data/Not reported	Heterogeneous data but overall inconclusive
Maguire et al 2014	Mostly yes, some minor issues reported/Mostly/Not reported	Yes/HCPs not sure about clinical utility, have reservations regarding time needed to implement and run the intervention/Not reported/Not reported	Pats mostly positive but HCPs skeptical about clinical utility and time needed to run intervention
Van der Weegen 2013	Not always/Not always/Not clear	Mostly/mostly but not unanimously/Not clear/Not clear	Mixed results, no unanimity on both pat and HCP side.

Brown-Johnson et al 2014	Not reported on all	Unclear	N/a
Chau et al 2010	Mixed, aging population, encountered numerous difficulties with technology and found sensors intrusive/Mixed not all/Not reported	Not reported on all	Mixed pat feedback, intrusive sensors and issues with tech due to age.
Fitzsimmons et al 2016	Not initially, but yes after training/Yes/Can't tell	Yes/Not reported/Not reported/Not reported	Pat ability improved after training
Lewis et al 2021	Overall not enough data	Not enough data	N/a
Brunton et al 2015	N/a	N/a	N/a
Jiang et al 2022	Appears to be limited, older generation and some are illiterate/Not clear/Not clear but depends on how independent	Unclear	Older generation generally unable to make important changes, study very small.

Table 4B. Inner context

Study	Do formal and informal leaders support implementation/Work culture support change/People's recent experiences of change	What is in place to support learning and evaluation?	Overall summary
Henshall et al 2020	Not reported	Not reported	N/a
Rassouli et al 2018	Not focus	Not focus	N/a
Knox et al 2021	Not focus	Not focus	N/a
Alwashmi et al 2020	Can't tell	Can't tell	N/a
Timmerman et al 2017	Unclear	Unclear	N/a
Knox et al 2021	Not reported	Not reported	N/a
Taylor et al 2014	Not reported	Not reported	N/a
Marklund et al 2021	Not reported	Not reported	N/a
Rubio et al 2017	Not reported	Not reported	N/a
Tang et al 2017	Not reported	Not reported	N/a
Nyberg et al 2019	Possibly, but not explicitly stated/Not reported/Mixed results, previous studies showed either a positive or null effect of similar interventions	Not reported	Unclear but overall implementation appears to be supported. Previous studies showed null or positive effect and thus not deleterious. Overall results not very solid.
Granger et al 2018	Not reported	Not reported	N/a
Simmich et al 2021	Not reported	Not reported	N/a
Obro et al 2020	Not reported/applicable to study	Not reported/applicable to study	N/a
Voncken-Brewster 2015	Not reported	Not reported	N/a
Broese et al 2021	Mixed. Not enough time on behalf of staff, but knowledgeable people	Lack of continuous resourcing was a barrier to implementation	Lack of time on HCPs' behalf and lack of continuous resourcing are problematic

	contribute to smooth implementation of the innovation/Not reported/Not reported		
Maguire et al 2014	Not reported	Not reported	N/a
Van der Weegen 2013	Not clear	Not clear	N/a
Brown-Johnson et al 2014	Not clear	Not clear	N/a
Chau et al 2010	Not reported	Not reported	N/a
Fitzsimmons et al 2016	Not reported	Not reported	N/a
Lewis et al 2021	Not reported	Not reported	N/a
Brunton et al 2015	Not applicable (SR)	N/a	N/a
Jiang et al 2022	Unclear	Unclear	Unclear

