

Towards what really matters for people with chronic conditions:

Design of a self-management support
guide from the patient perspective

Eline te Braake

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Towards what really matters for people with chronic conditions:

Design of a self-management support guide
from the patient perspective

DISSERTATION

to obtain
the degree of doctor at the University of Twente,
on the authority of the rector magnificus,
prof. dr. ir. A. Veldkamp,
on account of the decision of the Doctorate Board,
To be publicly defended
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by

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Chapter 1: General Introduction



Chronic Conditions

The prevalence of people with chronic conditions is steadily increasing, with chronic conditions being among the leading causes of disability and mortality worldwide (Hacker, 2024). Living with a chronic condition such as Chronic Obstructive Pulmonary Disease (COPD) (a heterogeneous lung condition characterised by chronic respiratory symptoms that cause persistent, often progressive, airflow obstruction (GOLD, 2025)) or Rheumatic and Musculoskeletal diseases (RMDs) (a wide range of degenerative, inflammatory, and autoimmune conditions that commonly affect the joints (Van Der Heijde et al., 2018)) impacts multiple aspects of one's life and poses an extreme burden on patients. These include, for example, managing symptoms, medication, appointments with Healthcare Professionals (HCPs), fatigue, loss of autonomous life, and the need to adjust to new limitations (Barakou et al., 2025; Hajat & Stein, 2018; Tumilty et al., 2020; Van Wilder et al., 2021).

The number of patients and healthcare costs are increasing, while facing a scarcity of HCPs, resulting in extremely long waiting lists and limited time for HCPs to treat patients (Abdullah Altassan et al., 2024; Polanco et al., 2025; Salisbury et al., 2023). To meet the increasing demands for healthcare now and in the future, current practices must evolve and adapt to a sustainable model that satisfies both individuals with chronic conditions and the healthcare system as a whole. Currently, most healthcare systems are designed to have a reactive model of care. This form of medical care addresses health symptoms after they have manifested and thus mainly focuses on treating symptoms and disease (Grant, 2024).

A more proactive model of care takes into account potential risk factors and lifestyle factors of a person's health and focuses on disease prevention, early detection, patient engagement, chronic disease management, and mental health (Grant, 2024; Talukder et al., 2020). For example, the proactive integrated care system in the study of Koff et al., (2009) consisted of remote home monitoring (e.g., on changes in symptoms), daily disease-specific education (e.g., medications and their use, oxygen therapy, and breathing techniques), teaching self-management skills at enrolment (e.g., use of an oximeter, increasing awareness of clinical changes, and appropriate calls to physician offices), and enhanced communication with study coordinators. This proactive model of care significantly improved the quality of life of people with COPD and had positive effects on healthcare costs (Koff et al., 2009). However, to achieve this paradigm shift from reactive to proactive care, it is essential that people with chronic conditions are

empowered to become active partners in their patient journey and supported to engage in self-management.

Self-Management

Self-management can be described as the tasks (e.g., role management, medical management) or skills (e.g., problem solving, decision making, action planning) one needs to perform to manage one's health (Lorig & Holman, 2003). Current literature varies widely in its definitions of self-management (Newham et al., (2017). For example, Harrison et al., (2015) defined self-management in the context of COPD as an action plan involving symptom monitoring, medical management, and education. Others mention that self-management requires an iterative interaction process between the participants and HCPs (Zwerink et al., 2014). However, we argue that self-management is more than an action plan, task, skill, or interaction process, given that it is broader than the medical context alone. Therefore, in this thesis, we define self-management as:

'The ability of an individual to manage one's symptoms, treatment, physical, social, and emotional consequences, and lifestyle changes. It includes means of empowerment, educating oneself, being autonomous, learning and adapting to new behaviours, acceptance, and adapting to a new balance in life' (te Braake, Vaseur, et al., 2025)

Self-management emphasizes a person's active role in their healthcare process and empowers people to become in charge of their own health (Auduly et al., 2010). Self-management support may help a person in the process of becoming an active participant. This support entails the support from a healthcare practitioner and healthcare system to better manage or improve health outcomes (Jones et al., 2011). In this thesis, we consider that self-management support should not only be limited to support within the healthcare context, as self-management also applies outside that context. Therefore, we extended the definition of self-management support specifically by stating that it also entails support from one's own environment or peers, or the support found from one's own efforts and search strategy (e.g., finding information on the internet).

One approach to support self-management is through self-management interventions, which are structured strategies to provide patients with the skills and tools to engage in self-management. According to Effing et al. (2016), a COPD self-management intervention is 'a structured but personalised and often multi-component,

with goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease'. Hence, self-management interventions aim to provide patients with skills to take responsibility for their chronic condition and to actively participate in their health (Jonkman, Schuurmans, Jaarsma, et al., 2016). These interventions may have different components (e.g., medication management, action plans, goal setting, education, coaching, symptom monitoring) but may also have various modes, such as individual sessions, group therapies, and eHealth technologies, among others (Jonkman, Schuurmans, Groenwold, et al., 2016).

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) report (GOLD, 2025) recognises that self-management education and coaching by HCPs should be a major component of the chronic care model. However, there is no golden standard available on what self-management support or interventions should entail or how they should be implemented in practice. As a consequence, there are many interventions available that show a wide variety in components, modes, underpinning theories, intensity, outcomes measured, and duration (Jonkman, Schuurmans, Groenwold, et al., 2016; MacIver et al., 2021). This leads to self-management interventions that do not cover the whole definition of self-management or do not end up being used in practice, as the literature about how to implement them in daily practice is also lacking. Besides, self-management interventions available in the literature are often targeted towards one specific chronic condition (e.g., Ammerlaan et al., 2016; Bourne et al., 2022). While in reality, chronic conditions have overlapping (behavioural) risk factors (Adams et al., 2019; Niebuur et al., 2023) and often occur with multimorbidity (Kudesia et al., 2021). Similar intervention elements may be important when self-managing a chronic condition. Therefore, we could hypothesize that self-management behaviours and self-management needs may be overlapping across chronic conditions.

There is a body of literature available investigating self-management support and interventions from a clinical perspective (e.g., nurses (van Hooft et al., 2015), physicians (Khairnar et al., 2019; Lamontagne et al., 2013), general practitioners (Morrissey et al., 2018)). However, little is known about the patient perspective of self-management. Their needs, context, values, preferences, or experiences when engaging in self-management remain underexplored. This raises the question of how we can truly support patients and design effective self-management interventions if we do not take into account their perspective in healthcare. The perspectives of people with chronic conditions are much

broader than clinical perspectives only. When making them part of the conversation, researchers can utilize their experience-based knowledge and ensure that the research performed has impact and meaning for them (Duffett, 2017). Therefore, it is important to shed light on the needs, wishes, and efforts of people with chronic conditions for their self-management by involving them in our research.

Involving People in Research

The active involvement of people living with chronic conditions extends beyond healthcare. It also applies to research, design, and development, ensuring that we investigate and build the right things in a way that aligns with their lived experiences. Such efforts are also known as Patient Engagement (PE). PE in health research has gained considerable interest for its ability to improve the relevance, quality, and impact of research outcomes (Mah et al., 2025). PE can be defined as ‘meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation’ (The Canadian Institutes of Health Research, 2014). The people involved in this partnership are often referred to as patient partners. Many similar approaches emphasize the active involvement of non-professional researchers, such as citizen science (Wiggins & Wilbanks, 2019) and action research (Oberschmidt et al., 2024), which, when applied in the healthcare domain, also involves patient partners. Many benefits of PE are reported, e.g., improved relevance of clinical trials (Gobat et al., 2025), helping knowledge translation, facilitating recruitment, and capturing preferences, experiences, and needs of patient partners (Belton et al., 2019; Forsythe et al., 2019; Kirwan et al., 2005; McVey et al., 2023).

Next to the benefits of PE in research, studies also reported on the reasoning and value of being a patient partner. A study of Chudyk et al., (2023) identified that altruism (e.g., experiences with the complexities of the healthcare system), professional background (e.g., in healthcare academia), desire for personal development and expression (e.g., wanting to challenge themselves), and personal history (e.g., being involved as research participants) were the main reasons for becoming a patient partner. The study of Ivany et al., (2023) found that patients value the possibility of contributing to research and supporting future patients. Furthermore, being a patient partner may also build a sense of community and promote support through creating relationships and communication with other patient partners (Ivany et al., 2023). Thus, PE is essential as it has many benefits for research and patient partners. Besides, movements like

‘nothing about me without me’ (British Columbia Ministry of Health, 2011) also show that it is not acceptable anymore to not include patients in research.

Involving patients within research in practice is not straightforward and requires continuous reflection on when, why, and how to involve whom. In this way, an adequate representation of the target group can be ensured while guaranteeing that their active collaboration with the researchers is feasible and also meaningful for them. Facilitating PE also entails, for example, dedicating time to partnerships, flexibility, training patient partners to provide them with necessary skills if needed, adopting ideas from patient partners, and communicating the value of patient partners (Bird et al., 2020). However, practice demonstrates that there is still much room for improvement. Richards et al., (2023) identified four statements of patient engagement gone wrong: 1) ‘Patient partners as a check mark’: inviting someone to participate but not listening to their perspectives, and thus not acknowledging their insights, contributions, or ideas, 2) ‘Unconscious bias towards patient partners’: lived experiences are often not viewed as true expertise and given less credence and respect, 3) ‘Lack of support to fully include patient partners’: failing to provide physical or other support so they may fully participate as team members, and 4) Lack of recognizing the vulnerability of patient partners: failing to appreciate that patient partners often re-live emotional or even traumatic parts of their lives for the sake of the project. One should reflect on and learn from these statements and strive to avoid them in their own research (Richards et al., 2023).

When making efforts to engage patients in research, there are different roles that one can take throughout various stages of a research project. Smits et al., (2020) developed the ‘Involvement Matrix’, which is a conversation tool for patients and researchers to discuss and explain their roles of involvement in research. It aims to support PE in research projects by being clear and transparent about roles and expectations (Smits et al., 2020). This matrix describes three different phases of the research project (Preparation, Execution, and Implementation) and five different roles in the project (Listener, Co-thinker, Advisor, Partner, and Decision-maker). The tool can be used both prospectively: to establish roles and expectations, and retrospectively: to reflect whether roles were conducted satisfactorily. In the context of this thesis, using this matrix can help to map PE throughout our different research studies, from which we can reflect upon our efforts and draw our lessons learned.

Problem Statement and Research Questions

Although self-management is frequently practiced and promoted, little is known about how to engage and support people with chronic conditions in their self-management based on their needs and preferences, and how such support could be successfully implemented in practice. Moreover, current literature about self-management is focused on the perspectives of HCPs. The patient perspective about self-management is underrepresented: the current self-management behaviours in daily living, the needs for self-management support, and the way self-management support can be facilitated are unclear. Therefore, this thesis aims to increase our understanding of self-management from a patient perspective and, by engaging people with chronic conditions, identify how the self-management of people with COPD and RMDs can be supported. This aim is achieved through answering the following research questions:

- I. What is the current body of knowledge in healthcare practice and literature?
- II. What are the current self-management strategies of people with COPD and RMDs from a patient perspective?
- III. What is the future perspective on supporting self-management?

Thesis Outline

This thesis is divided into three parts. **Part I** focuses on identifying the current body of knowledge of self-management in literature and in healthcare practice. In **Chapter 2**, a Pan-European service model for an eHealth intervention for COPD was developed in three countries (the Netherlands, Italy, and Estonia) to investigate how a potential self-management intervention could be implemented in practice. Such insight helps in understanding if practice is ready to support self-management and how interventions should be implemented in the future. **Chapter 3** investigates the current state-of-the-art of eHealth self-management interventions for people with COPD by conducting a scoping review. More specifically, the functionality, modality, technology readiness level (TRL), underlying theories of the technology, the positive health dimensions addressed, the target population characteristics, the self-management processes, and the behaviour change techniques (BCTs) were investigated.

Part II investigates the patient perspective of current self-management strategies and possible overlap between chronic conditions, specifically for people with COPD and people with RMDs. This includes the self-management activities they are engaged in, their motivations for starting a strategy, and their experiences with these

activities. In **Chapter 4**, an online survey was carried out to identify self-management strategies of people with RMDs. Throughout all phases of the study, a citizen science approach was used, which will also be reflected upon in the paper. **Chapter 5** investigates the self-management strategies that people with COPD apply in their daily lives. This study also explored how to increase response rates by focusing on offline approaches. Furthermore, this study uses the same analysis instrument as used for people with RMDs, enabling comparison of self-management categories between diseases. This helps us identify patterns in the needs of people with chronic conditions for self-management that may be disease-generic.

Part III focuses more on the future perspective by investigating what people with COPD and people with RMDs need for their self-management and how self-management can be optimally supported. **Chapter 6** investigates the needs for self-management support from a patient perspective within an iterative design process for co-creating a self-management tool to support the self-management journey of people with COPD and RMDs. Finally, **Chapter 7** provides the general discussion. There, we report our main findings and answer our three research questions. Next, we reflect upon our efforts of involving people in research by mapping our engagement in the Involvement Matrix of Smits et al., (2020).

Context of this research

The studies of this dissertation are performed within two projects: RE-SAMPLE and REIS.

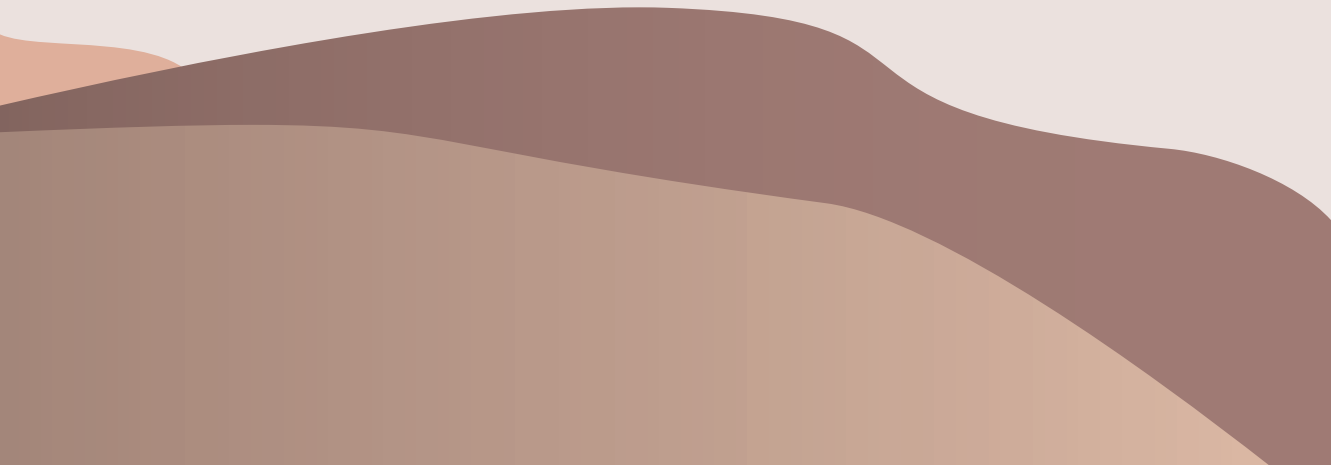
RE-SAMPLE is an acronym that stands for: RReal-time data monitoring for Shared, Adapptive, Multi-domain and Personalised prediction and decision making for Long-term Pulmonary care Ecosystems. It is a Horizon2020 research and innovation project (no. 965315) that aims to ‘empower patients with COPD and CCCs in self-care by developing a multidisciplinary, adaptive virtual companionship programme and to drive structural change in healthcare together with patients, healthcare professionals, scientists, policy makers, and industry’ (RE-SAMPLE, n.d.). The studies of Chapter 2, Chapter 3, Chapter 5, and Chapter 6 are conducted within that context.

REIS (‘journey’) stands for Reuma en Ik: Self-management (Rheumatism and I: self-management). This project investigates self-management strategies deployed by people with rheumatic conditions through a citizen science approach. The study was supported by the Dutch Arthritis Society Reuma Nederland (no. PB23-01-01), the

Interdisciplinary Consortium for Clinical Movement Sciences & Technology (ICMS) as part of the TOPFIT programme (University of Twente, Radboud University, Sint Maartenskliniek, and Roessingh Research and Development). Chapter 4 of this dissertation represents the work performed in this project.



Part I: The current body
of knowledge in healthcare
practice and literature





Chapter 2: Developing a Pan-European service model for an eHealth technology supporting self-management of people with COPD and comorbidities

Based on:

te Braake, E., Grünloh, C., & Tabak, M. (2024). Shifting Responsibilities: Developing a Pan-European Service Model for an eHealth Technology Supporting Self-Management of People with Chronic Obstructive Pulmonary Disease and Comorbidities. *International Journal of COPD*, 19, 175-192. <https://doi.org/10.2147/COPD.S432568>

Abstract

Introduction: Active participation of patients in their care via self-management is an important pillar to manage chronic conditions. Self-management education and continuous support are needed to improve patients' confidence to take such an active role. One way to do this is through eHealth technologies. However, those technologies can only be successful when actively used in daily practice and when integrated in overall care. Therefore, this study investigated how a self-management eHealth technology could be implemented that emphasises the active role of patients in their care.

Methods: The service modelling method was utilized as implementation strategy. The design process consisted of five phases with salient stakeholders and consortium members of a European project to develop the service model. Studies with salient stakeholders were carried out in three different countries (Italy, Estonia, and the Netherlands). A combination between face-to-face and online methods facilitated the participatory design process.

Results: Due to the pan-European context, different stakeholders in the three countries were identified. Research nurses and case managers were not yet established in practice, but once implemented, expected to contribute to optimal implementation. During service modelling, a crucial step was revealed: providing self-management training before technology use to let patients familiarise with the concept of taking an active role. As HCPs felt that they were not necessarily equipped to guide patients in terms of self-management, they also should have access to such self-management training.

Conclusions: By demonstrating a way for implementation while emphasising patients' active role, we also showed the complexity of the method in two ways. First, by demonstrating the fine line between the descriptive and prescriptive model. Thus, showcasing the need to recognise that prescriptive models may be hampered by the delay in changing work practices. Second, by highlighting the importance of identifying country-specific differences in the pan-European context, revealing that service modelling is not a one-size-fits-all approach.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a heterogeneous lung condition characterised by chronic respiratory symptoms (dyspnea, cough, expectoration and/or exacerbations) due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive, airflow obstructions (Agustí et al., 2023; GOLD, 2022). COPD is one of the major problems of public health and is steadily increasing in prevalence, morbidity, and mortality (Adeloye et al., 2022; GOLD, 2022; Jankowska-Polańska et al., 2016). Because of this increase, COPD was listed as the third leading cause of death in 2019 (Quaderi & Hurst, 2018).

The management of COPD is complex. One reason for this complexity is that COPD often coexists with other diseases, impacting the disease course (GOLD, 2022). These comorbidities worsen patients' outcomes and increases the economic burden and mortality (Iheanacho et al., 2020; Sethi et al., 2022; Shah et al., 2022). Because of these comorbidities, multiple different healthcare professionals (HCPs) are involved and ideally, need to work together to provide a multidisciplinary treatment strategy (Corlateanu, 2022). However, this may not always be the case in practice, making it challenging to align the different advice. Additionally, the chronic nature of the disease implies that the largest part of care is originated at the home of the patient without HCPs having the possibility to monitor or support them. The complexity also shows in that patients may experience acute exacerbations: “An episode of sustained symptom worsening that might require specialised treatment” (Chaudhary et al., 2023). Exacerbations negatively affect patients' health status and well-being, making early diagnosis and prevention essential (MacLeod et al., 2021). Therefore, to manage COPD, quite some effort is required from both HCPs and patients. An active role of the patient within their disease management is here essential. This is often referred to as self-management. Self-management can be defined as:

‘The ability of the individual, in conjunction with family, community, and HCPs, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions’ (Richard & Shea, 2011).

It challenges patients to take more responsibility and ownership towards their own health and well-being. With taking more responsibility, patients may take charge of their illness and become active participants in care (Auduly et al., 2010).

As recently concluded by Wang et al., (2022), patient empowerment may improve confidence and adherence to self-management, with self-efficacy mediating this relationship. Self-efficacy refers to the level of confidence in one's ability to perform self-management activities (Richard & Shea, 2011). Patient empowerment can be conceptualised as a process that “enhances the patient's feeling of control, self-efficacy, coping abilities, and ability to achieve change over their condition” (Small et al., 2013). In addition, it is increasingly advocated that clinical decision-making takes part in a collaboration between patient and clinician (i.e., shared decision-making, (Charles et al., 1997; Elwyn et al., 2012)). For a patient to be able to engage in shared decision-making in the first place, it can be assumed that some level of empowerment has to be reached already. Therefore, both mechanisms can be considered to be important in the process of self-management.

One way to empower patients and support them in their self-management is through eHealth technologies: ‘The actual technological instrument via which health, well-being and healthcare are supported, often information or communication technology’ (van Gemert-Pijnen et al., 2018). Many benefits are expected; it has the potential to reduce healthcare costs, to improve accessibility of healthcare, and to empower patients in their self-management (Ahmed et al., 2023; Kermelly & Bourbeau, 2022; Limna, 2023; Ossebaard & Van Gemert-Pijnen, 2016; Stefanicka-Wojtas & Kurpas, 2022). To eventually achieve these expected benefits for patients, it is important to involve them early on in the different stages of the development process, e.g., during requirement elicitation, prototype development, and usability testing. Such co-design approaches may enhance learning and empower patients (Cole et al., 2022). In this way, group-specific challenges (such as low (e) Health literacy and low motivation (Nyberg et al., 2017)) can be taken into consideration early on, and the technology can be fitted towards the specific needs and capabilities of the patients. In recent years, many self-management eHealth technologies have been developed, aiming to support patients with chronic diseases and positively change healthcare (e.g., Hallensleben et al., 2019; Kelly et al., 2022; Shen et al., 2019).

An example of such an eHealth technology aiming to improve healthcare and COPD self-management is RE-SAMPLE. RE-SAMPLE is a research and innovation

project (Horizon 2020 Grant Agreement No. 965315) that aims to develop an adaptive virtual companionship programme that supports people with COPD and comorbidities in their self-management (*RE-SAMPLE*, n.d.). In addition, a clinical dashboard will be developed to support HCPs in monitoring their patients and making decisions. *RE-SAMPLE* collects real-world data (RWD) from cohorts in 3 clinical pilot sites: Medisch Spectrum Twente (MST) in the Netherlands (NL), Gemelli hospital in Italy (IT), and Tartu hospital in Estonia (EST). The monitoring function of *RE-SAMPLE* will collect data from a Garmin smartwatch (activity, sleep, heart rate, oxygen saturation), data from several questionnaires, and from an Electronic Patient Reported Outcome measure (ePROMs). Such monitoring functionalities, ePROMS in particular, have been increasingly used in practice and shown to be beneficial for e.g. shared decision-making and supporting self-management (Holmes et al., 2019; Meirte et al., 2020). This data, among others, will be used to develop prediction models through artificial intelligence (AI) (*RE-SAMPLE*, n.d.). The virtual companionship programme includes self-management support by means of coaching. Thus, all aspects of the technology aim to engage and support people with COPD and comorbidities in their care.

These services can only be successful when actively used in daily practice. However, not much is known about the roles and responsibilities that stakeholders, especially patients and HCPs, should take when *RE-SAMPLE* is implemented in daily practice. To shape this new way of providing care, an implementation strategy should be prepared as early as possible during the development phase of the eHealth technology (van Limburg et al., 2011). This strategy should focus on identifying important stakeholders, structures, and processes within daily practice. Implementation models may guide this strategy and should be a central part of the eHealth technology development. To eventually improve care while using this eHealth technology, its implementation should be feasible and realistic, while empowering patients (Ross et al., 2016; Varsi et al., 2019).