Table 5B. Outer context

Study	**Do proposed changes align with strategic priorities of the health system?/Does health system provide incentives to support change?**	**Are there inter-organizational networks that support the change?**	**Overall summary**
Henshall et al 2020	Not reported	Not reported	N/a
Rassouli et al 2018	Not focus	Not focus	N/a
Knox et al 2021	Not reported	Not reported	N/a
Alwashmi et al 2020	Can't tell	Can't tell	N/a
Timmerman et al 2017	Unclear	Unclear	Unclear
Knox et al 2021	Trend towards telecare, but no further details/Not reported	Not reported	Trend towards telecare but not solid data
Taylor et al 2014	Unclear	Unclear	Unclear
Marklund et al 2021	Not reported	Not reported	N/a
Rubio et al 2017	Not reported	Not reported	N/a
Tang et al 2017	Not reported	Not reported	N/a
Nyberg et al 2019	Yes/Unclear	Unclear	Proposed changes align with health system
Granger et al 2018	Not reported	Not reported	N/a
Simmich et al 2021	Not reported	Not reported	N/a
Obro et al 2020	PARIHS does not seem applicable	N/a	N/a
Voncken-Brewster 2015	Yes/Can't tell	Can't tell	Proposed changes align with health system
Broese et al 2021	Not reported/Lack of continuous resourcing barrier to implementation	Not reported	Lack of continuous support key issue

Maguire et al 2014	Yes/Not reported	Not reported	Proposed changes align with UK health system
Van der Weegen 2013	Unclear	Unclear	N/a
Brown-Johnson et al 2014	Not clear	Not clear	N/a
Chau et al 2010	Not reported	Not reported	N/a
Fitzsimmons et al 2016	Yes/Not reported	Not reported	Proposed changes align with NHS
Lewis et al 2021	Unclear/Push for IT-based self-management ongoing but uptake slower than expected	Unclear	Intention to increase self-management interventions exists but uptake slow.
Brunton et al 2015	N/a	N/a	N/a
Jiang et al 2022	It appears China pursuing expansion of telehealth service but can't be fully ascertained from the text.	Not reported	China appears to promote telehealth, but unclear from study and references.

Appendix C – Example of data extraction form

File name	100422 AR Jiang et al
Title of study	Patients' and healthcare providers' perceptions and experiences of telehealth use and online health information use in chronic disease management for older patients with chronic obstructive pulmonary disease: a qualitative study
Study type	Qualitative descriptive study
Authors (year/ study type)	Jiang et al, 2022. Semi-structured interviews.
Quality appraisal	Summary of the quality appraisal for each study. In particular, identify any *significant* study weaknesses – and state to which aspect of the study these apply to. QUALITATIVE APPRAISAL Are there clear research questions? Yes Do the collected data allow to address the research questions? Can't tell. Is the qualitative approach appropriate to answer the research question? Y Are the qualitative data collection methods adequate to address the research question? N Is there coherence between qualitative data sources, collection, analysis and interpretation. N – I think the methods do not provide all the information needed to ascertain whether the results are solid. The questionnaire was not validated and it is hard to tell how people were recruited.
Programme description	'Patients recruited from local hospitals and healthcare teams delivering pulmonary rehab through Pulmonary Internet Explorer Rehabilitation' HCPs recruited from local hospitals. Purpose is to explore perceptions and experiences of older patients and HCPs in the application of telehealth and online health information for CDM and COPD. Patients from local hospitals and attended only routine follow-up visits for COPD: regular group Pats who participated in pulmonary rehabilitation through PeR: PeR group

	Pulmonary rehabilitation delivered face to face: FtF group. The same classification applies for HCPs.
Year(s) delivered	Unclear
Description of location(s) where delivered	Unclear, China.
Research methods	
Theoretical approach	Theoretical approach of research methodology i.e. Social Constructionist Grounded Theory (not interventions theoretical approach)
Sample	purposive sampling method
Participants	54 eligible participants (31 patients and 23 HCPs). 52 accepted (29 COPD patients, aged 60 and above, 23 HCPs).
Data collection	Self-designed questionnaires 'Separate interview guides developed for older patients with COPD and HCPs, piloted among two patients and two HCPs' 'First author teacher with experience in qualitative research and quantitative research' 'Second author is a postgraduate student majoring in geriatric nursing' 'No third person was present during the interviews' 'Participant recruitment, data collection and data analysis were carried out simultaneously' 'Interviews lated approximately 30 mins'
Analysis	Inductive thematic analysis