There are various methods available for developing an implementation model (Ammenwerth et al., 2006; Bitner et al., 2008; Greenhalgh et al., 2017; van Gemert-Pijnen et al., 2011; van Limburg et al., 2011). This study utilized the service modelling method (also referred to as service blueprinting) as it provides a complete picture of implementation processes and is clearly demonstrated by means of a service model. A service model is a schematic representation of how an eHealth technology should be implemented in practice (Broekhuis et al., 2021) and entails components such as: end-user actions, stakeholder actions, and support services (Bitner et al., 2008). It describes

all the activities and responsibilities of the stakeholders of a specific eHealth technology. An individual or an organization can be considered a stakeholder when they affect or are affected by the project (Freeman, 2004). Because the activities of stakeholders are part of the model and they will eventually use the service or support its implementation, it is critical to understand their needs, concerns, and expectations (Carr et al., 2009). By engaging stakeholders, their interests and needs can be identified and accounted for in the service model, by which support and motivation for future implementation of an eHealth technology may be created (Broekhuis et al., 2021).

This paper investigates how a newly developed eHealth technology could be implemented in practice, that emphasises the active role of people with COPD and comorbidities in their care. To support successful implementation, the service model was iteratively developed using the service modelling method (Bitner et al., 2008) with key stakeholders in three European countries. The paper contributes by detailing the process of the service model design and by describing a service model for a COPD eHealth technology that stresses the importance of taking responsibility within self-management.

Methods

This study is part of the RE-SAMPLE project. During the time of the current study, the project was in its development phase. To develop the service model, this study pursues the iterative and gradual design process as proposed by Broekhuis et al., (2021). In this process, salient stakeholders are continuously involved to incorporate their perspectives and needs and to gather their feedback on the different iterations of the service model, to ensure that their perspectives have been correctly understood and accounted for. Salient stakeholders are those stakeholders that are giving priority to within the project (Mitchell et al., 1997). Components of a service model, as defined by Bitner et al., (2008) (e.g. end-user actions, support processes) were taken into consideration during the design process, and project-specific components, such as the components of the RE-SAMPLE technology, were added to tailor the service model. In the empirical studies conducted at the start of the project (e.g. co-creating patient journeys, eliciting user needs, understanding the context), patients from all three countries participated in creating the basis for the service modelling. The insights from these studies (obtained from patients' needs, wishes, and experiences), together with the proposed vision within the RE-SAMPLE project, were used as input for the building blocks of the RE-SAMPLE eHealth technology. These building blocks served as starting point of the

service model design, consisting of: peer-to-peer contact (the possibility to be in contact with other people with COPD and CCC), data collection (data collected from the Garmin smartwatch, questionnaire data, and ePROMS), self-management and coaching (self-management support and coaching on different topics relevant for the patient), risk alert (alert from the system when unusual symptoms are detected), data review (process in which a HCP reviews the collected data of the patient when unusual symptoms are detected and a data review is requested by the patient), exacerbation (worsening of symptoms), and hospitalization. Figure 1 shows a simplified version of these building blocks. A more detailed version of this figure was used as a starting point to facilitate the first iterations.

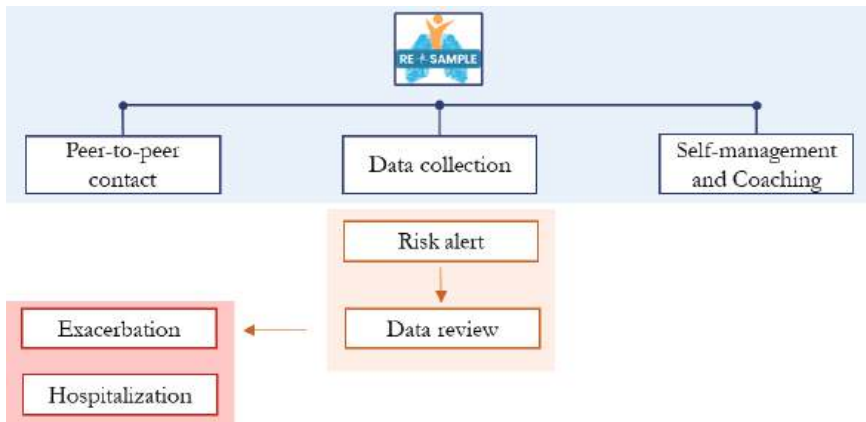


Figure 1. Building blocks of the RE-SAMPLE eHealth technology.

Design and Setting

Table 1 shows the service model design process consisting of 5 phases with salient stakeholders and consortium members to develop the service model involving three iterations of the model. Studies with salient stakeholders were carried out in the three different pilot sites of the RE-SAMPLE project. In the studies where consortium members were invited, the different pilot sites and different perspectives were discussed together in break-out and plenary sessions. The studies were carried out by the consortium partner leading the task “Service model development” (anonymised for submission) between January and August 2022. A combination between face-to-face and online studies facilitated the design process. All participants received information about the study and gave their (digital) informed consent before participating. The nature of this study does not require formal medical ethical approval. This was assessed by the

Medical Research Ethics Committee (MREC) Oost-Nederland in terms of the Medical Research Involving Human Subjects Act (WMO) obligation (File number: 2021–13,319). All procedures were in accordance with the Declaration of Helsinki and the Good Clinical Practice (GCP) guidelines.

Table 1. Overview Design Activities of the RE-SAMPLE Service Model.

Phase	Activity
1	Stakeholder Identification <ul style="list-style-type: none"> • <i>Method:</i> Workshop • <i>Content:</i> Identifying potential stakeholders, generating the top 15 • <i>Participants:</i> Clinical partners within the RE-SAMPLE consortium
2	Stakeholder Saliency Analysis <ul style="list-style-type: none"> • <i>Method:</i> Survey • <i>Content:</i> Rating of power, legitimacy, and urgency • <i>Participants:</i> Consortium members and potential stakeholders
3	Identification of Current Practice <ul style="list-style-type: none"> • <i>Method:</i> Workshop • <i>Content:</i> Inventory of current COPD care, desired roles, and responsibilities • <i>Participants:</i> Salient stakeholders
Design of Initial Service Model (Version A)	
4	Feedback (Consortium Partners) <ul style="list-style-type: none"> • <i>Method:</i> Workshop • <i>Content:</i> General impressions, desired activities, roles, and responsibilities. • <i>Participants:</i> Partners within the consortium
Optimization of Service Model (Version B)	
5	Feedback (Salient Stakeholders) <ul style="list-style-type: none"> • <i>Method:</i> Workshop • <i>Content:</i> General impressions, desired activities, roles, and responsibilities. • <i>Participants:</i> Salient stakeholders

Round 1. Stakeholder Identification (Clinical Partners of the Consortium)

As the first step in the service model development, potential important stakeholders were identified in all three pilot sites, by means of an online workshop conducted with the clinical partners within the project. This workshop aimed to identify stakeholders that might be important to put the eHealth solution into practice. Clinical partners from the RE-SAMPLE consortium were asked as domain experts (Sharp et al., 1999) to identify relevant stakeholders for the stakeholder identification. These members were first asked to create a general list of important stakeholders for their respective country and later created a top 15 of the most important stakeholders. Discussions during the workshop were audio recorded, and stakeholder identification exercises were documented within Mural (*Mural*, n.d.) an online platform for visual collaboration. Results from the Mural board were used as input for round 2.

Round 2. Stakeholder Saliency Analysis (Consortium Members and Potential Stakeholders)

Using the outcomes from the stakeholder identification workshop, an online stakeholder saliency survey (Multimedia Appendix 2.1) was designed in Qualtrics (*Qualtrics*, n.d.), applying the constructs: power, legitimacy, and urgency (Mitchell et al., 1997). The goal was to identify the salient stakeholders of the RE-SAMPLE project by help of direct stakeholders in each pilot country. The survey was designed in three parts representing the three constructs. For each construct, participants could rate on a 5-point Likert scale whether a certain stakeholder was salient (1: not at all - 5: very much). The survey was distributed via e-mail and shared with both HCPs and people with COPD. Outcomes were analysed using descriptive statistics. For each pilot site in RE-SAMPLE, the top 5 (the highest mean) were identified to be the most salient.

Round 3. Identification of Current Practices (Salient Stakeholders)

The results of the stakeholder salience survey were used to invite salient stakeholders to the first workshop. Three (online) workshops were carried out in the different pilot sites to collect input for the development of the initial service model (Version A). This workshop aimed to collect information about current COPD care practices and the desired roles and responsibilities within the eHealth technology in each pilot site. To achieve the workshop goals, an inventory of the current situation and identification of weak and strong points in care was made. A patient journey, developed in the early phase

of the project and based on interviews with both patients and HCPs in all 3 countries, was used during these activities to support the inclusion of the patient perspective (Simonse et al., 2019). In line with the user-centred design process (Idoughi et al., 2012), a persona- and scenario-based approach was utilized to understand and discuss the current care practices, which facilitates the design of the new situation (ie, using the eHealth technology in practice). The desired roles and responsibilities of salient stakeholders and potential strengths and weaknesses of the current practice of care were discussed. All workshops were audio-recorded, and workshop outcomes were documented within Mural or with the use of post-its (depending on whether the workshop was online or offline). Both documented and audio-recorded data collected during the workshops were combined and used as input for the initial service model development (Version A).

Round 4. Feedback (Partners Within the Consortium)

The goal of this workshop with consortium partners was to show the initial service model (Version A), receive feedback, and gather specific points for improvement. The workshop was designed in a funnel manner: starting with general impressions and gradually zooming in to the different activities and roles, and responsibilities within the initial service model. Meaning that the workshop started with gathering broad first impressions. Thereafter, detailed feedback was provided by looking into specific strong and weak points, the different roles and responsibilities, and ways to improve the service model. All exercises were facilitated using Mural. The workshop was audio-recorded and analysed using the Mural results. These served as input for another round of optimizing the service model (version B). This version would later be used during the subsequent workshops with the salient stakeholders.

Round 5. Feedback (Salient Stakeholders)

Three (online) workshops with stakeholders in each pilot site were held during the final round. Both stakeholders who were present and who could not be present during the first workshop were invited to participate in the second and final feedback workshop. Through the process of feedback, new roles were identified to be affected by the eHealth technology. Therefore, these additional stakeholders were also invited (such as GP nurses in Estonia). This workshop aimed to show the second version of the service model (Version B) and to receive feedback from the salient stakeholders. The same workshop design and its activities used during round 4 were applied to round 5. Data was analysed per pilot site using the audio recordings and documentation of Mural.

General improvements to the model were combined, and pilot site-specific differences were identified and incorporated to finalize the service model (Version C).

Results

As results from different study rounds in the three different pilot sites were collected, key findings of the studies are presented in the sections below.

Participants

A total of 50 unique stakeholders helped facilitate the design process of the RE-SAMPLE service model. 29 stakeholders filled in the survey anonymously, of whom some might have joined the workshops. Participants had different backgrounds: People with COPD, (clinical, senior) researchers, pulmonologist(s), healthcare specialist(s), nurse practitioner, specialized nurse, rehabilitation physician, GP, EU Affairs officer, clinical specialist, assistant professor, PhD candidate(s), social worker, head of institute at a university, program manager, pulmonary residents, research nurse, physiotherapist, postdoc student, EU Affairs Officer, epidemiologist, physician assistants, and participants from the ICT department (technical data consultant, and IT cloud and infrastructure-architect). Four participants only mentioned their workplace: city government, laboratory, Ministry of Social Affairs, and the health insurance fund. Some participants participated in multiple studies. An overview of participants per study can be seen in Table 2.

Table 2. Overview of Participants in Each Study Conducted in the Respective Country.

	The Netherlands	Italy	Estonia
Stakeholder identification workshop (Clinical Partners of the Consortium) Jan 2022		N=7 (NL N=1, IT N=5, EE N=1)	
Stakeholder Salience Survey (Consortium Members and Potential Stakeholders) 21.01.–25.03.2022	N=9	N=11	N=9
Identification of current practice (Salient Stakeholders) May/June 2022	N=6	N=9	N=5

Feedback (<i>Consortium partners</i>) June 2022	N=13 (NL N=6, IT N=2, EE N=2, others N=3)		
Feedback (<i>Salient stakeholders</i>) July 2022	N=12	N=10	N=3

The Service Model Design Process

Round 1. Stakeholder Identification (Clinical Partners of the Consortium)

Table 3 shows an overview of the stakeholder identification for all three countries. For Estonia, 33 potential stakeholders were initially identified and narrowed down to the following list of 15 most relevant stakeholders (these are randomly ordered): People with COPD, General Practitioner (GP), pulmonologist, pulmonary nurse, physiotherapist, caregiver (family member), cardiologist, information specialist, social ministry, management of laboratory, insurance company, Information and Communication Technology (ICT) department, legal department, head of pulmonary outpatient department, innovation manager. For Italy, a total of 40 potential stakeholders were mentioned in the first identification. As for Estonia, the list was narrowed down to the 15 most relevant stakeholders, namely: People with COPD, GP, pulmonologist, pulmonary nurse, physiotherapist, caregiver (family members or close people), cardiologist, diabetologist, nephrologist, radiologist, nutritionist, ICT department, hospital board, region/health institution, Specialized Continued Assistance Units (USCA). This list was randomly ordered. For the Netherlands, 37 potential stakeholders were mentioned in the first identification. Followed by the 15 most important stakeholders (these are randomly ordered): People with COPD, GP, pulmonologist, specialized nurses at outpatient department (e.g. self-management), physiotherapist primary [care], caregiver/family member, cardiologist, diabetologist (other specialist in general), psychologist/ psychiatrist, pharmacist primary [care], insurance companies, ICT department, hospital board, hospital purchasing department, innovation manager.

Table 3. Overview of the Stakeholder Identification in Three Countries (Estonia, Italy, the Netherlands).

Estonia	Italy	The Netherlands
People with COPD	People with COPD	People with COPD
GP	GP	GP
Pulmonologist	Pulmonologist	Pulmonologist

Pulmonary nurse	Pulmonary nurse	Specialized nurses at the outpatient department (e.g., self-management)
Physiotherapist	Physiotherapist	Physiotherapist primary [care]
Caregiver (family member)	Caregiver (family members or close people)	Caregiver/family member
Cardiologist	Cardiologist	Cardiologist
Information specialist	Diabetologist	Diabetologist (other specialist in general)
Social ministry	Nephrologist	Psychologist/Psychiatrist
Management of the laboratory	Radiologist	Pharmacist primary [care]
Insurance company	Nutritionist	Insurance companies
ICT department	ICT department	ICT department
Legal department	Hospital board	Hospital board
Head of the pulmonary outpatient department	Region/state health institution	Hospital purchasing department
Innovation manager	USCA	Innovation manager

Round 2. Stakeholder Saliency Analysis (Consortium Members and Potential Stakeholders)

The results from the different constructs of the stakeholder saliency analysis are shown in Table 4. The saliency analysis revealed several similarities of salient stakeholders between pilot sites. Nevertheless, some important differences were identified. First, there were differences when it came to certain HCPs. Physiotherapists were mentioned in both Italy and Estonia to be legit and justifiable stakeholders to include in the process. However, they were not stated to be most salient in the Netherlands. The GP, pulmonary nurse, and pulmonologist were identified in almost all categories in all the three pilot sites. Only the Netherlands did not rate the GP to have power in the process. There were also some differences in the rating of people with COPD. In Italy, people with COPD were rated to have power, but they were not rated to have power in Estonia nor the Netherlands. In the Netherlands and Italy, the needs and wishes of people with COPD were rated to be most urgent. In Estonia, people with COPD were also stated as urgent but others (e.g. pulmonary nurse) were rated to be more urgent. In Italy, people with COPD were not identified in the legitimacy category, although this is in contrast with their urgency rating. There were also some differences regarding other stakeholders or organisations. The insurance company was mentioned in the Netherlands to have

Table 4. Stakeholder Saliency Analysis (EST, IT, NL).

Construct	Power						Legitimacy						Urgency					
	EST		IT		NL		EST		IT		NL		EST		IT		NL	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
People with COPD	-	-	3.91	1.30	-	-	4.89	1.58	-	-	5.00	0.00	4.11	1.89	4.36	0.92	4.67	0.71
In formal caregivers	-	-	-	-	-	-	4.00	1.65	4.00	1.26	4.22	1.09	-	-	4.09	0.83	-	-
Pulmonologist	4.22	1.55	4.55	0.82	4.78	0.44	4.89	1.58	3.82	1.33	4.89	0.33	4.44	1.56	4.27	0.79	4.78	0.44
Pulmonary nurse	4.00	1.78	3.55	1.21	4.33	0.71	4.89	1.58	3.82	1.08	4.78	0.44	4.56	1.60	4.00	0.77	4.56	0.53
General practitioner	3.89	1.51	4.00	0.77	-	-	4.56	1.65	3.82	1.40	4.44	1.01	4.11	1.70	3.82	0.60	3.89	1.27
Specialized nurses at the outpatient department	-	-	-	-	4.22	0.83	-	-	4.36	0.81	4.56	0.53	-	-	-	-	4.44	0.73
Head of pulmonary outpatient department	3.89	1.51	3.73	1.62	-	-	-	-	-	-	-	-	3.89	1.84	-	-	-	-
Hospital board	3.89	1.84	-	-	3.78	1.39	-	-	-	-	-	-	-	-	-	-	-	-
Physiotherapist	-	-	-	-	-	-	4.11	1.49	4.09	0.54	-	-	-	-	-	-	-	-
Innovation manager	4.67	1.75	3.55	1.57	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Social ministry	-	-	-	-	-	-	-	-	-	-	-	-	3.89	1.90	-	-	-	-
Insurance company	-	-	-	-	4.44	0.73	-	-	-	-	-	-	3.89	1.90	-	-	-	-
ICT department	-	-	-	-	3.89	1.45	-	-	-	-	-	-	-	-	-	-	-	-
USCAR	-	-	-	-	-	-	-	-	-	-	-	-	4.33	2.77	-	-	-	-

power and in Estonia to be urgent but was not identified in any of the categories for Italy. The innovation manager was mentioned in Italy and Estonia to have power but was not mentioned at all for the Netherlands. The hospital board was identified in the Netherlands and Estonia, but not in Italy. Finally, the Social Ministry appeared to be important in Estonia but was not identified in any of the categories in the other countries.

Round 3. Identification of Current Practice (Salient Stakeholders)

The results showed some similarities between the pilot sites in ways to implement the technology in the future. In all pilot sites, participants indicated that some sort of HCP could play a role in introducing the eHealth technology to the patient and help with the onboarding and data review. However, the type of HCP differed between pilot sites. For example, in Italy, the physician or GP would fulfil most of the roles and responsibilities in the new situation. The GP is the first contact point of the patients and therefore very important to involve. The research nurse might help in the onboarding, but this is a new role within Italy that is not fully operating yet. In Estonia, most of the responsibilities regarding the onboarding will be for the pulmonologist, the nurse, or even a trained specialist. In the Netherlands, it appeared that this is the responsibility for the specialized nurses and the pulmonary nurse who apparently play a crucial part in the disease management of the patient with COPD. It also appeared that in Estonia, the Ministry of Social Affairs, the city government, and social welfare could possibly play some roles in terms of introducing the eHealth technology to the people with COPD. However, these stakeholders and roles were not mentioned in the other pilot sites.

The results also revealed challenges regarding how care is organized in the different pilot sites. In Italy, for example, there is no technical system available with which both the GP and the clinicians in the hospital can communicate results. Additional tests can be performed in or outside the hospital, and the patient needs to bring the results themselves to a GP or physician for them to analyse it. In the Netherlands, the communication between the hospital and the GP could be seen as a strength of current care, given that it is digital. Another difference is that in Estonia, patients are facing long waiting lists of specialized care, while in the Netherlands, there are short waiting times. These results demonstrated the need to differentiate between the different pilot sites within the service model.

Round 4. Feedback (Partners Within Consortium)

The results revealed that some important steps within the service model were missing.

It became clear that the service model is currently heavily focused on people with COPD. While this reflects the patient-centred approach of the project, clinical partners emphasized that HCPs also have an important role within the project, which, in their view, was underrepresented in Version A of the service model. For example, in Version A, the clinical dashboard for HCPs was not included, and neither was the potential value it could provide for professionals. Furthermore, it was critically discussed that the patient is notified that their symptoms worsen, and they are asked whether they want to have a data review from an HCP. The motivation behind this was that patients are aware of their context and might be able to assess whether they need an assessment. Thus, in terms of patient empowerment, they are responsible to take action instead of an automatic request that adds to the workload of professionals. However, this was critically discussed by the clinical partners in the consortium, given that some patients might ignore this. Some first suggested that this should go directly to the HCP, but after consideration about the workload, agreed that a notification could also be provided to the HCP after the patient has repeatedly ignored their notification. Thus, in the HCP dashboard, the possibility for the professionals to see the patient's exacerbation risk should be described. Although the responsibility to act still lies with the patient, the professional should be able to see any changes related to their exacerbation risk. Furthermore, it was also mentioned that there should be an eligibility screening added before the onboarding. Although multiple HCPs could inform the patient about the technology, the pulmonary department should be responsible for the eligibility screening. In this way, the responsibility lies within one specialty.

Another process that was missing in Version A was a self-management training before patients start using the application. The clinical partners reported that a lot of patients may not be familiar with self-managing their disease. Therefore, they should receive training about how to self-manage their disease, receive information about how the eHealth technology can support that, and create a possibility for patients to ask follow-up questions. In this way, the patient knows what to expect and is supported before starting the eHealth technology.

Finally, the partners stated that during an exacerbation, it is also possible that the patient receives home treatment. Not all patients need to be hospitalized when going through an exacerbation. This should therefore be added to the model. There were also some stakeholders missing in the initial version of the service model. These were mainly clinicians who are specialized in comorbidities. However, it was also mentioned that the outpatient clinic for Italy should be removed as a responsible stakeholder for the

onboarding, and that some (new) roles (e.g. research nurse) might be added, even though this is not a fully operating role yet. This means that the next version of the service model needed to include those processes and stakeholders that were currently missing.

Round 5. Feedback (Salient Stakeholders)

During the final feedback round, some general improvements were suggested by the stakeholders in the respective pilot site. First, the clinical dashboard should be separated from the application for the patients. It was not clearly shown how the clinical dashboard is something meant for HCPs, and that should therefore be changed. Furthermore, comorbidities were not represented in the model. It was not clear where actions or activities need to take place for the comorbidities, and who needs to be involved in this. These should also be visualized and described in the model. This version of the model is too much focused on COPD.

Regarding the self-management training that should take place before the start of the eHealth technology, it was explicitly mentioned that there should also be training for the HCPs responsible for training patients. This was mainly the case in Italy and Estonia, where it is sort of a new concept, but in the Netherlands, participants also said that there should be a clear manual with instructions. As regards to the self-management training itself, it should contain both face-to-face contact and technology-supported training. It was suggested that, for example, in the beginning, there should be more face-to-face contact to educate patients on how to self-manage their disease with a more controlling role from the HCPs. In this way, patients can gradually learn about self-management.

For the assignment of data reviews, it was discussed that the responsible HCP should have a wider clinical view. Because there are comorbidities involved, it may be the case that pulmonary nurses are not the ones who can answer all questions. Considering that case managers do not yet exist in Italy, Estonia, or the Netherlands, it was concluded not to be realistic for now of adding them with the full responsibility in the service model. However, it was mentioned to be a good alternative for the future when such roles have been introduced in practice.

Analysing the workshops showed that several differences between the pilot sites exist. In Estonia, there should be some sort of case manager (e.g. nurse) who will also help patients with technical support. However, in the Netherlands, it was explicitly stated that HCPs should not help with technical support. They should only be responsible for the symptoms and content-related questions; technical questions should

be answered by some sort of help desk. Furthermore, in Italy, it was explicitly mentioned that caregivers should also be included as a stakeholder. Since it is the case that the caregiver accompanies the patient at every appointment, it was discussed that they should also be involved with the self-management training. However, this was not at all discussed in Estonia and the Netherlands.

Finally, it was discussed in Italy that the ways of communicating exacerbation risks to the patients would require some serious attention for the eHealth technology development as a whole. They stressed the importance of not worrying patients too much if this is not necessary. Thus, they were cautious about showing the risk alert to patients in the first place. Participants in Italy indicated that it would be better to lie this responsibility at the HCPs. Thereby letting HCPs receive the risk alert and letting them be responsible for the subsequent action to take. Others agreed that if showing the risk, it should be thoroughly investigated how this can be best shown so that chances are reduced that patients would worry unnecessarily after seeing such an alert.