Time of follow-up	Unclear
Key points following PARIHS criteria	
2. Characteristics of the innovation	□ _Who is likely to be affected by the proposed innovation? COPD patients and their HCPs □ _What is the underlying evidence for the proposed innovation or change? Rapid ageing of population, chronic disease mgmt. in older people becoming more challenging, unequal distribution of health resources and cost issues exacerbate problem. Need to have more studies on older patients AND HCPs perspectives, not just single perspective from user's point of view.
2. The recipients of the evidence/innovation	**Think about the people who you want to implement the change and how they are likely to respond - both at an individual level and as a member of a clinical or service delivery team. Reflect on whether they want to introduce the innovation and if they are able to implement the required changes.** HCPs may want to introduce interventions to reduce travel requirements/costs for older people, especially if chronically sick, far away or during a pandemic. Implementing the required changes might be challenging, especially given the high average age and relatively low literacy of the target population.
3 – The inner context	**Think about the characteristics of the context in which the innovation is to be implemented – both the immediate local context in which the recipients are working and the wider organizational context in which their unit or department operates.**
	Unclear from the study what the current status of the department is.

4 - The outer context	**Consider what is happening in the wider health system that might affect the inner context. Whilst it may not be possible to directly influence the outer context, it is important to be aware of how the outer context might impact upon local implementation - and whether this creates opportunities from which the project might be able to gain leverage.**
	From the study, it appears that China is also pursuing an expansion of telehealth services, however this cannot be fully ascertained from the text, as the authors rely on external references to provide background.
Conclusions	The ability of patients to understand health information should be fully considered while facilitating access to online health information for older patients. The role of health responsibility and user experience in older people's participation and sustained use of telehealth and online health information needs to be emphasized. In addition, the complex social context is a determining factor to be considered, particularly the complex impact of a reliance on offspring and social prejudice on the behaviour of older adults using telehealth and online health information.
Author(s)' explanation of findings	'This study showed that there were a number of advantages to telehealth. However, the lack of inspection, palpation, percussion and auscultation, of the "four measures of TCM diagnosis", made patients and HCPs sceptical of the accuratcy of a telehealth diagnosis.During telehealth intercations, the lack of nonverbal emotional support made patients and HCPs feel distant. Therefore, both the telehealth service style and tele-technology need to be optimised.' 'The findings in this study suggested that in persuading and guiding people's participation in telehealth intervetions and online health information, a number of key elements reinforced the role of speech, such as the matching of voice and intonation and the use of rhetorical devices.' *Limitations* (Very few listed by authors) 'Sample only included COPD pats and HCPs' AR notes: The manuscript seems to somewhat lose focus in terms of the data collected and their conclusions. Some of the verbatim reports do not appear relevant to the original question, however not all. Small sample size, questionnaire not validated and trialled only on four total people. Is the population representative? Unclear where the study took place, how people were selected, how long after intervention the interview took place, I assume interview was taken at one point in time without follow-up.
Additional information	A space for adding information relevant to the DEX i.e. material excluded

Summary of intervention impact	- Participants reported that older patients' understanding of the health information available to them influenced their health behaviours - Some of the patients unable to read or write, hard for them to communicate with HCPs through mobile phone; most videos are in Mandarin and such people speak local dialect and don't understand Mandarin. - Lack of confidence, unable to memorize instructions long-term, busy baby-sitting and/or cooking - Lack of psychological comfort through remote sessions Some advantages were identified, however overall relationship felt distant. Hybrid online and offline healthcare services can meet different patients' needs. Study found both older people and HCPs are dependent on the offspring of older patients, something relevant to Chinese culture (taken for granted children must look after parents). Cultural characteristics should be considered when telehealth CDM or eHealth literacy interventions are developed. Study suggested overreliance on offspring hindered olders patients from practicing telehealth. When telehealth conducted, necessary to assess degree of reliance of older paitnets on their offspring and help with implementation of individualized interventions. There is a greater need for greater regulation by the relevant national authorities.
WHO classification	1.1 Targeted client communication 1.1.1 Transmit health event alerts to specific population groups 1.1.2 Transmit targeted health information to clients based on health status or demographics 1.1.3 Transmit targeted alerts and reminders to clients 1.1.4 Transmit diagnostics result, or availability of result, to clients