The RE-SAMPLE Service model

The various phases of the service modelling process, including the feedback provided by salient stakeholders and clinical partners within the consortium, enabled the development of the final service model (Version C) (Figure 2). This model shows the different activities, roles, and responsibilities within the three pilot sites, and is described below.

Introducing the RE-SAMPLE Application and Garmin Smartwatch

There are different groups involved in the current RE-SAMPLE technology; HCPs, the patient with COPD, and others. The patients may be informed about the technology (consisting of an application and smartwatch) in two ways: 1) The HCPs or others introduce it to the patient, or 2) The patient gets to know about the technology from their own search or by flyers in the waiting room from different departments and professionals. The patient then learns about the technology and decides whether or not he/she wants to join. If the patient wants to join, the eligibility screening can take place. During this screening, the pulmonary department (in case of the current project) checks if the patient is eligible for participation based on certain parameters. If the patient is eligible, onboarding can take place.

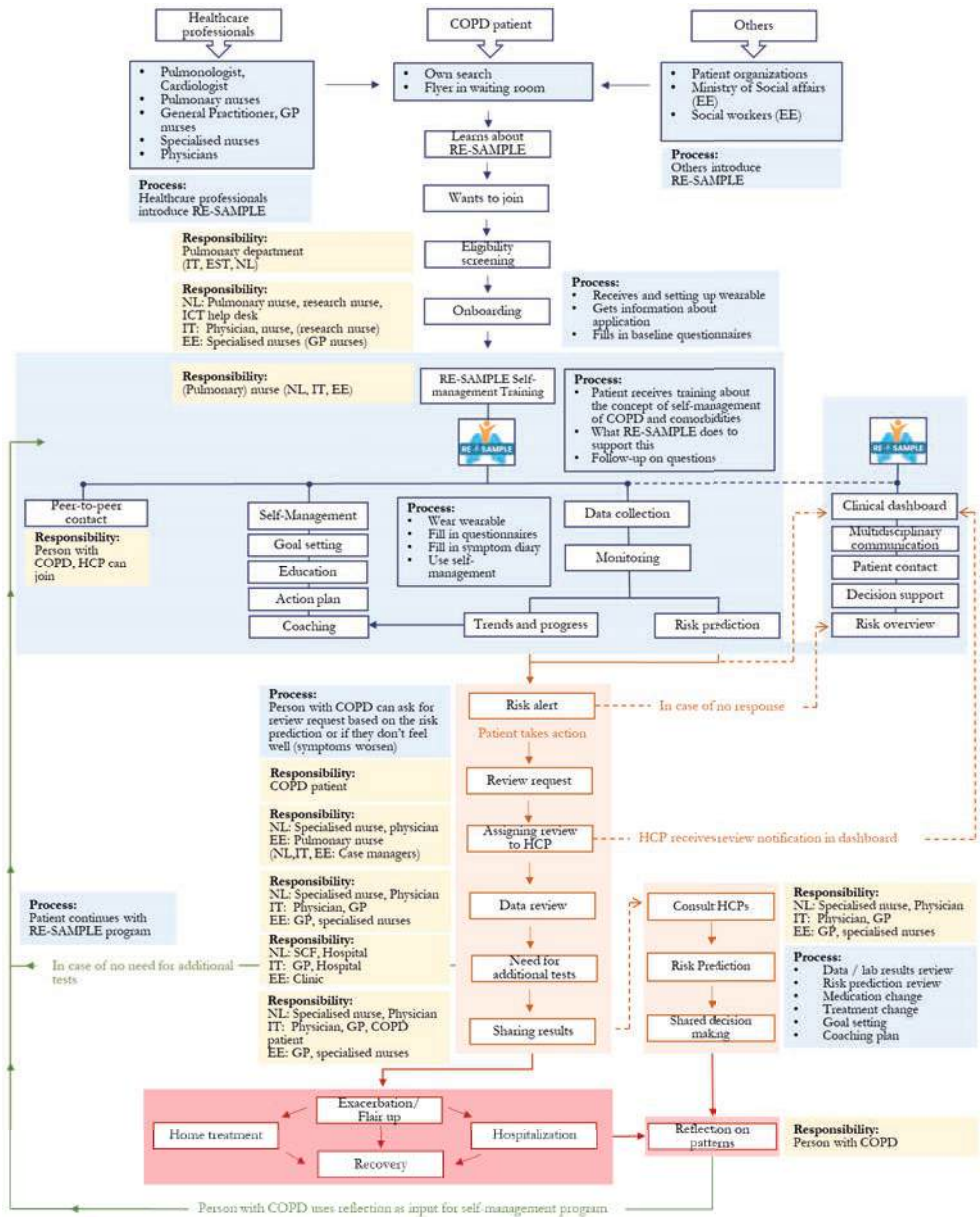


Figure 2. Final Service Model of RE-SAMPLE.

Onboarding

During the onboarding, the patient receives a wearable (which is set up during the appointment), gets information about the application, and fills in baseline questionnaires together with the one responsible, which differs per country. In the Netherlands, the pulmonary nurse, the research nurse, or the ICT helpdesk will be responsible. The onboarding itself is the responsibility of the pulmonary nurse or research nurse. In case of questions, the patient can ask content-related questions to these professionals. For technical support, or when experiencing technical issues, the patient can contact the ICT help desk from the hospital. In this way, HCPs save time and can answer more specific questions. In Italy, the onboarding is the responsibility of the physician or nurses. Since nurses see the patients quite often, they can do the onboarding with the patient. However, depending on the time and setting, physicians can also perform this activity. For Estonia, it is still unclear whether GPs will be involved. Depending on the decision that GPs are going to be actively involved in the implementation of the eHealth technology, GP nurses can perform the onboarding with the patients. Otherwise, physicians (e.g. pulmonologists) will be responsible for this step. In case research nurses will become a sustainable role in Italy in the future, this activity can then become their responsibility. However, this role is currently not fully operating in practice, but they are planning on doing so in the future.

Self-management Training

After the onboarding, the patient will receive self-management training on their disease and comorbidities. It is also explained what the eHealth technology does to support them in their self-management, and patients can ask follow-up questions. This will be the responsibility of the pulmonary nurses in all three pilot sites. The training is provided in a hybrid way. Meaning that the first appointment will probably take place face-to-face, and the HCP will have a more controlling role in the beginning. Depending on the patients' health literacy, it can be decided to increase or decrease the number of face-to-face appointments and the level of control the pulmonary nurse will have. However, before the ones responsible will provide the self-management training to patients, they should first receive a training themselves on how to educate patients and on how to support them in their self-management. In this way, all responsible pulmonary nurses can support the patient and learn self-management in the same way.

The RE-SAMPLE Technology

After the self-management training, the patient can start using the application. This

consists of peer-to-peer contact, self-management, and data collection. During the usage of the eHealth technology, the patient wears the wearable, fills in questionnaires and the symptom diary, and uses the self-management module. There is a separate application for HCPs, which is called “clinical dashboard”.

Peer-to-Peer Contact

The patient can make use of the peer-to-peer contact feature, by which (s)he can chat with other patients with the same disease. If the patient decides to not use the data collection part of the eHealth technology, (s)he can still use the chat. The peer-to-peer contact is the full responsibility of the patient. (S)he can also decide to not use this feature at all. The HCP can join the peer-to-peer contact. Details on in what exact way HCPs can join were not elaborated upon yet.

Self-Management

The self-management component consists of different activities. The patient can make use of goal setting, education, action plan, and coaching. With goal setting, the patient can define specific goals which might be set up during the shared decision-making in the consult or might be set up by the patient him/herself. Using the educational feature, the patient can learn more about specific topics (e.g. the technology, their disease, self-management, medication use, benefits of physical activity, etc.). Some of these modules might be useful for patients shortly after starting with the program. Others may be useful after an exacerbation or other events. A patient’s action plan can also be viewed on the technology. By including the action plan, the patient can follow certain steps themselves when a worsening of symptoms is happening before asking for a data review request. Finally, coaching will also be available. Being coached on a specific topic might be motivated by different sources, for example, they might be intrinsically motivated, be made aware by an HCP, or an interest was sparked when looking at trends and progress. As with the education feature, coaching will be provided for different topics. It is important to note that if the patient decides not to use the data collection, he/she can still use the self-management feature within the technology.

Data Collection

Data collection needs to be performed to support the monitoring feature and risk prediction. Data is collected by wearing a Garmin smartwatch (physical activity, sleep,

heart rate, oxygen saturation) and filling in questionnaires and ePROMS. Based on these RWD, trends and progress can be visualised, and risk predictions can be made. Both the trends and progress and the risk predictions are input for the risk alert. Here, the patients receive a notification when there is something out of the ordinary that indicates a higher risk of developing an exacerbation. The system then offers a data review performed by a HCP, which the patient can accept or decline. The control whether a data review is requested or not is the full responsibility of the patient. When a review is requested, it would be ideal to have an algorithm to assign the request to the appropriate HCPs, this is currently not included in RE-SAMPLE. Therefore, the case manager could have the responsibility to assign the review to an HCP. However, the case manager is currently not operating in practice in Italy and Estonia, but something they want to include in the future. The Netherlands does not have such a case manager to perform those tasks, nor is it planned to establish this role. Therefore, the specialised nurse or the physician needs to be responsible for assigning the review to HCPs. For Italy, this will be the responsibility of the physician or the GP. For Estonia, this will be the responsibility for the GP or the specialised nurses. The responsible HCP then reviews the data and risk predictions made and decides whether or not additional tests are needed. In case of no additional tests, the patient is informed and continues using the eHealth technology as usual. In case of additional tests, the patient is asked to have these tests performed. In the Netherlands, these additional tests are either the responsibility of the Shared Care Facility (SCF) or the hospital. For Italy, it will be the responsibility of the GP or the hospital to perform the additional tests. For Estonia, it will be the responsibility of the clinic. After performing these tests, the results need to be shared with the patient. This will be the responsibility of the pulmonary nurse or physician in the Netherlands, and the GP or specialised nurses in Estonia. For Italy, sharing the results are the responsibility of the physician (e.g. pulmonologist) or GP, although in some cases the patient also has some responsibility to transfer results between HCPs, because in Italy systems are not connected. Without patients taking responsibility, it might be that results are not shared; therefore, patients have a role in this activity. It may be possible that when sharing the results, a consult is necessary for additional explanation and follow-up. Here, the risk prediction will be discussed and through shared decision-making, next steps are decided upon. For example, it could be that it will be discussed that certain medication or treatment needs to be changed, other goals need to be set, or that the coaching plan will be changed. The same HCPs who are responsible for sharing results are also responsible for this step. After the consult, the patient is invited by the technology to reflect on their patterns to look what happened the days before the

worsening of the symptoms. This is the full responsibility of the patient. The patient can use the reflection so that over time, one might be able to identify their personal patterns (for example, too much exercise). They can thereafter use the application as usual.

Clinical Dashboard

HCPs are supposed to use the clinical dashboard. This dashboard has different features: multidisciplinary communication, patient contact, decision support, and risk overview. With multidisciplinary communication, HCPs can easily communicate with other care departments or specialists. Furthermore, the HCP can contact their patients, see the risk prediction, and trends and progress of the patients. When the patient him/herself does not undertake any action upon the risk alert, the professional receives a notification about the elevated risk. In this way, the responsibility still lies by the patient, but the HCP can see risk in case the patient is not responding to their notifications. The clinical dashboard will contain decision support which can then facilitate shared decision-making.

Worsening of Symptoms

The patient might experience an acute exacerbation or flare-up at some point, which may even lead to hospitalization or can be treated at home. After the hospitalization or at home treatment, the patient will hopefully recover. After the recovery, the patient is invited to have a reflection on patterns by using the symptom diary to look at the days before the worsening of the symptoms. Here, the patient will pay attention to potential symptoms that were experienced that could trigger a worsen of the symptoms. This reflection is the full responsibility of the patient. Thereafter, the patient can continue using the application as usual.

Discussion

The results outline the process and results of a service modelling process that also illustrate the complexities of implementing an innovative eHealth technology in practice. In the following, we will discuss the results related to (1) the role of patients within a service model for a COPD self-management eHealth technology and (2) the iterative method of service modelling for an innovative eHealth technology still under development.

Shifting responsibilities: empowering patients to actively engage in COPD self-management

This study revealed that, according to clinical partners and HCPs, not all patients are ready to take an active role and responsibility that was envisioned with this eHealth technology for self-management. It became clear that some patients need to be familiarised with the concept of patient empowerment and their new role before using the technology. This is especially important in countries where self-management is a relatively new concept. Empowerment will not happen overnight but can rather be seen as a process for “identifying needs, taking action, and gaining mastery over issues that are self-identified as important” (Funnell, 2016). It provides patients with knowledge, skills, and responsibility to effectively change their behaviour (Funnell et al., 1991). In this way, patients will gradually develop a better sense of self-efficacy, and this may lead to a better management of one’s disease (Raina & Thawani, 2016). In the final service model, we try to empower and prepare patients by providing self-management training before starting to use the technology which may have beneficial effects during the eHealth use. Thus, instead of solely looking at implementation of the technology, this study also revealed a crucial step before starting the actual technology use: preparing and empowering patients to reflect on their role and to take responsibility as active partner in their care, also often referred to as patient activation. When highlighting all aspects of patient activation, it can be effectively used to improve self-management and clinical outcomes (Shnaigat et al., 2022). As low levels of activation are common in patients with COPD (Peters et al., 2022), patient activation is in our opinion, a crucial step in every (e)Health intervention for this and other, target population(s). One might think of this as a rather simple step, but practice shows that this step of “activating patients” is often neglected (Yadav et al., 2018). Therefore, this paper acknowledges this importance by adding self-management training before starting to use the intervention to gradually familiarise patients with taking (some of the) responsibilities.

Besides, patients in some countries not being used to take responsibility, and results also revealed that not all HCPs can let go of their responsibility and their need to monitor and control. Some would rather receive notifications and take responsibility in an attempt to protect the patient from getting notifications, seeing their data, and maybe getting worried. Similar results were found by Grünloh et al., (2018), in which this paternalistic approach was also found to be present, even though HCPs did not seem to be aware of this. While this approach is likely based on good intentions, it defeats at the same time the purpose of self-management. Part of this aim is that patients take

responsibility for their disease management, e.g. taking responsibility of the risk alerts they receive. Undoubtedly, not all patients are immediately capable of fully taking this responsibility, and this should be guided by the HCP. Therefore, responsibility from HCP may still be required at times (e.g. receiving an alert if the patient does not take any action). This is in line with one of the conditions of Redman (2007) for successful empowerment, giving responsibility should be gradually. Hence, patients should be prepared for taking their own responsibility. To truly increase the self-management of patients in such technologies, the responsibility to act should eventually lie with the patient. For this reason, this service model highlights the possibility of self-managing one's disease by taking their own, but prepared, responsibility within the eHealth technology.

Methodological reflection on service modelling for implementing the eHealth technology

This study illustrated the importance of developing a service model from an early stage in the project. Through the process of modelling, new requirements were identified that impacted both the project and the technology design. For example, as mentioned before, it became clear that HCPs should receive an alert when no action is taken from patients. As a consequence, the technology should be able to send those notifications to the clinical dashboard of the HCPs, and further studies in the project should investigate the patient perspective of notifying the HCP of their inactivity and the effect of taking away a degree of responsibility from the patients. This was not uncovered during early requirements elicitation activities and showcases the necessity of early-stage service modelling.

Furthermore, this study also showed the importance of identifying context- and country-specific differences to increase the chances of successful implementation. The RE-SAMPLE project aims to implement its technology in three different countries. Thus, its implementation should also take place locally. Therefore, the service model had to take into account their context to fit to existing structures and possibilities within the healthcare systems of the respective countries. Revealing that service modelling is not a one-size-fits-all approach, not even within one project.

Finally, as previous research also revealed, the implementation of eHealth in general, and the use of implementation models and their related methods, is complex (Gemert-Pijnen et al., 2018; Nilsen et al., 2020; Pieterse et al., 2018). This study

demonstrated similar results by illustrating the complexity of the service modelling method. In particular, we encountered the challenge between developing a more descriptive versus a very prescriptive service model. On the one hand, it is important to develop a service model that aligns with current practice to facilitate the implementation process. If the service model is too far away from current practices, the implementation might fail, and/or HCPs might refuse to use the new technology. On the other hand, a new technology is also supposed to change current practices, making them more efficient, for example. So, while there are some descriptive elements (i.e. current practices, roles, responsibilities), there are of course also several prescriptive elements in the service model that describe the new ways of working. It is a delicate balance how far one can go with prescribing new ways of providing care, even with the support of stakeholders who share new visions or plans to change the provision of care. For example, in this study, research nurses in Italy were supposed to get more responsibilities in the future. However, this has not been established yet in current practice. Some roles (such as the case manager) are not yet operating, making it too risky to assign them with certain tasks or responsibilities in the service model. However, this may change over time, and therefore, a service model might be adapted even after implementation.

Limitations

A limitation of this study is the relatively low number of participants. This may also have affected the stakeholder identification and stakeholder saliency analysis at the beginning. For example, in Estonia, the GP nurse was omitted from the initial stakeholder saliency analysis based on the identification ranking. During subsequent studies, in which more participants were included, GP nurses seemed to be important to include in the process. This is a methodological issue in which results from a low number of participants served as the basis of the development process, marking its consequences during subsequent studies. However, because the salient stakeholders list was not fixed, we were able to adapt accordingly and invited stakeholders identified later in the process.

Another limitation of this study is that, due to the complex nature of the eHealth technology in this study, the actual service model design sessions were performed within the internal project team based on input provided by stakeholders. Stakeholders were not actively involved in the creation, for example, through co-creation. One may question the level of stakeholder engagement when not participating in the design session of the model. However, by adding several feedback rounds in the design process and focusing on specific points for improvements, we tried to collect

useful input for the design. Future studies may include stakeholder co-creation sessions in which the different versions of the service model are designed.

Finally, engagement of patients in the different phases was limited as explaining the concept and importance of service modelling was insufficient to motivate them to participate. In addition, we had some concerns in terms of safety for people with COPD to join the different sessions with other stakeholders (COVID, potential power imbalances (Cvetanovska et al., 2023)). However, everything we did during this study to develop the service model was based on earlier input provided by people with COPD (such as interviews, patient journeys). This is also reflected in the critique during one of the feedback sessions that the service model was too patient-centred. Nevertheless, we recommend future studies to include additional feedback rounds for patients or, if safe (when taken care of power imbalances), let people with COPD join the sessions with the different stakeholders.

Conclusion

This paper described how an innovative eHealth technology to support self-management for people with COPD could be implemented in practice, that emphasises the active role of patients in their care. It aimed to elaborate on an iterative service model development approach, trying to include the perspectives of stakeholders and highlights the self-management component throughout the implementation process.

We showed how an eHealth self-management technology for people with COPD can be implemented in three different countries, in which self-management plays a role in more parts than only within the eHealth technology itself. By illustrating this process, we invite eHealth researchers and practitioners to think beyond the scope of an eHealth solution and to consider the processes of changing roles and empowering patients in the service design.

Service modelling in an early stage can elicit new requirements that need to be addressed in the design and ensures that the implementation process is considered early on, together with key stakeholders. As we aim to positively change work practice with the use of technology, a service model needs to consider both current practice (to enable feasible implementation) and future practice (to improve quality of care). However, as this study demonstrates, there is a fine line between the two worlds. This complexity stresses the importance of continuous stakeholders' engagement and alignment of their

needs, wishes, and current possibilities. Service modelling is therefore not set in stone but shapes along with the dynamics of the changing daily practice.

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Chapter 3: The state of the art of eHealth self-management interventions for people with Chronic Obstructive Pulmonary Disease



Based on:

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Abstract

Introduction: Chronic obstructive pulmonary disease (COPD) is a common chronic incurable disease. Treatment of COPD often focuses on symptom management and progression prevention using pharmacological and nonpharmacological therapies (e.g. medication, inhaler use, and smoking cessation). Self-management is an important aspect of managing COPD. Self-management interventions are increasingly delivered through eHealth, which may help people with COPD engage in self-management. However, little is known about the actual content of these eHealth interventions. This literature review aimed to investigate the state-of-the-art eHealth self-management technologies for COPD. More specifically, we aimed to investigate the functionality, modality, technology readiness level, underlying theories of the technology, the positive health dimensions addressed, the target population characteristics (ie, the intended population, the included population, and the actual population), the self-management processes, and behaviour change techniques.

Methods: A scoping review was performed to answer the proposed research questions. The databases PubMed, Scopus, PsycINFO (via EBSCO), and Wiley were searched for relevant articles. We identified articles published between January 1, 2012, and June 1, 2022, that described eHealth self-management interventions for COPD. Identified articles were screened for eligibility using the web-based software Rayyan.ai. Eligible articles were identified, assessed, and categorised by the reviewers, either directly or through a combination of methods, using Atlas.ti version 9.1.7.0. Thereafter, data were charted accordingly and presented with the purpose of giving an overview of currently available literature while highlighting existing gaps.

Results: A total of 101 eligible articles were included. This review found that most eHealth technologies (91/101, 90.1%) enable patients to self-monitor their symptoms using (smart) measuring devices (39/91, 43%), smartphones (27/91, 30%), or tablets (25/91, 27%). The self-management process of “taking ownership of health needs” (94/101, 93.1%), the behaviour change technique of “feedback and monitoring” (88/101, 87%), and the positive health dimension of “bodily functioning” (101/101, 100%) were most often addressed. The inclusion criteria of studies and the actual populations reached show that a subset of people with COPD participate in eHealth studies.

Conclusions: The current body of literature related to eHealth interventions has a strong tendency toward managing the physical aspect of COPD self-management. The necessity

to specify inclusion criteria to control variables, combined with the practical challenges of recruiting diverse participants, leads to people with COPD being included in eHealth studies that only represent a subgroup of the whole population. Therefore, future research should be aware of this unintentional blind spot, make efforts to reach the underrepresented population, and address multiple dimensions of the positive health paradigm.

Introduction

Chronic obstructive pulmonary disease (COPD) is a common disabling lung condition characterised by chronic respiratory symptoms that cause persistent, mostly progressive airflow limitations (Bednarek et al., 2008). It is one of the major issues of public health, and its prevalence, mortality, and morbidity are increasing (Bednarek et al., 2008; Jankowska-Polańska et al., 2016; Mannino & Buist, 2007). COPD was listed as the third leading cause of death worldwide in 2019 (World Health Organization (WHO), 2023), and it is estimated that by 2040, deaths from COPD will rise to 4.4 million per year (Foreman et al., 2018). In addition, people with a lower socioeconomic status are at increased risk of developing COPD (Gershon et al., 2012). Although COPD may, in some cases, be the result of a genetic risk factor, it is, in most cases, caused by exposure to tobacco smoking and the inhalation of toxic particles and gases from indoor and outdoor air pollution (GOLD, 2024; Sin et al., 2023). People with COPD often experience symptoms such as dyspnea, fatigue, chest tightness, activity limitation, and cough that may be accompanied by sputum production (GOLD, 2024). Furthermore, they may experience acute events, known as exacerbations, which can lead to hospitalization. Although COPD is chronic and thus not curable, it is, however, treatable, and disease progression is preventable (Mannino & Buist, 2007; Valipour et al., 2022). Therefore, the treatment of COPD often focuses on reducing symptoms and future risks of exacerbation with the use of pharmacological and nonpharmacological therapies (e.g. inhaler use, vaccinations, smoking cessation, and self-management)(GOLD, 2024). Given its chronic nature and the impact of the disease on all facets of one's life, an important aspect of treating COPD and secondary prevention is chronic disease management.

An essential component of chronic disease management is self-management (Huygens et al., 2016). Owing to the variation in the literature regarding the definition of self-management in COPD, this paper defines self-management as follows: “The ability of an individual to manage one's symptoms, treatment, physical, social, and emotional consequences, and lifestyle changes. It includes means of empowerment, educating oneself, being autonomous, learning and adapting to new behaviours, acceptance, and adapting to a new balance in life.” It requires patients to take an involved and responsible role in their health, with the aim of becoming active participants (Auduly et al., 2010; Huygens et al., 2016). Self-management interventions or programs are developed to help patients engage in self-management, and their effectiveness is investigated in research.

Self-management interventions or programs are shown to have positive effects, for example, in supporting patients to develop and improve their self-management skills and disease knowledge (Effing et al., 2012; Hosseinzadeh & Shnaigat, 2019; Murphy et al., 2017). Camus-García et al., (2021) found that self-management interventions may improve clinical outcomes in COPD (e.g. improvements in health-related quality of life) and lower the probability of hospital admissions. The actual content of such self-management intervention programs for COPD is diverse (Effing et al., 2012), and it remains unclear which specific elements are essential for designing a successful program. In the following sections, some elements that can be considered when designing an intervention program will be briefly described: content for COPD self-management, processes of self-management, and behaviour change techniques (BCTs).

The diversity of content may be explained by the numerous objectives and endpoints of self-management intervention programs (Bourbeau & Van Der Palen, 2009). Interventions focus on acute exacerbation management and admission avoidance by incorporating exacerbation action plans (Lenferink et al., 2017) and often also include education, exercise training, and breathing strategies (Bourbeau et al., 2004). However, research suggests that intervention programs that only include education or action plans alone may not result in behavioural change, increased patient confidence, or the acquisition of new skills that patients learn or practice (Bourbeau & Van Der Palen, 2009; Russell et al., 2018).

Besides the content of self-management intervention programs, the design of the intervention program should also reflect that self-management consists of different processes. Schulman-Green et al., (2012) identified different self-management processes for chronic illnesses, such as “learning,” “taking ownership of health needs,” and “performing health promotion activities.” All processes are divided into specific self-management tasks (e.g. “learning about condition and health needs” and “changing behaviour to minimise health impact”) and skills (e.g. “acquiring information” and “reducing stress”)(Schulman-Green et al., 2012). Schulman-Green et al., (2012) concluded that the identification of such processes may help support and guide future self-management intervention programs. They also demonstrated that these various processes should be viewed within the broader context, as their significance to patients may vary depending on where they are in their patient journey (Schulman-Green et al., 2012). Therefore, more knowledge about such self-management processes within self-management eHealth intervention programs is needed to support the development of such interventions.

Self-management interventions may also aim to change a certain behaviour of the patient, so the incorporation of BCTs can be beneficial to designing a successful intervention program. A BCT is “a specific observable, replicable, and irreducible component of an intervention program designed to alter or redirect causal processes that regulate behaviour” (Michie et al., 2013) and can be included in the design of any type of self-management intervention program. By adding these “active ingredients” (e.g. “feedback” and “self-monitoring”), chances for achieving behavioural change may be increased (Michie et al., 2013). Thus, combining self-management processes and BCTs in intervention programs may lead to positive results for one’s self-management. However, to the best of our knowledge, no research is dedicated to investigating the presence of BCTs and self-management processes in current self-management interventions for COPD.

One way to support people with COPD in engaging in self-management is through the use of eHealth interventions. eHealth interventions can be defined as “An eHealth technology specifically focused on intervening in an existing context by changing behaviours and/or cognitions” (van Gemert-Pijnen et al., 2018). eHealth interventions to support self-management may help people with chronic diseases become more independent and empowered by, for example, gaining knowledge about their disease, monitoring and reporting daily symptoms, and learning specific self-management skills (Bourne et al., 2022; Effing et al., 2016; Lundell et al., 2020). Therefore, the use of eHealth interventions in COPD care represents a promising way of delivering health services, such as support in self-management (Marklund et al., 2021).

In the current literature, a diverse range of eHealth interventions aim to support patients in their self-management, and these are increasingly provided to support patients in health communication, self-monitoring, and their medical treatment (Huygens et al., 2016; Marklund et al., 2021). Available literature revealed that current eHealth interventions for COPD mainly focused on COPD care, education, smoking cessation, medication adherence, exercise, diet, and symptom management (Hallensleben et al., 2019; McCabe et al., 2017). This indicates a tendency toward managing the physical aspect of COPD in self-management eHealth interventions. However, the physical aspect of one’s disease is only 1 dimension of the positive health paradigm. As conceptualized by Huber et al., (2011) “Health includes the ability to adapt and self-manage in the face of social, physical, and emotional challenges,” also referred to as “positive health”. Huber et al., (2016) stated that positive health as a concept has several important health indicators, categorised into 6 dimensions: “bodily functions,”

“mental well-being,” “meaningfulness,” “quality of life,” “social participation,” and “daily functioning” (Huber et al., 2016). They stressed the fact that paying attention to these indicators could support shared decision-making and bridge the gap between health care and the social context. Therefore, these dimensions are all important to consider when self-managing one’s disease. However, no research is available regarding the extent of positive health dimensions addressed in current self-management eHealth interventions for COPD.

Furthermore, using eHealth to support people with COPD might entail some challenges, as low health literacy is prevalent among people with COPD (Kale & Federman, 2015; Roberts et al., 2008). In addition, moderate levels of self-reported eHealth literacy are common among people with COPD (Stellefson et al., 2018). Some studies revealed that people with COPD experienced technical barriers when using eHealth interventions for self-management (Nguyen et al., 2008). However, Williams et al., (2014) indicated a few technical issues experienced by people with COPD when using eHealth to support self-management, leading to uncertainty about whether such eHealth technologies are suitable for the whole COPD population. Although some information about eHealth use for this population is available (Bakker et al., 2019; Hallensleben et al., 2019; McCabe et al., 2017; Stellefson et al., 2018; Williams et al., 2014), little research is dedicated to investigating whether current eHealth interventions account for the wider population of people with COPD (such as those with eHealth literacy). Therefore, it should be investigated whether there is a difference between the intended population that eHealth interventions aim to target and the eventual included population in those studies. As knowledge and new insights derived from those studies often serve as a starting point for future work, it can be very valuable to look into the representation of the COPD population within studies.

To summarize, little is known about the actual content and design of self-management eHealth interventions for people with COPD. Therefore, this scoping review aimed to investigate the current state-of-the-art eHealth interventions for COPD self-management and identify potential gaps in the literature, which may provide insight into or serve as inspiration for the development of future eHealth self-management interventions. “State of the art” within the context of this study can be defined as follows: “The collection of all underlying components that form the basis for the eHealth self-management interventions for people with COPD.” Figure 3 shows how the different parts of this review contribute to an overall picture of the current literature and highlights the specific aspects explored in this review. More specifically, we aimed

to unravel the state of the art of eHealth self-management interventions by using the following sub-questions:

- What is the ‘e’ in eHealth self-management?
- What is the ‘health’ in eHealth self-management?
- Who is the ‘self’ in self-management?
- What is the ‘management’ in eHealth self-management?

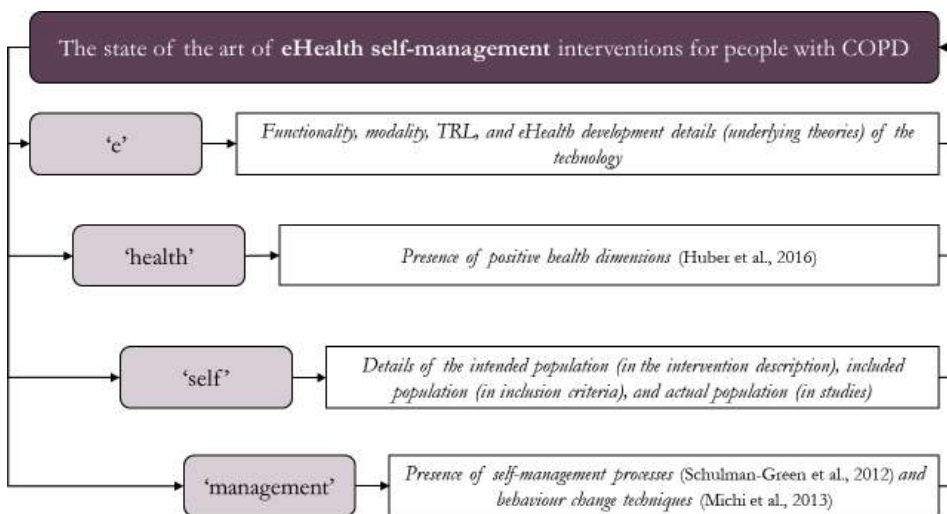


Figure 3. Flowchart of Research Questions. COPD: Chronic Obstructive Pulmonary Disease; TRL: Technology Readiness Level.

Methods

Overview

A scoping review was performed to investigate the currently available literature. According to Munn et al., (2018), a scoping review is an ideal tool for providing, for example, an overview of existing literature, identifying key characteristics, and highlighting knowledge gaps, among others. Hence, this was deemed the most suitable method for answering the proposed research questions. Parts of the PRISMA-ScR (Preferred Reporting Items For Systematic Reviews and Meta-Analyses extension for Scoping Reviews) protocol (items 1-7, 9-11, and 13-21), as proposed by Tricco et al., (2018), were followed and tailored to this study to ensure a systematic approach for

answering the research questions. The PRISMA-ScR checklist is provided in Multimedia Appendix 3.1 (Tricco et al., 2018). The protocol for this review was not published.

Search Strategy

The first reviewer (EtB) was responsible for identifying relevant articles in the databases PubMed, Scopus, PsycINFO, and Wiley. Combinations of the search terms “self-management,” “COPD,” and “eHealth” were used to generate the search string. The search string that was used for this review is provided in Multimedia Appendix 3.2.

Study Selection

Studies were considered eligible if they were original research and portrayed an eHealth intervention supporting the self-management of COPD. The eHealth self-management intervention should actively involve and engage individuals with COPD, ensuring they experience personal benefits from their self-management efforts, supported and encouraged by the intervention. By definition, self-management aims for patients to become active participants in their care, which means that patient involvement within self-management eHealth interventions is essential to be able to fulfil an active role. Therefore, we did not consider that eHealth interventions actually support self-management when patients themselves are not involved (e.g. if the interaction with the eHealth service is limited to collecting data). Furthermore, articles needed to be published between January 1, 2012, and June 1, 2022. As of 2012, eHealth technologies were upcoming, and their relevance for future health care appeared to be promising. For example, national efforts to implement eHealth in current care were presented in 2012 in the Netherlands (e.g. Nederlandse Patiënten Consumenten Federatie (NPCF) et al., (2012)). The complete list of assessment and eligibility criteria is presented in Textbox 1

Textbox 1. Assessment and Eligibility Criteria for Studies.

Concept

- Studies describing an eHealth intervention supporting the self-management of chronic obstructive pulmonary disease (COPD) were included.
- Studies not fulfilling the inclusion criteria were excluded.

Population

- Studies involving adults aged ≥ 18 years diagnosed with COPD (and other chronic conditions, provided that the eHealth technology has a dedicated part toward COPD) were included.
- Studies using general terms such as “older adults,” “rural patients,” or “communities”, or referencing unspecified multimorbidity or chronic conditions without any clarification about the population were excluded.

eHealth technology

- Studies where eHealth technologies were used to support people with COPD in engaging in self-management, involving patients in their intervention, were included if they used at least 1 self-management process, as defined by Schulman-Green et al., (2012), and in the case of sole monitoring, where patients were able to see their data.
- Studies collecting data solely for research purposes to train machine learning or artificial intelligence algorithms without any further patient engagement were excluded.

Study design

- Original research studies were included.
- Reviews, protocols, abstracts, letters, conference proceedings, commentaries, notes, short surveys, and erratum were excluded.

Language

- Studies in English were included.
- Studies not fulfilling the inclusion criteria were excluded.

Year of publication

- Studies published between January 1, 2012, and June 1, 2022, were included.
 - Studies not fulfilling the inclusion criteria were excluded.
-

Procedure

The screening was performed on June 3, 2022, with screening supported by the web-based software Rayyan.ai (Rayyan, 2022). To screen articles for title and abstract, both reviewers (EtB and RV) adhered to the eligibility criteria that were discussed before the start of the screening (Textbox 1). One reviewer (EtB) screened all articles for title and abstract. The second reviewer (RV) screened 20% (118/588) of the titles and abstracts

of those studies. After this first screening, a discussion took place to compare discrepancies and come to a consensus between reviewers (EtB and RV). Both reviewers had previous experience with performing a systematic review. After this first screening, it was necessary to revise and clarify some of the inclusion criteria to arrive at a satisfactory level of agreement between reviewers. This means that with the use of the revised inclusion criteria, clear and substantiated decisions could be made on whether to include a certain article in this review. For the full-text screening, the same process was applied. In this screening, the level of agreement between reviewers was satisfactory. Reasons for excluding articles during the full-text screening were recorded. Before extracting the data, a data extraction form was developed, discussed, and agreed upon with 3 authors (EtB, CG, and MT). This form was piloted after the full-text screening to reduce errors during data extraction. Data extraction was performed by the first author (EtB) using Atlas.ti (version 9.1.7.0; Lumivero) (ATLAS.ti Scientific Software Development GmbH., 2021), based on the data extraction form. Some of the data to answer the subquestions were directly extracted (e.g. type of study and year of study), some data were the result of an assessment or categorization of the reviewers (e.g. positive health dimensions), and some data were a combination of both (e.g. BCTs). After the extraction, data were clustered and charted in various ways (e.g. bar charts, tables, and descriptive presentations). Finally, charted data were scrutinized and synthesized by 1 reviewer (EtB) before discussing the results with 2 authors (CG and MT). Thereafter, results were written down to answer the proposed research questions. An overview of how the articles were extracted and charted is provided in Multimedia Appendix 3.3.

Results

Search Results

Figure 4 shows the detailed flowchart of the inclusion of studies. A total of 893 articles were identified during the initial search, of which 305 (35.1%) duplicates were removed, and the remaining 588 articles were screened on title and abstract; this screening phase resulted in 189 (32.1%) articles that could be assessed for full text. After full-text screening of 189 articles, 88 articles (46.6%) were excluded, resulting in 101 articles (53.4%) being included in this scoping review.

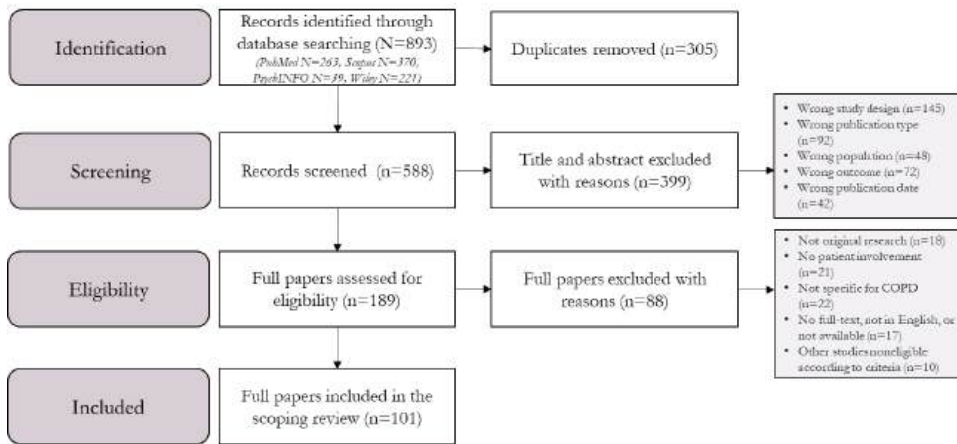


Figure 4. Flowchart of the Inclusion of Studies.

Study Characteristics

The included papers represented 101 unique studies. Most articles (18/101, 17.8%) were published in 2021, followed by 2020 (15/101, 14.8%) and 2017 (13/101, 12.9%). As shown in Table 5, the most common study types were either randomised controlled trials (18/101, 17.8%) or (prospective) pilot studies (16/101, 15.8%).

Table 5. Type of studies (N=101).

Type of studies	Frequency, n (%)
Randomised controlled trials	18 (17.8)
Prospective pilot study	17 (16.8)
Evaluation study	10 (9.9)
Feasibility study	9 (8.9)
Qualitative study	9 (8.9)
Retrospective or secondary analysis	7 (6.9)
Observational study	6 (5.9)
Design or development study	4 (4)
Implementation study	3 (3)
Mixed methods study	3 (3)
Exploratory study	3 (3)
Others	12 (11.9)

The e in eHealth

This section focuses on the functionality, modality, technology readiness level (TRL) (Jansen-Kosterink et al., 2022), and eHealth development details of the used technologies. Details about the functionality and modality of the eHealth interventions are provided in Multimedia Appendix 3.4. Of the 101 included studies, 76 (75.2%) mentioned the name of their eHealth technologies. Some articles reported on studies using the same eHealth technologies (e.g. “EDGE” (Farmer et al., 2017; Hardinge et al., 2015; Velardo et al., 2017; Whelan et al., 2019; Williams et al., 2014), “It’s Life!” (Van Der Weegen et al., 2013, 2015; Verwey et al., 2014), “MasterYourBreath” (Voncken-Brewster et al., 2013, 2014, 2015, 2017), and “COMET” (Bourbeau et al., 2016; Kessler et al., 2018). In some cases, studies using the same eHealth technology together portrayed the process of developing, testing, and evaluating an eHealth intervention. A total of 50 unique eHealth technologies were found in this review.

Most articles (91/101, 90.1%) included self-monitoring (e.g. monitoring of symptoms) as a function of their technology. Of the 101 articles, 69 (68.3%) included the function of educating or informing (e.g. education on COPD) and 27 (26.7%) supported communication (e.g. eConsults with HCPs and peer-to-peer support chats). Most articles (68/101, 67.3%) included >1 function within their technology.

Table 6 shows that a (smart) measurement device (e.g. wearable or monitoring system) was the most common (39/101, 38.6%) modality used in the studies, followed by a smartphone (27/101, 26.7%) and tablet (25/101, 24.7%). If studies used >1 device, the most common combination was a (smart) measurement device with a tablet (19/101, 18.8%) or smartphone (8/101, 7.9%).

Table 6. Overview of modalities of the eHealth technologies. Some articles had used >1 device, resulting in 131 modalities within 101 articles.

Modalities of the eHealth technology	Frequency, n (%)
Smart measurement and monitoring devices	45 (34.4)
Smartphone	26 (19.8)
Normal phone or landline	16 (12.2)
Computer, laptop, or whiteboard	16 (12.2)
Tablet	15 (11.5)
Not mentioned	9 (6.9)
Television	3 (2.3)

Other	1 (0.8)
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This review found no article that explicitly stated their TRL. According to our assessment and categorization, 47 eHealth technologies in the articles were assessed to be in the development phase (TRL 4 to TRL 6), 53 in the deployment phase (TRL 7 to TRL 9), and 0 in the research phase (TRL 1 to TRL 3).

Details about the eHealth development process showed that only 14 (13.9%) out of 101 studies explicitly mentioned using either a user-centred design, participatory design, scenario-based methods, reflective lifeworld research, or action research approach. Furthermore, of the 101 studies, 18 (17.8%) reported details about the theories on which their self-management intervention was based. Some of these were targeted toward BCTs independent of technology use, while others were technology related and more targeted toward technological adoption or persuasive design. Table 7 lists the various theories identified as underlying the eHealth interventions. Theories that were present could be divided into the following categories: behavioural change, technological adoption, or persuasive design, and unspecified. This review found 11 different behaviour change theories, 3 different technological adoption or persuasive design theories, and 3 unspecified theories. Of all the different theories within the different categories, the social cognitive theory was most often used (5/11, 45%).

Table 7. Theories used within the eHealth self-management interventions.

Categories and theories	References
<i>Behavioural change</i>	
Health Belief Model (HBM)	(Alharbey & Chatterjee, 2019; Voncken-Brewster et al., 2017)
Social cognitive theory	(Coultas et al., 2018; Coventry et al., 2019; Jolly et al., 2018; Park et al., 2020; Voncken-Brewster et al., 2017)
Self-care theory	(Bugajski et al., 2020)

Transtheoretical model	(Coultas et al., 2018; Voncken-Brewster et al., 2017)
Five A's model	(Verwey et al., 2014)
Attitude-Social Influence-Self-Efficacy Model (ASE)	(Voncken-Brewster et al., 2017)
Self-efficacy theory	(Hoaas et al., 2016)
I-Change model	(Voncken-Brewster et al., 2013, 2014, 2015, 2017)
Self-determination model	(Miller et al., 2021)
Tech to Goal (TGG)	(Thomas et al., 2017)
Theory of Planned Behaviour	(Voncken-Brewster et al., 2017)
<i>Technological adoption or persuasive design</i>	
Technology Acceptance Model (TAM)	(Bentley et al., 2020)
Unified Theory of Acceptance and Use of Technology (UTAUT)	(Robinson et al., 2020)
eHealth-based Person-Centred Care (PCC)	(Barenfeld et al., 2020)
<i>Unspecified</i>	
Goal-setting theories	(Voncken-Brewster et al., 2017)
Implementation theory	(Voncken-Brewster et al., 2017)
Health promotion	(Hoaas et al., 2016)

The Health in eHealth Technologies for Self-Management

Table 8 shows how many eHealth technologies used in the studies addressed the different positive health dimensions. All the included articles (N=101, 100%) addressed (at least) the dimension of bodily functioning, 45 (44.6%) addressed daily functioning, 13 (12.9%) addressed participation, and 12 (11.9%) addressed mental well-being. We were not able to identify any indications that the dimensions of meaningfulness and quality of life were explicitly addressed in any of the eHealth technologies supporting self-management. Details about the positive health dimensions are provided in Multimedia Appendix 3.5.

Table 8. Distribution of the positive health dimensions. Some technologies addressed >1 dimension, which are counted separately in this table, resulting in 172 dimensions found within 101 articles.

Positive Health Dimension	Frequency, n (%)
Bodily functioning	101 (58.7)
Daily functioning	46 (26.7)
Participation	13 (7.6)
Mental well-being	12 (7)
Meaningfulness	0 (0)
Quality of life	0 (0)

Most studies (48/101, 47.5%) focused on 1 specific dimension, namely, bodily functioning. Other articles (42/101, 41.6%) focused on 2 dimensions, 11 (10.9%) on 3 dimensions, and only 3 (3%) on 4 dimensions within their eHealth technology. The combination of the dimensions of bodily functioning and daily functioning was the most common (33/101, 32.7%), followed by the combinations of bodily functioning, daily functioning, and mental well-being (5/101, 5%); bodily functioning and participation (4/101, 4%); bodily functioning, daily functioning, and participation (3/101, 3%); bodily functioning, mental well-being, and participation (3/101, 3%); body functioning, mental well-being, participation, and daily functioning (3/101, 3%); and bodily functioning and mental well-being (1/101, 1%).

To investigate whether there may be an increase or decrease in certain positive health dimensions over time, we compared the presence of certain dimensions with the years of the studies (Figure 5). Such information can be useful to see whether the target dimensions of eHealth interventions are changing with time. When comparing the presence of the dimensions with the years of the studies, we found that in the years 2013 to 2015 and 2017 to 2018, the dimension of bodily functioning is dominantly present, followed by daily functioning. From 2017 to 2021, a small increase in the presence of the dimension of mental well-being could be seen over the years. In the years 2020 and 2021, the presence of the dimensions of daily functioning and participation was almost equal compared to bodily functioning.

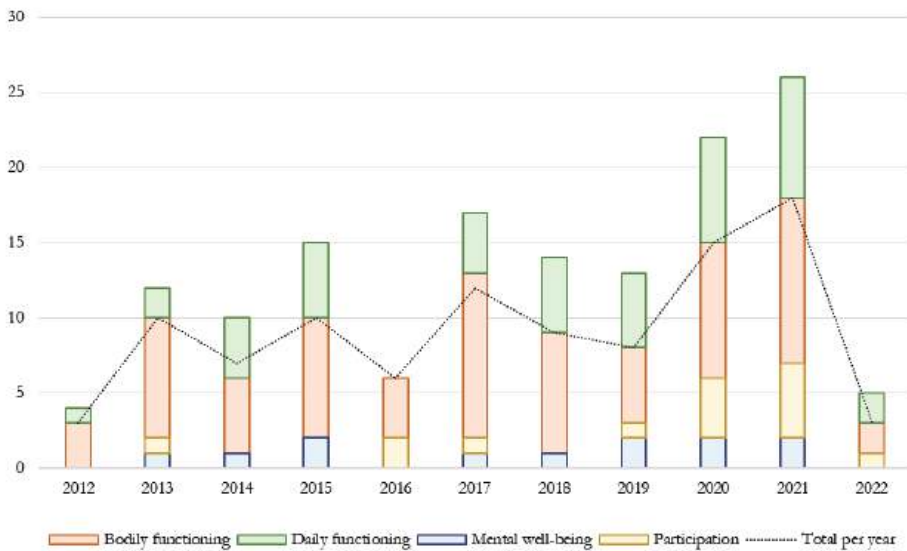


Figure 5. Distribution of the positive health dimensions in articles over time. Dimensions of “quality of life” and “meaningfulness” were not displayed, as no included articles explicitly addressed these.

The Self in Self-Management

Overview

All 101 included papers (partly) described the intended population for the intervention (as stated in the intervention description), the included population (as stated in the inclusion and exclusion criteria), and the final actual study population (as stated in the demographics of study participants). In some studies, certain inclusion criteria were required to participate, thereby restricting the group of eligible participants (ie, the actual population). This scoping review extracted the following inclusion criteria: disease-specific (needing to have a certain severity of COPD), capability-related (needing to be cognitively capable, able to read and write, understand certain language, willing or able to provide consent), age-related (needing to have a minimum or maximum age), smoking history–related (being a current or former smoker), and technology-related (needing to have digital skills, internet access, own a certain device). More details about the concept of the self in self-management are provided in Multimedia Appendix 3.6.

Intended population

There was some variation in the specific intended populations targeted in the articles. As shown in Figure 6, most studies (59/101, 58.4%) were targeted at persons with COPD in general, with 23 (22.8%) focusing on ≥ 1 specific COPD severities and 19 (18.8%) focusing on COPD in combination with other chronic conditions. Some articles included >1 comorbidity.

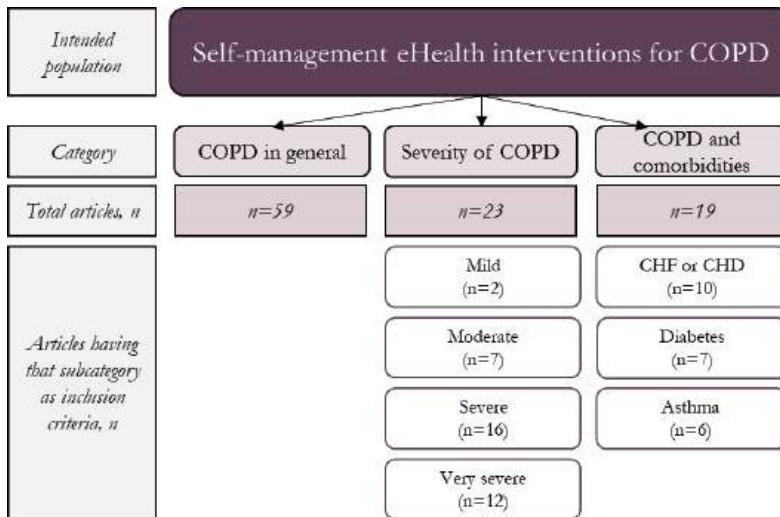


Figure 6. Intended Population.

Included Population

Figure 7 presents an overview of the identified included population. More studies (50/101, 49.5%) than outlined in the Intended Population section (23/101, 22.8%) had disease-specific inclusion criteria (focusing on ≥ 1 COPD severities). Of the 101 articles, 50 (49.5%) had capability-related inclusion criteria, requiring participants to, for example, be cognitively capable or able to write and read to be eligible for participation. Furthermore, in 37.6% (38/101) of the articles, participants needed to have a certain minimum age, with 40 years being the most common. In 7.9% (8/101) of the articles, the age needed to be below a certain maximum. The maximum age of 70 years was the most commonly mentioned inclusion criterion, cited 4 times. A total of 12 (11.9%) out of 101 articles had inclusion criteria regarding smoking (history) in which participants needed to be, for example, a former smoker. Finally, 38.6% (39/101) of the articles had technology-related inclusion criteria. Participants needed, for example, to own a smartphone or tablet and have digital skills to participate. Only 1 study explicitly

mentioned having no exclusion criteria based on age, comorbidities, and previous participation in pulmonary rehabilitation. Furthermore, in the same study, participants did not need to have previous experience using digital technology.

Included population						
Inclusion criteria to participate in eHealth self-management intervention studies for COPD						
Category	Disease specific	Capability	Minimum age	Maximum age	Smoking history	Technology
Total articles, n	n=50	n=50	n=38	n=8	n=12	n=38
Articles having the subcategory as inclusion criteria, n	Mild (n=4)	Cognitively capable (n=12)	18 years (n=12)	70 years (n=4)	Former smoker (n=11)	Own a certain device (n=21)
	Moderate (n=21)	Able to write and read (n=10)	35 years (n=1)	75 years (n=2)	≥10 pack years (n=11)	Potential internet access (n=17)
	Severe (n=28)	Understand language (n=24)	40 years (n=20)	80 years (n=1)		Have digital skills (n=7)
	Very severe (n=20)	No sensory/physical/psychiatric impairment (n=15)	45 years (n=4)	85 years (n=1)		
		Willing to or able to provide consent (n=5)	65 years (n=1)			

Figure 7. Included Population.

Actual Population

Figure 8 shows the actual population included in the studies. In 24.7% (25/101) of the articles that mentioned the severity of their participants, most participants had moderate or severe COPD. Out of the 101 articles, only 21 (20.8%) shared a clear description of the education level of their participants, which were then categorised for this study. The educational level of participants could be categorised as low, medium, and high, which were almost equally distributed. Of the 70.3% (71/101) of the articles that shared the mean age of their participants, we calculated the combined mean age, which resulted in 64.85 years. The gender of participants was clearly mentioned in 88 (87.1%) out of 101 articles and was almost equally distributed. In 29.7% (30/101) of the articles that shared the smoking history of their participants, almost half of the participants (51%) were reported as current or former smokers. In 10.9% (11/101) of the articles that described technology-related experience, 89% of the participants had experience with technology.

The Management in Self-Management

This section describes which self-management processes and BCTs were found within the different eHealth technologies. Details about this section are provided in Multimedia

Appendix 3.7 (overview of self-management processes) and Multimedia Appendix 3.8 (overview of BCTs).

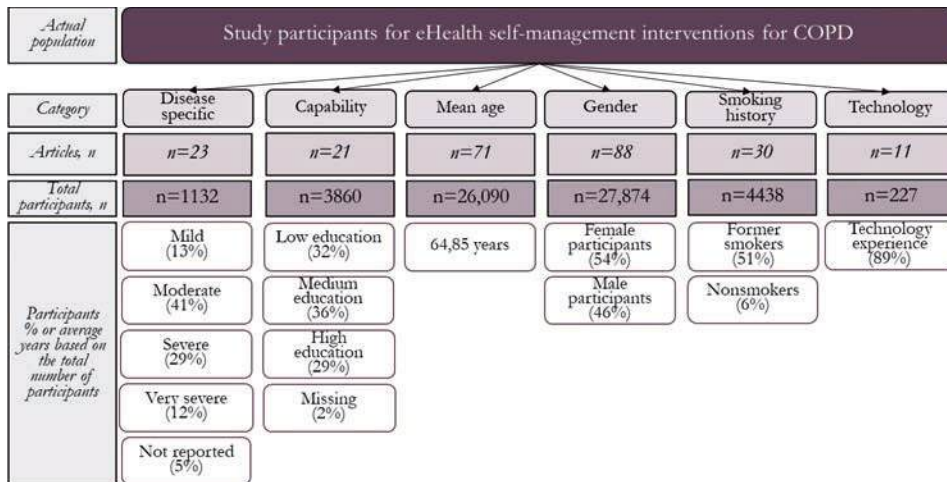


Figure 8. Actual Population.

Self-Management Processes

Table 9 shows the self-management processes found in the articles. No article explicitly described which self-management processes were reflected in the intervention design. When analysing how self-management processes were supported within the different studies, we identified that most studies (94/101, 93.1%) addressed the process of taking ownership towards health needs (e.g. by including self-monitoring of symptoms or setting goals). Of the 101 included studies, 71 (70.3%) focused on the process of learning (e.g. by including education within their technology), 27 (26.7%) on health care resources (e.g. by enabling communication with health care professionals within the technology), 23 (22.8%) on performing health promotion activities (e.g. by performing exercise or skill training), 17 (16.8%) on social resources (e.g. by involving caregiver and family or peer-to-peer support), 1 (1%) on adjusting (e.g. ways to cope), and 1 (1%) on integrating illness into daily life (e.g. alternating daily lives to conserve energy). We found no eHealth technologies specifically focusing on the self-management processes: meaning making, spiritual resources, psychological resources, processing emotions, or community resources.

Table 9. Self-management processes within eHealth technologies. Each process is counted separately in this figure resulting in 234 self-management processes within 101 articles. “Meaning making,” “spiritual resources,” “psychological resources,” “processing emotions,” and “community resources” were not displayed, as these processes were not included.

Self-management process	Frequency, n (%)
Taking ownership of health needs	94 (40.2)
Learning	71 (30.3)
Health care resources	27 (11.5)
Performing health promotion activities	23 (9.8)
Social resources	17 (7.3)
Adjusting	1 (0.4)
Integrating illness into daily life	1 (0.4)

BCTs Used

Table 10 shows the BCTs extracted in this study. Only 2 (2%) out of 101 studies explicitly stated which BCTs were used. When analysing the descriptions in the studies, we identified that feedback and monitoring were mostly used in the different articles (88/101, 87.1%; e.g. monitoring activity status). This was followed by shaping knowledge (66/101, 65.3%; e.g. receiving education), goals and planning (38/101, 37.6%; e.g. action planning), associations (23/101, 22.8%; e.g. receiving status updates), social support (14/101, 13.7%; e.g. communication with other people with COPD), regulation (11/101, 10.9%; e.g. addressing medication adherence), repetition and substitution (10/101, 9.9%; e.g. habit formation), rewards and threat (6/101, 5.9%; e.g. receiving visual rewards), natural consequences (5/101, 4.9%; e.g. information about health consequences), self-belief (5/101, 4.9%; e.g. increasing self-efficacy), comparison of behaviour (5/101, 4.9%; e.g. follow along exercise video), comparison of outcomes (2/101, 2%; e.g. information about the effect of physical activity), antecedents (1/101, 1%; e.g. adding objects to the environment), and identity (1/101, 1%; e.g. prompt identification as a role model). The BCTs of covert learning and scheduled consequences were not observed in the studies.

Table 10. Behaviour change techniques within eHealth technologies. Each technique was counted separately in this figure. Resulting in 275 behaviour change techniques within 101 articles. “Scheduled consequences” and “covert learning” were not displayed, as these processes were not included.

Behaviour change technique	Frequency, n (%)
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Feedback and monitoring	88 (32)
Shaping knowledge	66 (24)
Goals and planning	38 (13.8)
Associations	23 (8.4)
Social support	14 (5.1)
Regulation	11 (4)
Repetition and substitution	10 (3.6)
Rewards and threat	6 (2.2)
Natural consequences	5 (1.8)
Comparison of behaviour	5 (1.8)
Self-belief	5 (1.8)
Comparison of outcomes	2 (0.7)
Identity	1 (0.4)
Antecedents	1 (0.4)

Discussion

Principal Findings

This scoping review outlines the state of the art of eHealth self-management interventions for COPD. In the current literature, most eHealth technologies for COPD self-management focus on the physical aspect of self-management. eHealth technologies that include other aspects (e.g., the social or mental aspects) are currently underrepresented in the literature. Moreover, it appeared that although eHealth interventions often aimed to target the whole COPD population, mostly only a subgroup of the COPD population was represented within the eHealth technology studies.

Self-management of COPD

Underlying Theories, Techniques, and Processes

Only a few studies (32/101, 31.7%) reported on using underlying theories and specific BCTs supporting their self-management eHealth interventions. No article explicitly mentioned focusing on certain self-management processes. This is surprising, given the fact that all studies aim to improve self-management and thus aim to achieve some sort of behavioural change. As the concept of self-management varies in the literature, reporting on the use of such processes, techniques, and theories may be beneficial for understanding underlying structures and processes that will initiate behaviour change to

improve self-management. Building on these processes, techniques, and theories and providing more detailed reports on what was perceived as useful, beneficial, and desirable for this target population can help advance the field and contribute to the existing body of work. This may simultaneously be valuable for informing future eHealth self-management initiatives as they can take into account these theories, techniques, and processes in their developments. When looking at the literature, the lack of reporting on underlying theories was prevalent in the review of Heimer et al., (2023), in which only 3 of the included studies reported specific BCTs. Furthermore, other studies encountered the problem of low reporting on BCTs; Hardeman et al., (2008) and Lorencatto et al., (2013) concluded that fewer than half of the planned BCTs were specified in the final published articles. In addition, a review from de Bruin et al., (2021) revealed that reporting about the active content of behavioural interventions varies considerably between studies. This limits the readers' ability to compare, interpret, and generalize the effects of these studies (de Bruin et al., 2021). Thus, including such theories in eHealth interventions and transparency in later reporting may lead to opportunities for achieving sustainable behavioural change.

The Physical Aspects of Self-Management

As we found in this review, there is a tendency toward managing the physical aspect of one's disease in current eHealth technologies for COPD self-management. This is reflected throughout the different findings of this review. First, the functionality "self-monitoring" and the BCT "feedback and monitoring" were most often addressed. Although self-monitoring is very valuable and exacerbations may be detected at an early stage, this, nonetheless, demonstrates that the main focus lies on what happens with or inside the body. Second, the dominant physical aspect also manifests itself when looking at the self-management processes that are supported by the different technologies: "psychological resources," "spiritual resources," and "community resources" were not found to be included. The self-management process of "taking ownership of health needs" was mostly present, followed by "learning." However, other processes, such as "integrating illness into daily life" and "adjusting," were only observed once, although the target group had to deal with these aspects every single day (Kaptain et al., 2022). We believe that not addressing these processes is a missed opportunity, given that supporting people with COPD during their day-to-day activities might lead to even better improved outcomes of self-management. Finally, the dimensions of bodily functioning and daily functioning were most frequently used. This illustrates the current underrepresentation of other dimensions within current eHealth technologies for

COPD self-management. Other dimensions (e.g. participation and mental well-being) were not as dominantly represented or not observed at all (e.g. meaningfulness and quality of life). As we observed a small increase in dimensions over the past few years, we might notice a small change of focus. However, this is not as fundamental and still leaves a lot of room for improvement on this matter. When examining other chronic diseases (e.g. rheumatoid arthritis), a review by Seppen et al., (2020) identified 4 different types of eHealth interventions used in the included articles. Although not explicitly stated, interventions were all related to the physical aspect (ie, medication adherence, activity plan, information, disease monitoring, and activity monitoring) (Seppen et al., 2020). Thus, the tendency of the physical domain may not only be limited to COPD. Therefore, future studies should investigate whether this view is also present in other chronic diseases.

Inclusiveness and Representation of People with COPD

As all eHealth technologies target people with COPD as end users, only 14 (13.9%) out of 101 articles reported involving the patient perspective in their design or development process. This raised the question of whether and how the needs and perspectives of patients were taken into account. As including the perspective of end users leads to a better fit and increases the chances of successful adoption and sustained use (Kip & van Gemert-Pijnen, 2018), researchers should consider using such design principles when developing future eHealth technologies. This may provide many opportunities for improvements in self-management eHealth technologies for COPD.

Furthermore, it appeared that although articles outlined the target group to be the general population of people with COPD, they often recruited a specific subset of people with COPD. Certain inclusion criteria are made within the studies (e.g. needing to own a smartphone and needing to have a certain disease severity). The consequence of such inclusion criteria leads to a restriction, in that only a selected group of individuals are included in the studies. While this may be due to practicalities (e.g. the complexity of COPD as a progressive lung disease), the question remains whether the intervention is generalizable or applicable to the wider population of people with COPD, especially if they were not part of the studies in the first place. This is particularly relevant as there is no golden standard to determine, for example, when someone is considered too old to participate, and opinions on such matters are likely to vary widely among researchers. Even when the restricting the patient group may be justified for the study purposes, it still affects the generalizability of study results. Therefore, awareness and transparency

should be provided regarding these potential restrictions related to the patient group within such studies.

Given that the most often used device is a (smart) measurement device (in combination with), a smartphone, or tablet, the group of people eligible to use these technologies in daily life is further limited. Effectively, this means that certain groups of people (e.g. those who lack resources to buy these devices) are not included in the research and, therefore, the intervention might not be tested on people who are unfamiliar with smart devices or have low digital literacy. Previous studies showed that moderate levels of eHealth literacy and low levels of health literacy are prevalent among the COPD population (Roberts et al., 2008; Stellefson et al., 2018). Thus, we cannot assume that this population has access to eHealth technologies and has mastered the skills to manage such interventions without any support. Therefore, guidance should be made available to help those who need support in using these eHealth technologies. Furthermore, although there might be some practical reasoning behind the inclusion criteria (e.g. lack of budget to provide devices for all participants), it may simultaneously widen the gap between people included in eHealth technology studies and the group of people who might need the support the most. This, in turn, could make health care accessible only to those with high (digital) literacy and those already equipped with the necessary resources to improve their health. This is most likely an unintentional and undesirable direction to head, but without proper awareness, it may easily become the blind spot in current and future eHealth intervention studies. Future studies must, therefore, be aware of possible subgroups, make efforts to include the underprivileged population, and be transparent in their research regarding the population reached. While we acknowledge the challenge of successfully recruiting participants who are representative of the population as a whole and recognise that this is extremely difficult to achieve, we nevertheless recommend that future studies strive to reach those people who are underrepresented and difficult to reach.

Strengths and Limitations

This review provides a very first overview and a diverse insight into different underlying components of self-management eHealth interventions for COPD. It highlights the existing gaps in the literature and uncovers opportunities for the development of eHealth self-management interventions. To the best of our knowledge, no research has yet examined all these various aspects.

However, this review also has its limitations. First, data extraction and categorization were challenging due to the style of writing in articles (which comes with certain formats and word count limitations), the lack of explicit reporting on certain aspects, and the overlap between some processes and dimensions. It might be the case that through incomplete reporting in articles, certain self-management processes, BCTs, health dimensions, aspects of the technology, or details about the “self” could not be extracted. However, albeit being a scoping review, we followed a very systematic approach to mitigate this limitation as much as possible. Therefore, we believe that we were able to give a complete picture of the current literature about eHealth technologies for COPD self-management.

Second, some dimensions of positive health and self-management processes are closely related, intertwined with, or support each other. For example, the dimension of “quality of life” was not observed to be explicitly addressed within the eHealth interventions. However, studies may have an overarching goal of increasing the quality of life of people through the use of their intervention. One should be aware of this when interpreting these results, as the quality of life of people with COPD might still be affected by the use of eHealth interventions.

Third, most articles (470/588, 80%) were screened by 1 reviewer, leaving room for potential subjective judgment. However, by implementing several measures to ensure alignment (e.g. extensive discussion of eligibility criteria, 20% of the screening conducted by 2 reviewers, and discussions to resolve discrepancies), we minimised possible implicit biases.

Finally, this scoping review investigated a broad range of aspects to grasp the state of the art, but not all. For example, this paper did not assess the effectiveness or impact of the interventions, and it also did not evaluate the quality or strength of the evidence. As this is a relatively new area of research, we should map the existing literature first. Furthermore, this review included only English articles, used COPD as a search term while it included a broad spectrum of lung diseases (such as emphysema and chronic bronchitis), and had a search date limitation. Consequently, some studies might have been missed, or some aspects may not have been investigated. However, to the best of our ability, we tried to provide a first overview while leaving opportunities for future research to focus on the aspects that were not covered within this scoping review. As such, this state-of-the-art overview could serve as a starting point for future systematic reviews and original research that will dive into more specific research areas.

Conclusions

This scoping review provides an overview of the state-of-the-art eHealth technologies for COPD self-management interventions. We showed that current eHealth technologies tend to address the physical aspect of COPD self-management. These findings reveal a gap in the available literature, as many dimensions of the positive health paradigm and self-management processes are not addressed in current eHealth interventions for COPD self-management. However, as COPD is a chronic disease and exerts its impact on all aspects of one's life, the underrepresented dimensions and processes might be very important to include. This might give people with COPD the tools needed to be able to adapt toward a new balance in life, and this would consider the person as a whole instead of only the bodily representation in the context of a disease. Our review also showcases another gap, namely, the effect of inclusion criteria that leads to a subgroup of people with COPD being included in eHealth technology studies. Therefore, one should be cautious when interpreting results, as this may give a distorted view of the COPD population within these studies. These gaps demonstrate the need for more inclusive research and design of eHealth self-management interventions for people with COPD, focusing on multiple dimensions of the health paradigm. Future work should, therefore, go beyond the physical dimension and focus on including individuals in research who could benefit most from eHealth self-management interventions.

Acknowledgements

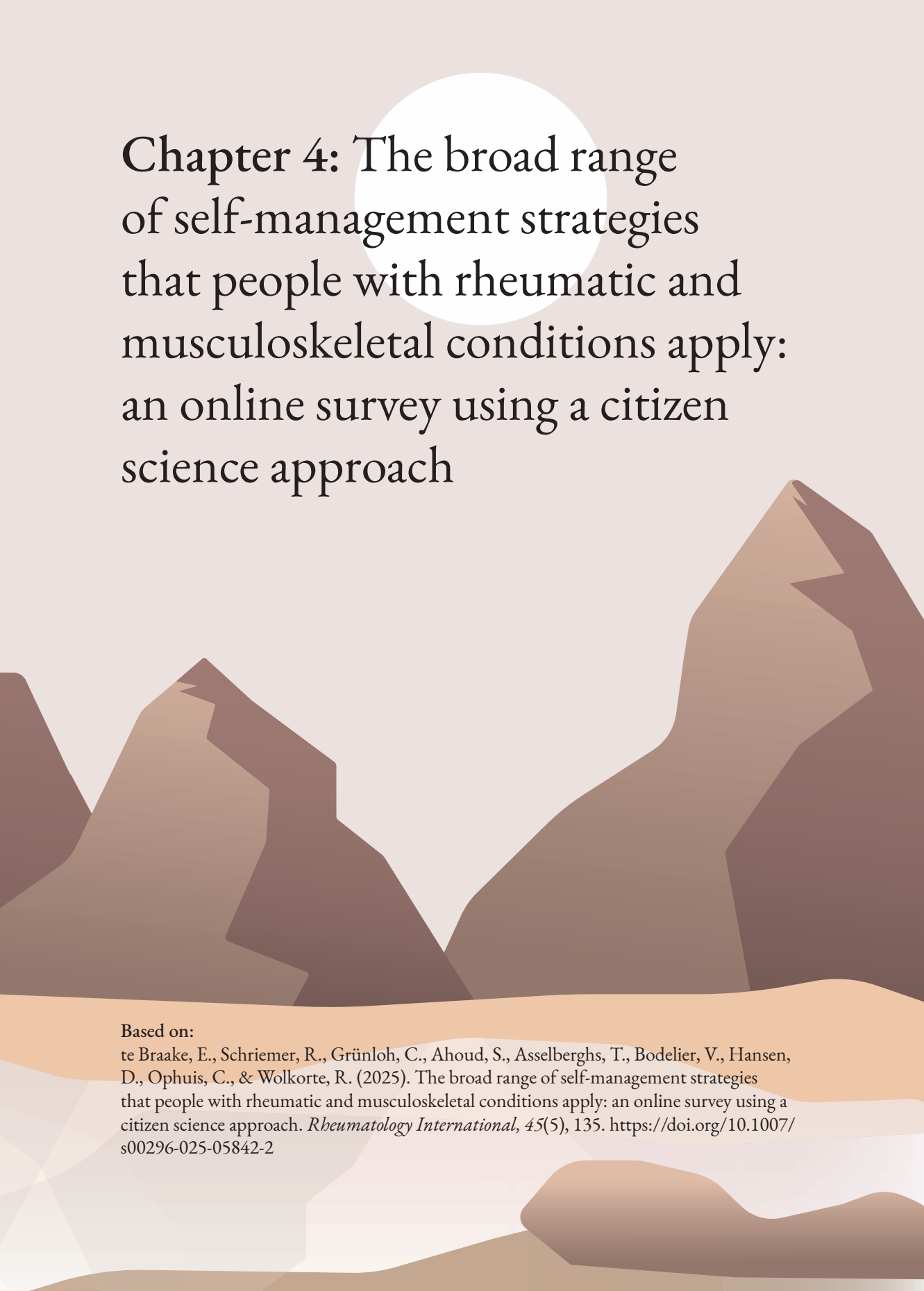
The research is supported by the European project RE-SAMPLE, which is funded by the European Union's Horizon 2020 research and innovation program (965315).



Part II: The current self-management strategies from a patient perspective







Chapter 4: The broad range of self-management strategies that people with rheumatic and musculoskeletal conditions apply: an online survey using a citizen science approach

Based on:

te Braake, E., Schriemer, R., Grünloh, C., Ahoud, S., Asselberghs, T., Bodelier, V., Hansen, D., Ophuis, C., & Wolkorte, R. (2025). The broad range of self-management strategies that people with rheumatic and musculoskeletal conditions apply: an online survey using a citizen science approach. *Rheumatology International*, 45(5), 135. <https://doi.org/10.1007/s00296-025-05842-2>

Abstract

Introduction: Rheumatic and musculoskeletal diseases (RMDs) cause several restrictions in daily living. Self-management is an important aspect of managing RMDs. However, little is known about the self-management strategies that are currently applied in daily life. This study aimed to identify the current self-management strategies that people with RMDs apply through a citizen science approach.

Methods: An online survey was iteratively developed together with people with RMDs. The survey was distributed among people with all types of RMDs. Survey responses were collected within Qualtrics, and once anonymized, analysed using Atlas.ti. General self-management strategies and motivations to start performing a strategy were deductively coded by two reviewers, after consultations with patient partners.

Results: 250 complete surveys were collected. 91.2% of the respondents were female. 1305 self-management strategies were mentioned, and 669 elaborations were given. Most participants applied self-management strategies within the ‘physical activity’ category in their daily lives (e.g., walking, biking). Motivations to start performing a certain self-management strategy mostly originated from the bodily functioning dimension (e.g., reducing pain). 1275 facilitators to start a self-management strategy were mentioned, which were mostly related to the ‘support’ category. Barriers (N=480) were most frequent in the ‘condition-related’ category.

Conclusions: Self-management is an important aspect of managing a person’s condition in daily life. People choose one or several strategies based on the challenge they are facing, depending on their feasibility and preferences in line with their personal context. The comprehensive overview of strategies informs both patients and healthcare professionals to support a personalized self-management journey.

Introduction

Rheumatic and musculoskeletal diseases (RMDs) entail a wide range of degenerative, inflammatory, and auto-immune conditions, that commonly affect the joints (Van Der Heijde et al., 2018). People with RMDs experience a high disease burden (Cao et al., 2024; Hassen et al., 2024; Sebbag et al., 2019) and face multiple everyday challenges that are complex and interrelated (Harmsen et al., 2022). Complaints such as fatigue, anxiety, and chronic pain are common among people with RMDs, thereby affecting daily life activities and impacting their quality of life (Abdelrahman et al., 2024; Briggs et al., 2016; Elefante et al., 2020; Humphreys & Verstappen, 2022; Villalobos-Sánchez et al., 2024; Zhou et al., 2024). Often, medication is offered to deal with and manage symptoms. Several recommendations are made to complement pharmacological treatment, such as a healthy lifestyle and patient education (Courel-Ibáñez et al., 2025; Gwinnutt et al., 2023). Thereby, indicating the importance of the responsibility of the patient to become an active participant in their care and carry out these lifestyle recommendations, and hereby engage in self-management.

This paper defines self-management as: “The ability of an individual to manage one’s symptoms, treatment, physical, social, and emotional consequences, and lifestyle changes. It includes means of empowerment, educating oneself, being autonomous, learning and adapting to new behaviours, acceptance, and adapting to a new balance in life” (te Braake, Vaseur, et al., 2025). People with chronic conditions differ in their support needs for self-management (Bartlett et al., 2020). A previous scoping review showed that people with rheumatoid arthritis expressed the need for more informational, social, practical, and emotional support (Zuidema et al., 2015).

Self-management interventions in RMDs exert their positive effects (e.g., improvements in physical functioning and self-efficacy) (Marquis et al., 2015; Shao et al., 2021; Yang et al., 2025). However, even though self-management is considered an important aspect of managing one’s disease, little is known about which self-management strategies people with RMDs apply. As has been shown in research investigating self-management or self-care in Parkinson's, the activities that are part of the everyday life of a person with a chronic condition might not fit into a medicalized frame of self-care (Nunes & Fitzpatrick, 2018). In addition, as patients are the health experts on all aspects of their lives, it might be very useful to look outside the clinical setting and look into the self-management practices of people living with the disease every day.

This study aimed to investigate which self-management strategies people with RMDs apply in their everyday lives, utilizing a cross-sectional survey. Both positive and negative experiences with the strategy were collected. With such a survey, the self-management activities in and outside the clinical setting can be captured, thereby potentially striving towards creating a complete overview of day-to-day self-management from a patient perspective. Such insights may inform and inspire other patients in their journey to self-management, guide clinicians in increasing their knowledge which may contribute to providing patients with the right self-management support and encourage researchers to form new hypotheses for developing evidence-based interventions.

Methods

A citizen science approach was followed throughout the study to ensure that the outcomes are relevant for the target group, that the design of the study is feasible, and that we ask the right questions to yield high-quality results. Citizen science encompasses a range of participatory models for involving patient partners as collaborators in scientific research (Wiggins & Wilbanks, 2019). In this study, people with RMDs were considered partners in the project. The patient partners were people with at least one rheumatic condition who were not employed by the research units. No specific training or skills were required to participate as a patient partner, other than being able to join the online meetings. Some had been involved in previous projects and/or had formal or informal training on different aspects of research. Patient partners were provided with a gift voucher after each meeting they attended to show the researchers' appreciation. Throughout the project, 16 patient partners were involved. Each meeting was attended by between 4–8 patient partners and 2–5 researchers (/ research assistants). Every step in the study was decided upon in co-creation between researchers and people living with RMDs: formulating research questions, setting up the study design, finding the most suitable ways for data collection and analysis, developing and testing the survey, interpreting the results, and communicating results. The data management plan was also formulated in co-creation. After a decision was made, the work was carried out by the researchers.

Study Design and Survey Development

The cross-sectional study consisted of an online survey. This study followed the items of Zimba & Gasparian (2023) for reporting survey studies. As existing self-management surveys in literature (e.g., Mancuso et al., 2009; Öberg et al., 2019; Osborne et al., 2007)

did not address this specific topic, we iteratively developed our own survey. Figure 9 shows the process of this project involving patient partners in every research stage. Before starting with the design of the study, we reached out through our existing network to people living with RMDs to join us in an initial meeting. In the first meeting with 7 patient partners and 4 researchers, we collaboratively explored the relevance of doing such research for identifying self-management strategies (Phase 1: Relevance check). Thereafter, the second meeting with a total of 6 partners and 3 researchers took place to better understand what self-management means for people living with a rheumatic condition (Phase 2: Understanding self-management). The survey itself was designed together with patient partners (N = 8) and researchers (N = 3) during the third meeting (Phase 3: Questionnaire design). Based on this co-creation, the first version of the online survey was developed using Qualtrics (Qualtrics, Provo, UT). This version was used as input for the fourth meeting in which one-on-one online think-aloud sessions with 3 patient partners were carried out (Phase 4: Think-aloud testing). Unclear sentences, complicated wording, and errors were identified during these sessions, and improvements were made to develop the final version of the survey. After testing, the survey was rated as highly relevant and feasible by co-researchers. In total, 16 patient partners collaborated with us with varying frequencies.

Survey

The survey consisted of 3 domains. First, questions regarding self-management strategies that people considered were asked (domain 1, 3–5 questions). Optionally, people could expand to describe their experiences, motivations to start, barriers, and facilitators (domain 2, 16 questions in case of one elaboration). Finally, demographic data was collected (domain 3, 14 questions). Completing the survey took 20–30 minutes on average. The final version of the online survey can be found in Multimedia Appendix 4.1.

Survey Distribution

The survey was launched on the 2nd of July 2023 and closed on the 24th of November 2023 (Phase 5: Data collection). A convenience sample of people with RMDs was targeted. The survey was shared through multiple channels including online outlets (e.g., social media channels, email), hospitals, patient organizations, newspapers, and universities. For a complete overview, see Multimedia Appendix 4.1.



Figure 9. Roadmap of Activities within the REIS Project.

Data Preparation

Survey responses collected in Qualtrics were exported to a secured Excel file where data was anonymized and incomplete survey responses were deleted, as stated in the informed consent form. Survey responses were considered complete when participants filled in all obligated demographics questions at the end of the survey. This was also clearly communicated to participants in the information given at the start of the survey,

providing an opt-out option during survey participation. All survey responses were anonymized by one author and 2 student assistants (EtB, KvM, YS), any information that could be traceable to a particular person was removed and replaced by the topic of that information (e.g., [place], [name]). The anonymized dataset is available upon reasonable request from the researchers (Wolkorte, 2024).

Data Analysis

To describe the participants' characteristics, the mean, or range was calculated. Initially, we aimed to deductively code the data by using the “Taxonomy of Everyday Self-management Strategies” (TEDDS) (Auduly et al., 2019) for the different strategies that people shared (i.e. “What did they do?”), and to deductively code the motivations behind applying the self-management strategy using the positive health model (Huber et al., 2016) (i.e., “Why did they do it?”). This was discussed and jointly agreed upon during one of the meetings. Twenty survey responses were separately coded by two reviewers (YS, EtB) using these two models, already raising questions about the mutual exclusiveness of the categories within the TEDDS model while doing so. After this initial coding, four online one-on-one meetings were organized to discuss the codes with patient partners (Phase 6: Data analysis). The objective of this meeting was to verify whether the codes assigned to the data aligned with how the patient partners interpreted these codes and whether they would assign the same codes. During these meetings, it became clear that the positive health model was suitable to use, but the TEDDS model used for the general part of the survey was much harder to fit the data that was collected. There was too much overlap between different self-management categories as they were not mutually exclusive (e.g., healthy behaviour and disease-controlling strategies) and also did not match the everyday language and frame of reference of people with RMDs. Together, we concluded that by using this model, the goal of this survey would not be achieved; namely, creating an overview of which self-management strategies people currently apply, which is easily interpretable not only for academics but also for healthcare professionals (HCPs) and people with RMDs. Thus, after several discussions within the research team, it was concluded that an inductive approach to analyse the data was more appropriate. Given that the researchers had already familiarised themselves in-depth with the data, a set of codes with definitions was developed and discussed. With this new coding scheme, the two coders (YS, EtB) coded the first 30 survey responses independently. Thereafter, a discussion took place to compare the coded data. The Krippendorff's c-Alpha- binary was calculated to be 0.819, indicating good inter-rater reliability. Discrepancies in coded data were solved through discussion to reach a

consensus between the coders, and categories and definitions were revised to be precise and exclusive. This resulted in the categorisation shown in Table 11, which was also discussed with patient partners who agreed that these categories were suitable and clear. Thereafter, the remaining survey responses were divided between the two coders (YS and EtB) and were coded separately.

Table 11. Self-Management Categories used to Analyse Data Following the Question 'What did they do?'

Category	Definition
Energy distribution	Strategies that are used to use energy more efficiently by adjusting, spreading, or controlling the activity level with the aim of being able to continue to carry out daily activities.
Physical activity	Physical activities performed to maintain, and/or improve health and vitality in daily life.
Nutrition and supplements	All dietary lifestyle adjustments and/or lifestyles, including the use of vitamin or mineral supplements.
Healthcare Professionals	Care by accredited health care professionals aimed at improving your body functions and maintaining your health, such as physical therapy or occupational therapy.
Mental health	Mental/cognitive internal strategies or beliefs used with the aim of accepting the consequences of the illness and/or generating mental peace.
Participation	(Social/leisure) activities to (continue to) participate in and/or contribute to society
Medication	Condition-specific medication and/or medication for symptom management/prevention.
Assistive devices	Objects or services that support [participation in] daily activities.
Alternative medicine	Alternative or complementary treatments, therapies, means, and techniques that deviate from conventional medical care and/or are not recognised as a medical profession/therapy/means with the aim of relieving symptoms.
Information and patient education	Searching for information about the disease, self-management, solutions, and problems in order to gain more

	knowledge. In addition, specifically education and learning about the disease and its consequences.
General lifestyle alterations	All general strategies to make lifestyle adjustments that do not fit the other categories and were not further specified.
Other	Other self-management strategies that do not fall under any of the above-mentioned categories.

The motivation why people apply a certain self-management strategy was an optional part of the in-depth elaboration questions. The motivational aspect was then coded using the model of positive health (Huber et al., 2016) as planned from the beginning. This model characterises health as ‘the ability to adapt and self-manage in the face of social, physical, and emotional challenges’ and entails six dimensions, which are outlined in Table 12.

Table 12. Dimensions of Positive Health (Huber et al., 2016) used to Analyse Data Following the Question ‘Why did they do it?’

Category	Definition (Authors’ translations from examples of Positive Health Dialogue Tool 2.0)	Examples from Positive Health Dialogue Tool 2.0
Bodily functions	The primary motivation is health. This dimension focuses on movement, sleep, symptoms, and pain.	Feeling healthy, feeling fit, no physical complaints and/or pain, sleeping, eating, sexuality, physical condition, physical activity.
Mental well-being	A person's state of mind. In addition, rest and relaxation are also central here.	Being able to: remember things, concentrate, communicate, handle change, be cheerful, accept yourself, feel in control.
Meaningfulness	About lust for life. Alongside this is the importance of faith and religion, or the search for it	Having a meaningful life, having a zest for life, pursuing ideals, feeling confident, accepting life, being grateful, and lifelong learning.

Quality of life	The focus is on a new perspective on life with the disease.	Enjoyment, being happy, feeling good, feeling well-balanced, feeling safe, intimacy, housing circumstances, having enough money.
Participation	Participation is about participating in society and being able to engage in social activities. But also getting support and asking for help from the social environment.	Social contact, being taken seriously, doing fun things together, having support from others, sense of belonging, doing meaningful things, being interested in society.
Daily functioning	Daily functioning has as the primary motivation to continue to function in daily/ordinary life.	Taking care of yourself, knowing your limitations, knowledge of health, managing time, managing money, being able to work, being able to ask for help.
Other	Motivations that could not be applied to one of the other dimensions	

The possible categories for barriers and facilitators were included in the survey so that participants could fill in their experience directly in the categories of ‘knowledge’, ‘time’, ‘condition-related’, ‘money/compensation’, ‘support’, or ‘others’. Responses were carefully analysed and where applicable, reassigned to the correct category. Responses in the ‘others’ category were revised to decide whether they could warrant a separate category.

Other Collaborations and Citizen Science Activities

During meetings 6 and 8, results were shared (Phase 7. Sharing research results) and potential questions for future research based on the outcomes of the current study were discussed (Phase 8. Formulating new research questions). As part of this citizen science approach, opportunities for potential collaborations in the dissemination phase were actively sought (e.g., going to conferences, designing research posters, co-authoring, interviews with patient magazines, among others). Therefore, during the different phases

of this research, several meetings took place to organize and discuss these opportunities (Transcending phase: Phase 9. Other collaboration activities).

Results

250 complete survey responses were collected. The results have no missing data as all replies were mandatory. A total of 1305 self-management strategies were reported by people with RMDs of which 669 (51,3%) were also elaborated on in-depth. Both strategies that participants experienced as positive (86%) and negative (14%) were mentioned. The amount of self-management strategies reported by a participant ranged from 1 to 10 strategies.

Demographics

The majority of respondents were female (N = 228, 91.2%), with a mean age of 59.9. Most participants (60.1%) had high educational backgrounds, with higher professional education being the most common. Osteoarthritis (N = 148) and rheumatoid arthritis (N = 94) were the most prevalent types of RMDs. Participants ranged in terms of year(s) living with the rheumatic condition(s) from less than a year to more than 20 years. Half of the participants also had comorbidities. An overview of all demographics collected within this study can be found in Multimedia Appendix 4.3.

Self-Management Strategies: What did they do?

Table 13 shows an overview of the self-management categories, including frequencies and examples. The results reveal that people who took part in the survey deploy multiple strategies, covering a broad range. Most self-management strategies fit within the physical activity category. Strategies in the ‘other’ category were not categorised as self-management strategies on itself, as they were mostly related to a process, such as patient empowerment, needed to perform such strategies. Either way, this process is still equally important within self-management and, therefore, worth mentioning.

Table 13. Frequencies and Examples of Self-Management Strategies in Respective Categories (Total N=1305). The Categories are Ranked from Most Common to Least Common. Common Examples are Highlighted with Bold Text.

Self-management strategy	N	Examples
Physical activity	260	Walking, biking , swimming, sports, staying active

Assistive devices	197	E-bikes , walking aids (e.g., frames, walkers), adapted kitchen knives, specific tools to open cans, regional transport services for people with disabilities
Healthcare Professionals	146	Physiotherapy sessions , rehabilitation, occupational therapy, vitality coach
Nutrition and Supplements	124	Diet , vitamin supplements, inflammation-reducing foods
Mental health	121	Acceptance following illness, mindfulness , meditation, speaking out about the rheumatic condition, and communicating personal boundaries timely
Energy distribution	109	Taking more rest , pacing, spreading tasks, planning, and taking breaks
Participation	108	Employment or volunteering , education, recreational time, hobbies, peer-support groups
Alternative medicine	84	Cannabidiol oil, Homeopathic remedies , attending the sauna, cold water exposure, self-hypnosis, hot bath, acupuncture
Medication	78	Over-the-counter medication (Analgesic medication, pain medication), prescribed RMD medication, and tapering off medication
Information and patient education	56	Searching for information on the internet , reading books about their rheumatic condition, following classes for a specific rheumatic topic, reading flyers
General lifestyle alterations	37	Losing weight, changing/adapting lifestyle , being healthy
Other	20	Having a say in medical appointments , being assertive with healthcare professionals and other organizations

Motivation to Perform Strategy: Why did they do it?

In total, participants chose to elaborate in depth on N=669 strategies. Part of this elaboration reflected the motivation for why they performed a certain strategy, which was categorised using the positive health model (Table 14) (Huber et al., 2016). Some strategies had more than one motivation. Most strategies (N=421) fitted within the bodily functioning dimension. Not many motivations fitted in the ‘meaningfulness’ and ‘quality of life’ dimensions.

Some motivations were mentioned that were unrelated to any of the dimensions in the model, and/or no motivation was provided in the responses. For example, ‘Look at previous question’ (RSP202), or ‘Because many doctors and nurses just express unsubstantiated opinions’ (RSP163). These ‘other’ motivations were so diverse that we could not identify a pattern or theme that would warrant an extra category.

Table 14. Motivation for Performing Self-Management Strategies Categorised in the Positive Health Dimensions, as Part of the Elaborations of N=669 strategies. The Categories are Ranked from Most Common to Least Common. Important Parts of the Quotes are Highlighted with Bold Text.

Category	N	Example quotes
Bodily functioning	421	<p><i>‘Because the pain got worse, we switched to this [strategy]. . . [we] tried to see if it [the strategy] had an effect and whether it reduced the pain’ (RSP018)</i></p> <p><i>‘My muscles are always under tension. I wanted to make my muscles stronger so that I would hopefully experience less and less pain and restlessness in my body’ (RSP071)</i></p> <p><i>‘I would like to limit my dependency on medication, so I try other ways to minimise the use of pharmacological means, I’m happy to do so’ (RSP036)</i></p>
Daily functioning	135	<p><i>‘Spread domestic chores in particular over a day or week. Rest periods in between. No longer wanting to cram everything in one day. . . . Energy runs out quickly’ (RSP1)</i></p> <p><i>‘Make a plan in advance, learn to respect and express my limitations. . . Support for daily life’(RSP39)</i></p> <p><i>‘I use a mobility scooter when we go out for a whole day with the family. I use earplugs when I am in a busy environment for a long</i></p>

		<i>time. . . . Aids give me more freedom to do fun things and be less dependent'</i> (RSP196)
Mental well-being	108	<i>'I found, and still find, it difficult to accept that I am ill. It feels weak. I hoped that yoga and mindfulness could help me with the process of accepting, to be able to live more in the present'</i> (RSP36) <i>'To learn to accept so that I would no longer overstep my boundaries and distribute my energy better'</i> (RSP183) <i>'To achieve mental balance'</i> (RSP66)
Participation	81	<i>'I would like to mean something to the people around me. If I am creative, this is also possible with limitations due to a chronic condition'</i> (RSP114) <i>Friends, family, movies, history lessons, and most importantly: work and being busy. I forget the rheumatism'</i> (RSP228) <i>'Contact with peers and [to] gain more knowledge'</i> (RSP16)
Quality of Life	38	<i>'I refuse to give up my freedom if there is an opportunity to do so'</i> (RSP6) <i>'[To] Extend and improve my quality of life'</i> (RSP48) <i>'Awareness of what is possible. . . because I like life, I want to make something of it'</i> (RSP228)
Meaningfulness	15	<i>'Reflecting on what is permanent in me, [on] what my essence is.'</i> (RSP114) <i>'I find my life too passive'</i> (RSP257) <i>'My job at the time had stopped at some point, and I especially did not want to exclude myself from society and dedicate my time and energy to advocacy for other people with RMDs'</i> (RSP236)

Facilitators and Barriers

In the survey, we already provided categories for facilitators and barriers as multiple-choice options. During the analysis, it appeared that many experiences mentioned in the 'other' category were related to 'emotional/mental processes'. Therefore, this was added as a separate category.

In total, 1275 facilitators were reported regarding 669 strategies (Table 15). Most facilitators were related to the 'support' category. Facilitators in the 'other' category

were diverse and could not warrant a separate category. Some ‘other’ facilitators mentioned were, for example, about having positive experiences with a strategy and having no other choice than doing the strategy, among others. Furthermore, participants reported 480 barriers to starting a strategy (Table 15). Most barriers were related to the category ‘condition-related’. Barriers mentioned in the ‘other’ category included, for example, bad experiences with a strategy and having difficulties with persevering in a certain strategy.

Table 15. Experienced Facilitators and Barriers when Performing Self-Management Strategies. The Categories are Ranked from Most Common to Least Common. Important Parts of the Quotes are Highlighted with Bold Text.

Category	Facilitators (N=1275)		Barriers (N=480)	
	N	Example quotes	N	Example quotes
Knowledge	223	<p>‘Reading other people’s experiences and talking to family members who also have rheumatism’ (RSP48)</p> <p>‘A lot of knowledge gained because of the occupational therapist’ (RSP101)</p>	28	<p>‘Not much was known among other patients with RMDs about which self-medication worked best’ (RSP67)</p> <p>‘The information about this is not clear’ (RSP181)</p>
Time	239	<p>I am retired, so [I have] enough time’ (RSP9)</p> <p>‘I gave myself more time because I didn’t do things or did things differently that suited my situation better’ (RSP25)</p>	61	<p>‘Applying for resources takes a lot of time/energy’ (RSP61)</p> <p>‘It takes a lot of time to figure everything out’ (RSP183)</p>
Condition related	206	<p>Mindfulness gives direction and rest, [it] is a decrease of disease activity’ (RSP12)</p>	118	<p>Physical activity is difficult at times because of too much pain’ (RPS129)</p>

		'Rheumatic condition was stable ' (RSP22)		'Osteoarthritis complaints are severe most of the time and limit my actions ' (RSP103)
Money/ Compensation	252	'[The strategy] Was fully reimbursed by insurance ' (RSP2)	84	'It [the strategy] is expensive, so you have to set priorities ' (RSP4)
		'I had enough money to buy an e-bike ' (RSP52)		' Little reimbursement from health insurer ' (RSP32)
Support	266	'The substitute General Practitioner took my complaints seriously ' (RSP197)	89	'It [the disease] is often not understood. I have lost quite a few "friends" because of this because they think I am acting out or not showing interest ' (RSP127)
		'[My] environment is supportive ' (RSP252)		'It is difficult to find someone who can help with this [the strategy] (RSP183)
Emotional/ Mental processes	26	'I wanted to get my life back on track ' (RSP129)	56	'A bit of acceptance that some things are no longer possible or need to be done differently ' (RSP25)
		' Trusting your own feelings, I do what feels right for myself ' (RSP56)		' Emotion! Emotion sometimes makes it difficult to adjust your life ' (RSP41)
Other	66	' If your older when replacing prosthetics, it you're more likely to have complications ' (RSP5)	44	'In hot weather they are less comfortable and give off because you sweat ' (RSP153)
		'I slowly began to experience the positive effects ' (RSP50)		' Getting started is not that difficult. Persevering is what it's all about ' (RSP36)

Discussion

This paper identified a large number of diverse self-management strategies that people with RMDs apply in their daily lives. Many can be categorised as strategies related to ‘physical activity’ and ‘assistive device’ categories. Most strategies are initialized to improve bodily functioning. The paper provides information for patient organizations and healthcare professionals to educate and guide patients towards optimizing their personalized self-management activities.

Self-Management Strategies

People with RMDs apply a variety of self-management strategies in their daily lives. Although it is known that clinical treatment is an important aspect of managing a chronic condition, many people apply additional non-pharmacological strategies (Antunes et al., 2024; Audulv et al., 2021; Nunes & Fitzpatrick, 2018; Rimmer et al., 2023). Specifically, participants in our study reported an average of 5 self-management strategies that they have tried and tested. In dialogue with our patient partners, it was emphasized that support in finding relevant self-management strategies is important, as they may not always be obvious or known to a large audience. Patient education and patient empowerment on this issue may help reduce disease burden and improve quality of life, especially for those with lower health literacy who are less likely to learn about specific strategies (Lee & La, 2024; Woodward et al., 2024). Therefore, it is important that HCPs are aware of the efforts of people with RMDs, as they are often seen as their primary and trusted source of knowledge.

Although these self-management strategies occurred in diverse categories, most were in the physical activity category and were mostly motivated by bodily or daily functioning. The prevalence of physical activity strategies might be explained by several reasons. First, the importance of an active lifestyle is quite well-known among the population and is often encouraged and recommended to them by HCPs (Bannuru et al., 2019; Kolasinski et al., 2020; Macfarlane et al., 2017; Moseng et al., 2024; Parodis et al., 2024). Second, being active is relatively easy to incorporate in daily life (e.g., by doing home-based physical activity (Sieczkowska et al., 2021). Third, this is one of the few strategies that is evidence-based and is known to alleviate physical symptoms such as pain and discomfort (Athanasidou et al., 2024; Gwinnutt et al., 2022; Mundell et al., 2024). Notably, it might be the case that current systems to support self-management are designed to focus on supporting the physical aspect, and that other aspects are underrepresented, as physical activity is the most consistent recommendation people

receive from their HCP. Socio-psychological aspects are also very important when it comes to self-management and self-care (Zuidema et al., 2015), however, fewer motivations to start a self-management strategy were related to meaningfulness, participation, and quality of life. When discussing these results with our patient partners, they were surprised at how few motivations were recorded in the quality-of-life dimension. While it may be the case that people living with RMDs are less aware of certain strategies, our patient partners also mentioned that quality of life might be a dimension of positive health that is likely to be addressed indirectly. For example, one can easily imagine that assistive devices directly reduce symptoms and thus in the long run increase quality of life. Therefore, in future research, it is important to distinguish between immediate factors that are addressed and domains that are improved long-term as a result. Additionally, it is recommended to understand whether there is a lack of feasible interventions for certain goals, or whether some are actually more urgent than others.

People reported more facilitators that helped them to initialize a strategy, than barriers. Possibly, the presence of barriers would have prevented people from even considering a strategy and therefore, not reporting it in our survey. Although some barriers were deemed condition-related, which are hard to target (i.e., fatigue-prohibited exercise), others have the potential for change. For example, it was mentioned several times that financial issues (i.e., no reimbursement from the insurance for physiotherapy or to purchase assistive devices) served as a barrier. Health insurance companies and society, in general, should reflect on the barriers mentioned in this study and consider reimbursements if this would increase the quality of life or self-sufficiency through self-management. Moreover, the barriers mentioned in this study could also clarify to HCPs why people are more or less inclined to practice self-management. HCPs should be aware that even when patients seem motivated to perform self-management strategies in their daily lives, barriers may present that restrict them from doing so (e.g., a lack of social support network). At the same time, knowledge was a strong facilitating factor, stressing the importance of educating people with RMDs about possible self-management options. Therefore, we invite HCPs to be aware of these barriers and facilitators when discussing and recommending self-management activities to their patients.

The Methodological Approach used for Data Analysis

A previously developed self-management model by Audulyt et al., (2019) did not suit the rich data in the current study. Therefore, after careful consideration and multiple discussions with patient partners, we iteratively formulated our own self-management categories derived from the data in our study. Using an inductive approach and creating our own categories was the most suitable approach to reflect the wealth of data and fit the needs of people within our project and hopefully, the wider population of people with RMDs. Furthermore, the rising prevalence of comorbidities indicates that self-management should preferably be symptom- or problem-oriented rather than condition-oriented. Therefore, it is interesting to investigate whether the self-management categories that we developed also apply to other patient groups exceeding the RMD population.

Creating Conditions for Citizen Science

Throughout the different stages of this study, people with RMDs were involved as patient partners (Schoemaker et al., 2023; Shirk et al., 2012). Some steps were designed together, and on other occasions, proposed processes and next steps were changed after a meeting took place with patient partners. Although the inclusion of the knowledge and expertise of patient partners added value to the project, it is important to note that it takes extra time and effort and should not be taken for granted. Therefore, we will share our joint lessons learned during this project. We experienced that both patient partners and researchers valued the close collaboration. According to patient partners, researchers listened to everyone and took input and feedback seriously. Decisions about this project were made after consultation with patient partners, which were always organized to be highly accessible with no training or preparation that was demanded in advance. Several actions facilitated relevant participation in all phases of the research. First, researchers provided clear information to patient partners before every meeting and gave them sufficient time in advance to read it. Second, researchers provided summaries of meetings and decisions so that people could check, give feedback, and/or add missing pieces, which simultaneously lowered the threshold for the people who weren't able to participate in the meeting to participate the next time. Third, researchers established a sufficient community size (e.g., between 10 and 20 patient partners). This lowered the pressure and burden of participating in each round, while simultaneously enabling the group to complement each other and to represent multiple viewpoints (Jongsma & Friesen, 2019). The group size also increased a sense of belonging as patient partners felt supported by one another. Fourth, the researchers actively looked for

opportunities for patient partners to increase their involvement and show appreciation for their involvement. This was done by inviting patient partners to participate in congresses, co-authoring publications, and offering gift vouchers as a way of compensation and appreciation for the expertise provided. Fifth, the trust and sense of common interest established by the steps above facilitated the sense of co-ownership of the project. To conclude, this participatory approach based on citizen science has had a huge positive impact on the current project.

Limitations

This study provides an overview of self-management strategies that people with RMDs apply. However, even though many people recorded their strategies and the level of personal success they have had with these, this does not warrant any claims about their effectiveness on a group level. Thus, we cannot make recommendations to people with RMDs to perform particular self-management strategies. Furthermore, this study does not provide a complete insight into the needs of people with RMDs towards self-management. We only identified which strategies were carried out. Therefore, future research should identify whether additional self-management strategies are warranted and focus on investigating the effectiveness of these strategies mentioned in this study, to generate an evidence base to make specific recommendations.

In spite of the numerous online and offline distribution methods for recruiting participants, the survey itself was only available online. Although efforts were made to create an accessible survey, people with low digital skills were likely unable to participate in the survey. However, this study served as a starting point for identifying the current self-management strategies of people with RMDs, and we collected a rich dataset.

Finally, despite efforts to reach a large audience, the vast majority of participants have been living with their RMDs for several years, were female, and higher educated. This may jeopardize the generalizability of the results, and one should be aware of this limitation when interpreting the results. The female dominance may be due to the online nature of this study, as previous research concluded that response rates for only surveys are higher among the female population (Wu et al., 2022). As it is known that there are gender differences in coping and self-management strategies (Flurey et al., 2015; Lindgren et al., 2025), future research should investigate strategies of the male population by e.g., by focusing on offline data collection methods.

Conclusion

This study revealed that people with RMDs apply multiple and diverse self-management strategies in their daily lives. Most strategies were related to physical activity, and the motivation to start a strategy is often to address a physical issue. This study showed that people with RMDs do much more for their health than solely following the clinical path and being passive recipients of medical care. As managing a chronic condition affects all aspects of one's condition, management during everyday activities is needed. People with RMDs in this study are intrinsically motivated to improve their situation and take responsibility for their condition by applying different self-management activities, and through trial and error, experiencing what works best for them to become active participants in their care. These findings are not only important for people with RMDs but also serve as an important foundation for clinicians to enhance their knowledge about self-management support.

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Chapter 5: Identifying self-management strategies that people with Chronic Obstructive Pulmonary Disease apply in their daily lives: a qualitative survey

Based on:

te Braake, E., Grünloh, C., & Tabak, M. (2026). Identifying the self-management strategies of people with chronic obstructive pulmonary disease in their daily lives: A qualitative survey. *Heart & Lung*, 76, 124–131. <https://doi.org/10.1016/j.hrtlng.2025.11.022>

Abstract

Introduction: Chronic Obstructive Pulmonary Disease (COPD) is an incurable chronic disease, and self-management is often used to support patients. Current research often targets clinical aspects, while actual self-management is performed by the patient at home. However, little is known about the patient experience. This research identifies which self-management strategies people with COPD apply and what the facilitators and barriers are to adopting these. Specific attention is given to the recruitment approach, aiming to increase response rates and the generalizability of the self-management model.

Methods: A self-management survey developed for people with rheumatic and musculoskeletal diseases (RMDs) was adapted for COPD, pilot-tested, and disseminated via traditional (e.g., via email) and enhanced (e.g., offline support) recruitment routes. Anonymized responses were deductively coded, using the self-management model for RMDs and the model of positive health.

Results: From 33 respondents, 152 self-management strategies were identified. All strategies could be categorised using the self-management model. ‘Physical activity’ was the most common category. Motivations to start a strategy are mostly derived from the ‘bodily functioning dimension’. Participants reported 122 facilitators and 41 barriers, such as ‘time’ and ‘support’. Passive approaches, in which participants themselves have to sign up, to improve response rates, were not substantial.

Discussion: People with COPD perform diverse self-management strategies. These efforts may not always be visible in the clinical setting, as these are often initiated by one’s search journey and thus are additional to standard Healthcare Professionals’ (HCP) advice. Future research should investigate alternative approaches to reach the wider COPD population.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) has been defined as: ‘A heterogeneous lung condition characterised by chronic respiratory symptoms (dyspnoea, cough, sputum production and/or exacerbation) due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive, airflow obstruction’ (GOLD, 2024). COPD poses a substantial and increasing economic burden and is one of the top causes of morbidity and mortality worldwide (GOLD, 2024; Iheanacho et al., 2020; Quaderi & Hurst, 2018; Shah et al., 2022). It is a complex, progressive, yet treatable disease, which makes it important for patients to be on top of their disease to deal with all the different aspects (e.g., medication use, worsening of symptoms, acceptance of disease). This includes, but is not limited to, self-management. Self-management has been defined as: ‘The ability of an individual to manage one’s symptoms, treatment, physical, social, and emotional consequences, and lifestyle changes. It includes means of empowerment, educating oneself, being autonomous, learning and adapting to new behaviours, acceptance, and adapting to a new balance in life’ (te Braake, Vaseur, et al., 2025). Self-management requires an empowered and active role from the patient so that they become in charge of their health. In literature, COPD self-management interventions often target education, smoking cessation, medication adherence, symptom management, or physical activity, and can use technology to support this (Hallensleben et al., 2019; McCabe et al., 2017; te Braake, Vaseur, et al., 2025).

People with COPD need to cope with and self-manage their disease every single day. Clinical care (e.g., care from the pulmonologist or pulmonary nurse) is often provided during a short consultation during scheduled (half-)yearly visits. Thus, most of the time, people are dealing with their COPD on their own outside the clinical system. This subsequently means that they need to be responsible for their health by, for example, applying self-management strategies in their daily lives. These strategies may be interventions that have been studied in a controlled environment (te Braake, Vaseur, et al., 2025) but may also include strategies that are based on common knowledge (e.g., physical activity, healthy eating) or alternative medicine (e.g., homeopathy). Or may relate to aspects of their lives that are not targeted by common interventions (e.g., integrating illness into daily life, participation in society, supporting mental well-being (te Braake, Vaseur, et al., 2025). Little is known about which self-management strategies people with COPD apply. Such research on the patient experience can be valuable for increasing our understanding of what people with COPD already do towards self-

management that is also outside a clinical setting, and may provide insights into where self-management support is still needed in practice.

To get these insights, one should take into account the perspectives of the wider COPD population. Certain strategies could, for example, not be feasible for people with low (health) literacy or low socioeconomic position (SEP), as they might not have the necessary resources to perform them. Studies have shown that people with a very low socioeconomic position (SEP), and people with low economic, social, and cultural resources (Long & Renbarger, 2023) are also twice as likely to have poor COPD outcomes (Gershon et al., 2012). Thus, it is important to involve this group when developing and evaluating self-management interventions, as they may benefit the most from such interventions. However, this group is often considered underrepresented in research, leading to a sampling bias that excludes those who might benefit the most and results that may not fit with the needs of this group (Stuber et al., 2020; van Velsen et al., 2022). Reasons for the low participation of low SEP populations can vary. For example, people lack awareness of the program, there is mistrust or perception that the participation may cause harm, or does not yield any benefit, or the recruitment approach is unsuitable for the target group (Stuber et al., 2020). Furthermore, some studies require, by their design, that people have certain skills or resources and thus potentially exclude people with low SEP (e.g., online surveys or eHealth intervention studies that require participants to have their own device) (te Braake, Vaseur, et al., 2025). Therefore, one should explore suitable recruitment and data collection strategies within their research to increase the chances of including the wider COPD population.

Earlier research has investigated self-management strategies applied by people with rheumatic and musculoskeletal diseases (RMD) (te Braake, Schriemer, et al., 2025). Their study developed a survey together with people living with that condition and yielded a high response rate, with a total collection of 1305 self-management strategies. A self-management model was created in their study to categorise the various self-management strategies into different categories (e.g., energy conservation, nutrition, and supplements). This model was developed for people with RMDs. It might be interesting to investigate whether the self-management strategies of other diseases, such as COPD, fit within this model. This may give insights into differences and similarities and may inspire future self-management efforts across diseases. Thus, in the current study, we aim to carry out the same data collection and analysis approach as te Braake, Schriemer, et al., (2025).

This research aims to identify which self-management strategies people with COPD currently apply in their daily lives and what the facilitators and barriers are to adopting these strategies. These insights may help increase our understanding of the current health behaviours of people with COPD. In our approach, we pay specific attention to increasing our response rates by using enhanced recruitment approaches that we hoped would better reach the target population. Thereby, assuming to simultaneously increase the chances of reaching the wider COPD population (e.g., those who are underrepresented). With the results, we will explore the generalizability of the self-management model for RMDs by discussing whether this model can be applied to the self-management strategies of people with COPD.

Methods

Ethical Statement

To be eligible to participate, all participants needed to be 1) 18 years or older, and 2) have COPD. All respondents received information about the study at the start of the survey and needed to give their (online) informed consent to participate. According to Dutch law, the nature of this study does not require formal medical ethical approval, which was assessed and confirmed by the Medical Research Ethics Committee Oost-Nederland (File number 2024-17042). All procedures were in accordance with the Declaration of Helsinki and the Good Clinical Practice (GCP) guidelines.

Survey Development

The self-management survey of te Braake, Schriemer, et al., (2025), which was created together with people with RMDs, served as a starting point and was slightly adapted to fit the specific context of COPD. In this qualitative self-reported anonymous survey, participants first filled in their general self-management strategies. Thereafter, participants could elaborate on the in-depth questions about their motivations underlying starting a self-management strategy to better understand why participants performed these. Given the voluntary nature of this survey and free choice, participants could decide for themselves which and how many self-management strategies they want to answer the follow-up questions for. The survey ended with several demographic questions.

For this study, additional questions related to participants' social life and the judgement and feelings about their own health were added. Thereafter, the survey was pilot tested with four people with COPD to ensure relevance and a fit with their

practices. The dimension ‘Emotional/Mental processes’ was added to the facilitators and barriers, as participants in the pilot tests mentioned missing a category to fill in such related experiences. The full survey can be found in Multimedia Appendix 5.1.

Survey Distribution

The survey was open from the 30th of January 2024 to the 6th of May 2024. We developed two distribution routes (see Figure 10): a traditional route and an enhanced route. The traditional route entails sending the online survey via email to people with COPD who participated in previous research and indicated wanting to keep participating, a patient organization network, LinkedIn, and local physiotherapy practices in the Netherlands. Printed versions of the survey were shared with the local physiotherapy practices. With this route, relationships are built, and participants are in the loop of the project by providing them with summaries of research activities. Despite these efforts, past experiences with this route did not result in high response rates. Therefore, we developed the enhanced route with the intention to reach those patients who are less likely to respond to our traditional way of recruitment (e.g., those with low digital skills, no financial resources, or with low SEP in general). In the enhanced route, we added offline routes within communities (e.g., libraries, community centres), and provided support for people with low (digital) literacy and/or those who do not own a computer: providing offline support to fill in the survey and the possibility to reach the researcher via a printed contact form with pre-paid return envelopes. Facebook was also added as a type of communication, as several COPD support groups can be found there. Thus, within the enhanced route, new places were sought within communities. To get insight into which people were reached with our efforts, we asked participants about their social life, concerns about their finances (as asking to grade one’s actual financial situation without knowing a person’s context does not say much), highest education, and their cultural background, given that SEP concerns the social, economic, and cultural resources (Long & Renbarger, 2023). This gives us an indication from which we can draw lessons on how to improve our recruitment strategies for future studies. We separately monitored the two routes.

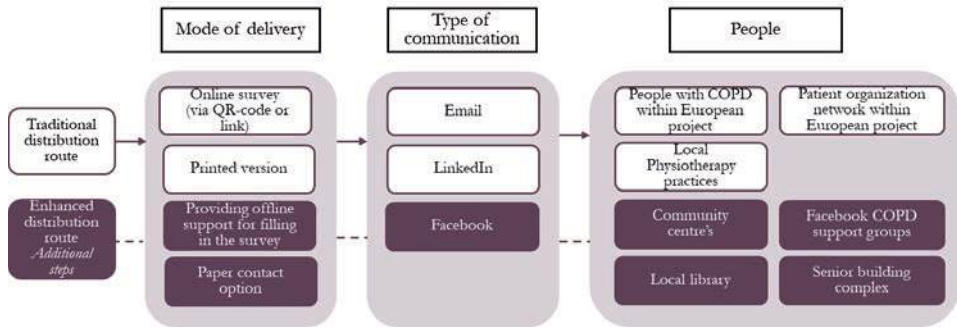


Figure 10. Distribution of Survey

Data Preparation

Qualtrics (*Qualtrics*, n.d.) was used to collect online survey responses. After closing the survey, all survey responses were exported to a secure Excel file, and incomplete responses were deleted. Responses were considered complete when all demographic questions were filled in, as these were obligatory and presented at the end of the survey. This served as a feasible cut-off point and meant that all participants needed to fill in 98% of the survey. The complete responses were anonymized. In the case of the offline survey, all complete survey responses were manually anonymized and transferred to a secure Excel file. The anonymization process entailed removing any identifiable information from the full-text responses and replacing it with general themes of that information (e.g., [place], [name]). The anonymized dataset is available upon reasonable request from the researchers (te Braake, 2025).

Data Analysis

Data was analysed with Atlas.ti version 24. We utilized the same qualitative analysis models as (te Braake, Schriemer, et al., 2025) to deductively code the data. First, we coded the self-management strategies using the categories developed by te Braake, Schriemer, et al., (2025) (Table 16), which were applied to categorise the self-management strategies. Hereby, we simultaneously aimed to investigate whether these categories could be applied to the COPD population. Second, we coded the in-depth elaboration questions about motivations to perform a certain strategy using the Positive Health model of Huber et al., (2016). Two reviewers (EtB and CG) initially coded 10 responses separately. Thereafter, the inter-code reliability was calculated. Krippendorff's Alpha was set to be .837, indicating reliability. After the separate coding, a discussion

took place to solve discrepancies between the two reviewers. Subsequently, one reviewer (EtB) coded the remaining data.

Table 16. *Self-management strategies according to (te Braake, Schriemer, et al., 2025).*

Category	Definition
Energy distribution	Strategies that are used to use energy more efficiently by adjusting, spreading, or controlling the activity level with the aim of being able to continue to carry out daily activities.
Physical activity	Physical activities performed to maintain, and/or improve health and vitality in daily life.
Nutrition and supplements	All dietary lifestyle adjustments and/or lifestyles including the use of vitamin or mineral supplements.
Healthcare Professionals	Care by accredited health care professionals aimed at improving your body functions and maintaining your health such as physical therapy or occupational therapy.
Mental health	Mental/cognitive internal strategies or beliefs used with the aim of accepting the consequences of the illness and/or generating mental peace.
Participation	(Social/leisure) activities to (continue to) participate and/or contribute to society
Medication	Condition-specific medication and/or medication for symptom management/prevention.
Assistive devices	Objects or services that support [participation in] daily activities.
Alternative medicine	Alternative or complementary treatments, therapies, means, and techniques that deviate from conventional medical care and/or are not recognised as a medical profession/therapy/means with the aim of relieving symptoms.
Information and patient education	Searching for information about the disease, self-management, solutions, and problems in order to gain more knowledge. In addition, specifically education and learning about the disease and its consequences.
General lifestyle alterations	All general strategies to make lifestyle adjustments that do not fit the other categories and were not further specified.

Other	Other self-management strategies that do not fall under any of the above-mentioned categories.
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The motivational aspect was coded using the model of positive health by Huber et al., (2016), which characterises health as ‘the ability to adapt and self-manage in the face of social, physical, and emotional challenges’ and entails six dimensions, which are outlined in Table 17. Some motivations entailed more than one dimension (for example, targeting both bodily functioning and participation), which was then counted separately.

Table 17. Dimensions of Positive Health (Huber et al., 2016), used to analyse data following the question “Why did they do it”

Category	Definition translation from Authors (te Braake et al., 2025)	Examples from Positive Health Dialogue Tool 2.0
Bodily functions	The primary motivation is health. This dimension focuses on movement, sleep, symptoms, and pain.	Feeling healthy, feeling fit, no physical complaints and/or pain, sleeping, eating, sexuality, physical condition, physical activity.
Mental well-being	A person's state of mind. In addition, rest and relaxation are also central here.	Being able to: remember things, concentrate, communicate, handle change, be cheerful, accept yourself, feel in control.
Meaningfulness	About lust for life. Alongside this is the importance of faith and religion, or the search for it	Having a meaningful life, having a zest for life, pursuing ideals, feeling confident, accepting life, being grateful, lifelong learning.
Quality of life	The focus is on a new perspective on life with the disease.	Enjoyment, being happy, feeling good, feeling well-balanced, feeling safe, intimacy, housing circumstances, having enough money.

Participation	Participation is about participating in society and being able to engage in social activities. But also getting support and asking for help from the social environment.	Social contact, being taken seriously, doing fun things together, having support from others, sense of belonging, doing meaningful things, being interested in society.
Daily functioning	Daily functioning has as the primary motivation to continue to function in daily/ordinary life.	Taking care of yourself, knowing your limitations, knowledge of health, managing time, managing money, being able to work, being able to ask for help.
Other	Motivations that could not be applied to one of the other dimensions	

For facilitators and barriers, participants could fill in their experiences directly using the categories ‘money/compensation’, ‘emotional/ mental processes’, ‘knowledge’, ‘support’, ‘time’, ‘condition-related’, and ‘others’. All responses were carefully analysed and considered by one researcher (EtB). When applicable, responses that were placed incorrectly in the provided categories were moved to the fitting category (e.g., a barrier filled in by the ‘other’ category that described a ‘time’ barrier). When in doubt, the movement of responses was discussed and agreed upon with another author (MT).

Results

A total of 33 complete survey responses were collected (51 people started answering the survey). Of the extra different options offered to fill in this survey, most were filled in online (N=27). Only 6 participants filled in the paper version, which was a result of the usual route. Only one complete response was collected from the enhanced route. Not one contact request for offline help was made.

Demographics

Nineteen participants were male, 13 were female, and one preferred not to say. Participants had an average age of 70. The GOLD stage ranged among participants. No participant mentioned having GOLD 1. On average, participants rated their own health

to be at 5.3 (scale from 0=very bad to 10=very good), indicating they judged their own health to be moderate. Furthermore, participants indicated having moderate to slightly high concerns about their own health (average of 4.4, scale from 0=high concerns to 10=high concerns).

Socio-Economic Position

To get an indication of the SEP, questions about social life, financial status concerns (graded from 0=serious concerns to 10=no concerns at all), highest education, and cultural background were asked. The majority of participants were daily among people, implying that they have social lives and do not live in social isolation. Five participants, however, mentioned being mostly on their own. In addition, most participants had average to high educational backgrounds. Participants' financial concerns had an average of 6,75, indicating to be above average. This suggests that participants do not worry greatly about their finances, which might be a slight indication that they are somewhat more capable of buying or utilizing certain self-management strategies. All participants were born in the Netherlands. The majority of the parents of the participants were also born in the Netherlands, meaning that most participants have a Dutch cultural background.

Self-management Strategies

In total, 152 self-management strategies were mentioned, and 75 in-depth elaborations were given. The number of strategies stated by a participant ranged from two to ten. Participants mentioned the strategies that they experienced to be both positive (89%) and negative (11%).

General Self-Management Strategies

Table 18 shows the frequencies and examples of self-management strategies. Overall, participants reported applying a diverse range of self-management strategies in their daily lives. Most strategies (N=44) fit within the physical activity category (e.g., walking, biking), followed by self-management strategies in the mental health category (N=24) (e.g., stress reduction). The category 'alternative medicine' (e.g., using herbs) was mentioned less frequently (N=8) compared to some of the other categories. The least amount of self-management strategies (N=4) were performed in the 'Nutrition and supplements' category (e.g., eating healthy, taking vitamin supplements).

Table 18. Frequencies and examples of self-management strategies.

Self-management category	N	Examples
Physical activity	44	Walking, biking, fitness, move more
Mental health	24	Acceptance of the disease, stress reduction, staying positive
General lifestyle alterations	23	Smoking cessation, staying healthy (without further explanation), changing lifestyle, staying indoors in certain weather conditions
Medication	21	Adhere to medication, combine intake medication at one time, prednisolone treatment for emergencies
Assistive devices	18	Walking with a walking stick, using a walker, stairlift
Healthcare Professionals	16	Long rehabilitation, physiotherapy,
Energy distribution	13	Take more rest, stop on time, pacing
Participation	13	Performing interests and hobbies, contact with peers, (voluntary) work
Information and patient education	10	Gathering disease knowledge, collecting information,
Alternative medicine	8	Using herbs, CBD oil, steaming with herbs, and salt
Nutrition and supplements	4	Vitamin supplements, eating healthy, not roasting products
Other	10	Using body language, filling in this survey, and when I lie in bed, I cough a lot

Motivation to Perform Strategies

Table 19 shows an overview of the different motivations for starting to perform a certain self-management strategy, categorised using the dimensions of the positive health model of Huber et al., (2016). Most motivations (N=46) were related to the Bodily functioning dimension (e.g., experiencing symptoms like shortness of breath). The dimension of Mental health (e.g., wanting to accept the disease) was also mentioned quite often

(N=13). Only two motivations to perform a certain strategy were derived from the Meaningfulness dimension (e.g., wanting to continuously learn). None of the motivations mentioned was related to the Quality of Life dimension.

Table 19. Motivations to perform self-management strategies categorised using the dimensions of Positive Health by Haber et al., (2016). Some motivations entailed more than one dimension (for example, targeting both bodily functioning and participation), which was then counted separately.

Positive health dimension	N	Example quotes
Bodily functioning	46	<p><i>'Shortness of breath and too low of a saturation'</i> (RSP30)</p> <p><i>'For more endurance, and trying to stay fit'</i> (RSP35)</p> <p><i>'To manage the disease better. To increase the physical condition'</i> (RSP8)</p>
Mental well-being	13	<p><i>'Without acceptance, you are nowhere. Becoming aware of not being able to do everything as before has had a huge impact'</i> (RSP2)</p> <p><i>'Too unhappy with myself because I could not do certain things'</i> (RSP05)</p> <p><i>'Accepting versus fighting. You cannot fight COPD; you will lose that fight anyway. It is better to take certain losses and use the energy that remains differently'</i> (RSP10)</p>
Participation	7	<p><i>'Expand relevant network. . . Establish contacts with researchers and respond to messages'</i>(RSP7)</p> <p><i>'Despite symptoms [I] continued to work, downplayed deteriorating health, and continued to do so until [my] health no longer allowed. Tried to hide it [COPD] from those around you. . . . In addition, putting the importance of "just" wanting to get on with work, income, and your life above the importance of your own health. Hoping that it [COPD] will blow over'</i> (RSP13)</p> <p><i>'When the COPD diagnosis became known, [I sat] down with the employer to discuss what was within the possibilities'</i> (RSP26)</p>
Daily functioning	4	<p><i>Last year [we had an] intensive renovation so that we now have a bathroom and bedroom on the ground floor. Because of this I no longer have to walk upstairs. . . [I] could not climb the stairs at night when I was tired or too tired'</i> (RSP5)</p> <p><i>'Walking the stairs was became increasingly difficult'</i> (RSP30)</p>

		<i>'Long underwear, long-sleeved shirt, body warmer [I] feel uneasy because of the cold' (RSP29)</i>
Meaningfulness	2	<i>'I want to keep learning' (RSP26)</i> <i>'Need for self-regulation' (RSP7)</i>
Quality of Life	0	n/a
Other	3	<i>'I always do like that, [I] don't know any other way. One day is not the other, but of course that applies to everyone' (RSP1)</i> <i>'I had to' (RSP34)</i> <i>'COPD' (RSP4)</i>

Facilitators and Barriers to Performing Self-Management

In total, 30 incorrectly placed responses were re-categorised as they did not fit within the provided category (N=16) or were stated as barriers while they reflected facilitators and vice versa (N=14).

A total of 120 facilitators were reported regarding 75 strategies (Table 20). Most facilitators (N=30) were experienced in the 'time' category (e.g., having sufficient time to perform the strategy). The category 'support' (e.g., being understood) represented the second most commonly reported facilitator (N=21). Facilitators in the other provided categories (e.g., 'knowledge' (N=19), 'condition-related' (N=18), and 'emotional' (N=16)) were also mentioned several times.

Furthermore, participants reported a total of 43 barriers (Table 20). Although participants mentioned diverse categories, the emotional barriers (e.g., difficulties accepting, feelings of shame, denial) were experienced the most (N=17). Barriers in the categories 'condition-related' (N=7) (e.g., the active disease) and 'knowledge' (N=6) (e.g., no information available) were also mentioned several times. Barriers in the 'other' category (N=4) were so diverse that they could not warrant a separate category.

Table 20. Experienced Facilitators and Barriers

Category	Facilitators (N=120)		Barriers (N=43)	
	N	Example quotes	N	Example quotes
Knowledge	19	<i>'I searched for information a lot' (RSP22)</i> <i>'I've read about what is best for COPD. It appeared to be movement' (RSP8)</i>	6	<i>'I didn't know anything about these herbs' (RSP2)</i> <i>'There was less information available' (RSP27)</i>

Time	30	<i>'Enough [time]. I'm retired'</i> (RSP24)	2	<i>'Work, private life, and children literally get in the way of sports on a regular basis'</i> (RSP6)
		<i>'Sufficient time to experiment'</i> (RSP7)		<i>'Time indeed'</i> (RSP1)
Condition related	18	<i>'In case of breathlessness e.g., when climbing or headwind on the bike, understand lower pace'</i> (RSP6)	7	<i>'With active COPD, I, obviously, achieve a different, lower level, I have to keep laboriously catching up with that later'</i> (RSP6)
		<i>'To prevent COPD from worsening'</i> (RSP4)		<i>'COPD was active'</i> (RSP28)
Money/ Compensation	10	<i>'We were able to finance it'</i> (RSP5)	3	<i>'It costs €50 a bottle, and with a retirement, it's not always easy to pay, but I try.'</i> (RSP14)
		<i>'Health insurance compensates it for 1 time a week'</i> (RSP35)		<i>'When I started, everything was still reimbursed. since a few years, there is a restriction'</i> (RSP16)
Support	21	<i>'Understanding from bystanders, you are not always understood'</i> (RSP21)	4	<i>'I'm too proud to ask for help'</i> (RSP2)
		<i>'[My] home situation perfect [there is] no barrier to do anything'</i> (RSP22)		<i>'Understanding from others'</i> (RSP21)
Emotional/ Mental processes	16	<i>'Especially NOT accepting my new situation'</i> (RSP13)	17	<i>'Feelings of guilt that I could not be at every occasion, e.g., funerals and parties'</i> (RSP6)
		<i>'Search for acknowledgement'</i> (RSP27)		<i>'I didn't want any attention'</i> (RSP27)
Other	6	<i>'Clean air and quiet streets'</i> (RSP33)	4	<i>'Addiction'</i> (RSP16)
		<i>'It went well because I took it one step at a time'</i> (RSP12)		<i>'It took some time to see if side effects occurred with the new tablet'</i> (RSP20)

Discussion

The most common self-management strategies were from the category ‘physical activity’, and motivations to start a certain strategy were mostly related to the ‘bodily functioning’ dimension. Participants reported more facilitators than barriers when performing certain strategies. Furthermore, the enhanced route only resulted in one additional participant (survey filled in online), who was also not necessarily commonly underrepresented (e.g., active social life, average educational background).

Reflection on Self-Management of People with COPD

Results indicate that people with COPD currently employ a diverse set of strategies for the self-management of their disease. It should be noted, however, that no claims or assessments about the effectiveness of the self-management strategies mentioned by the participants can be made. The investigation in this study focused on what people with COPD currently do for their self-management and how they experienced it. Future research could investigate whether these strategies can be proven effective.

In literature, most (eHealth) interventions for COPD are targeted towards the physical aspect of one’s disease (te Braake, Vaseur, et al., 2025). This is not surprising, given that self-management provided within primary care is often supported by action planning, smoking cessation, medication adherence, and physical activity (Hallensleben et al., 2019; McCabe et al., 2017; te Braake, Vaseur, et al., 2025). However, as we can conclude from this study, participants perform many self-management strategies that do not necessarily lie within the range of clinical-care supported strategies. Such strategies are often the result of patients’ own search efforts and experiences in daily lives, and healthcare professionals (HCPs) might not be aware of their patients performing these, as these are often not discussed within the (half-)yearly consultations. This means that there might be a gap between self-management strategies that are taught to patients within clinical care and the strategies that people perform in their daily lives. This begs the question of whether there is insufficient awareness and/or knowledge of, and/or lack of available support for, self-management strategies outside the clinical frame.

Our study showed that self-management strategies are often driven by a bodily functioning need (e.g., reducing symptoms or pain). No indicators were found that participants were directly motivated by categories like ‘quality of life’ or ‘meaningfulness’. However, we cannot draw clear conclusions that other dimensions are not also affected when performing a certain self-management strategy. For example, when increasing

one's physical activity to reduce pain (bodily functioning), one might also improve one's mental health (physical activity improves mental health (Martín-Rodríguez et al., 2024)), thereby, in time, potentially improving the overall quality of life. A self-management strategy is, therefore, not affecting a singular dimension of one's health. It is intertwined with, related to, and affects all dimensions of one's health.

Methodological Reflection on the Self-Management Model

We analysed the self-management strategies by adhering to the self-management model created by te Braake, Schriemer, et al., (2025) for people with RMDs. It appeared that this model could be used for the COPD population. Some small nuances were noticeable. For example, smoking cessation and taking into account weather conditions were recurring themes for people with COPD, and did not occur in the RMD population. Furthermore, people with RMDs put a more prominent focus on nutrition and supplements, while this was only mentioned 4 times in the COPD population. However, this poses no restrictions to the model as all strategies could be fitted within the different categories (e.g., smoking cessation fitted within the category 'General lifestyle alterations'). Thus, although there are some differences within each category (e.g., different types of exercises, different nutrition, different lifestyle alterations), the self-management strategies mentioned in this study could all be applied to the categories created in the study with people with RMDs. In addition, people with comorbidities may already tackle their self-management disease-generic as themes might overlap.

Furthermore, this study showed that some categories (e.g., information and education, participation, nutrition, and supplements) were not performed that often. This underperformance might have several reasons. First, it may be that because of the low response rates of the survey, the data is not saturated yet. Thus, more responses might indeed reveal a higher tendency towards those categories. Especially because in the study of te Braake, Schriemer, et al., (2025) with high response rates, these categories (information and education, participation, nutrition, and supplements) were performed quite often. Second, given the high amount of facilitators in the 'time' category ($N=30$), it may be that self-management strategies that benefit from having sufficient time (e.g., time to perform physical activity) are easier to accomplish by the participants. People who, for example, experience 'time' as a barrier might have more difficulties with performing such a self-management strategy. Third, the underrepresentation of certain categories may indicate that participants might not be aware of the possibilities for self-management within such categories, while those might indeed support participants in

their self-management journey. The unawareness of self-management in such categories may then reflect a gap in current self-management support and yield several opportunities for change. We therefore implicate that HCPs should be made aware of the different possibilities for self-management and should recognise the importance of discussing this with their patients. Consequently, HCPs should shed light on the different categories while taking into account the SEP of their patients within their consultations to inform and support people with COPD with the diverse paradigm of self-management.

Towards Reaching the Wider COPD Population

Several efforts were made to increase the response rates. However, our actions seemed insufficient as we were not able to increase the number of survey responses, nor did we thereby reach the wider COPD population (e.g., those who are underrepresented). This outcome calls for critical reflection and improvement of efforts. Due to time constraints, our approaches were mostly passive: no relationship was built with the communities before data collection, and our main goal was to ask something first (e.g., filled-in surveys) without directly giving anything in return. To increase engagement, it is important to utilize active strategies (Stuber et al., 2020) to engage with the community and to build relationships with the people needed to provide input for such research as much as possible. Therefore, we implicate that researchers should strive towards increasing response rates in their research by: 1) being aware of the time it costs and plan (take into account extra time in advance to establish active approaches), 2) working on building a research community, preferably before the start of the study, and make efforts to identify, engage, and establish a relationship with so-called local ‘gatekeepers’ who then can actively engage potential participants (Darley & Carroll, 2022), 3) deliberately considering different options to find the right platform to recruit participants that suits the target population (e.g., by local newspapers (Tunc et al., 2023)), and to increase chances of higher response rates, and 4) acknowledging and acting upon the importance of giving something back to the population (e.g., research summaries, giving time back to participants by, for example, having conversations and drinking coffee together, for their time invested in the study) to show appreciation towards participants and/or financial compensation to lower barriers for marginalized populations to participate (Richards et al., 2018).

Strengths and Limitations

People with COPD do much more for their self-management than may be known by clinicians, as efforts do not necessarily fit with clinical recommendations. We also show that self-management categories designed for the RMD population can be applied to the population of COPD. This indicates that categories for self-management may be generic across chronic diseases. To the best of our knowledge, no COPD self-management study has revealed such an outcome.

This study also has its limitations. Despite our efforts to increase response rates, this study still has a small sample size, and one should be aware of this when interpreting the results. This study can be seen as the first identification of self-management strategies in daily living. One may question the value when not reaching sufficient responses. We argue that this study has important outcomes going beyond the survey results. We also draw lessons from our enhanced approaches and reflect on the usefulness of the RMDs self-management model. Future researchers can build upon our efforts.

Some motivations to perform a strategy fit more than one dimension, while others do not directly fit within one dimension but can rather be seen as the overall outcome (e.g., quality of life), which is not necessarily the main motivation for why people start a certain strategy. Thus, our study targeting the self-management of people with COPD concurs with the study of te Braake, Schriemer, et al., (2025) that the categories of positive health as developed by Huber et al., (2016) are not the most suitable for categorizing motivational aspects. The general self-management strategies of people with COPD, on the other hand, could be easily applied to the model of RMDs developed by te Braake, Schriemer, et al., (2025).

There might be some confusion between the categories ‘nutrition and supplements’ and ‘alternative medicine’. Some of the strategies mentioned in the ‘nutrition and supplements’ categories could have been used by participants for their underlying healing beliefs. One could argue that such strategies are related to traditional Chinese medicine, thereby belonging to the ‘alternative medicine’ category. As data was limited, we could not identify whether participants saw a strategy as Chinese medicine or purely as nutrition.

Finally, we encountered the limitation of a self-reported survey in two ways. First, people needed to self-report their COPD diagnosis and their GOLD level. As this survey was anonymous, people might have inaccurately filled in their GOLD level or

misdiagnosed themselves. Future research should use spirometry data to confirm diagnoses. Secondly, even though there were open-ended questions, participants' self-reported answers were short. Often, the context was missing, making it difficult to categorise some of the strategies and motivations. However, to the best of our ability, we tried to assign the self-management data into categories.

Conclusion

People with COPD currently perform diverse self-management strategies in their daily lives. These efforts may not always be visible in the clinical setting, as these are often initiated by one's own search journey and thus are usually additional to standard HCP advice. It should, therefore, not be underestimated how active people already are regarding their self-management. This study provides a first step in identifying self-management strategies in the daily lives of people with COPD. Future research should investigate whether these strategies apply to the larger COPD population and people with other chronic diseases. Our study also reflected on our efforts to increase response rates and thereby, at the same time, aim to reach the wider COPD population. It highlighted the difficulty of recruiting participants with passive approaches, where people needed to sign up themselves to participate. Thus, future efforts to increase response rates should not be limited to passive approaches and one-time data collection.

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Part III: The future perspective of self-management support





Chapter 6: Designing a self-management support guide from a patient perspective: a participatory design process

Based on:

te Braake, E., Grünloh, C., Hurmuz-Bodde, M., & Tabak, M. Developing a self-management support guide from the patient perspective: a participatory design process. *(Submitted for publication)*

Abstract

Introduction: Self-management is a crucial aspect of managing chronic conditions. People receive recommendations from their health care professional in clinical practice, but these often do not reflect the more diverse strategies that people actually perform in daily life. At the same time, people with chronic conditions report a lack of suitable self-management support within their patient journey. Therefore, this study aimed to 1) investigate the problems in current practice and needs and wishes towards self-management support from a patient perspective and 2) develop self-management support by engaging patients in the design process, both through Patient Engagement (PE).

Methods: A participatory design process was followed, consisting of three phases (Exploration, Iterative Design, and Final Evaluation) in seven study rounds. These rounds consisted of online and face-to-face sessions with people with Chronic Obstructive Pulmonary Disease (COPD) and people with Rheumatic and Musculoskeletal Diseases (RMDs), and an online survey with healthcare professionals (HCPs). In subsequent sessions, a self-management support guide was iteratively developed with patient partners.

Results: In total, 40 people (with COPD, RMDs, or HCPs) participated in the design process. Results from Phase 1 showed that participants experienced a lack of self-management support (e.g., missing information) in practice. The self-management support guide (phase 2) aims to support people with chronic conditions in their self-management journey by providing them with information and letting them fill in several questions to holistic self-management categories. The PE in this study was highly beneficial to the research process, design, and development of the end product. In the Final Evaluation (phase 3), the guide was rated on a 5-point Likert Scale (1= totally disagree to 5= totally agree. Participants rated the guide to be above average (perceived usefulness (avg.=4.5), intention to use (avg.=3.6), and ease of use (avg.=3.7)).

Conclusion: The self-management support guide enables making a first step towards self-management and can be tailored to the specific needs of each person. Future research should investigate whether this guide can be used for other chronic conditions and look into ways of implementing the guide in daily practice, for example, through campaigns and onboarding.

Introduction

Chronic conditions are among the leading causes of disability and mortality worldwide (Hacker, 2024). People with chronic conditions (such as Chronic Obstructive Pulmonary Disease; COPD, and Rheumatic and Musculoskeletal Diseases; RMDs) often experience multiple challenges in all areas of their life (e.g., reduced quality of life, high healthcare costs, managing medications, loss of autonomous life, adjusting to limitations, and managing symptoms (Barakou et al., 2025; Hajat & Stein, 2018; Tumilty et al., 2020; Van Wilder et al., 2021).

Self-management is a crucial aspect of managing one's disease. Self-management can be defined as: 'The ability of an individual to manage one's symptoms, treatment, physical, social, and emotional consequences, and lifestyle changes. It includes means of empowerment, educating oneself, being autonomous, learning and adapting to new behaviours, acceptance, and adapting to a new balance in life' (te Braake, Vaseur, et al., 2025). Many examples of self-management interventions for chronic conditions are available in the literature (e.g., eHealth, action planning (Effing & Lenferink, 2020; Im et al., 2024; Kuipers et al., 2019)). However, these are mostly focused on the physical aspect of self-management (te Braake, Vaseur, et al., 2025).

Healthcare professionals (HCPs) play a crucial role in introducing the concept of self-management and providing guidance to support patients on their self-management journey. However, current healthcare systems are also under considerable pressure due to factors such as high workload, limited healthcare staff, and long waiting lists (Abdullah Altassan et al., 2024; Salisbury et al., 2023). Challenges such as a lack of time, beliefs and values of HCPs and patients about individual responsibility, and short-term priorities dominating daily tasks, can hinder the provision of self-management support (Franklin et al., 2017; S. van Hooft et al., 2025). For example, van Hooft et al., (2025) stated in their study that self-management support provided by nurses was primarily focused on medical management, and daily practice led them to focus on 'getting the job done'. Such barriers simultaneously hinder patients' knowledge about existing self-management strategies and interventions. As self-management support provided by HCPs might not be feasible in practice and currently focuses on medical management, we need to investigate if and how people with chronic conditions want to shape self-management support.

Current self-management interventions in the literature do not necessarily reflect the variability of strategies that people with chronic conditions perform. For

example, self-management performed in the daily lives of people with COPD and RMDs also includes strategies in the categories of physical activity, mental health, alternative medicine, nutrition, and supplements, amongst others (te Braake, Schriemer, et al., 2025). However, these strategies do not always align with clinical care recommendations and are more holistic than medical self-management only. A focus on medical management can hinder patient care, as spending supportive time (such as self-management support) is, due to time constraints, often the first to be neglected, and a broader perspective on the patient journey could be very beneficial (van Hooft et al., 2025). In addition, people with chronic conditions may need more support than medical management only, as they have to deal with their condition in all aspects of their lives. However, not much is known about what self-management support people with chronic conditions prefer. Their perspectives regarding this topic remain underrepresented. This reflects a knowledge gap in the literature, as current self-management interventions may not support the true needs of people with chronic conditions.

Patient Engagement (PE) may help uncover the perspectives of people with chronic conditions regarding self-management support in this context. Patient engagement (PE) can be defined as ‘meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation’ (The Canadian Institutes of Health Research, 2014). The people involved in this type of collaboration are often referred to as patient partners. Many benefits of PE are stated in the literature (e.g., that patient partners’ preferences, experiences, and needs can be included, as well as supporting knowledge translation, and facilitating recruitment (Belton et al., 2019; Forsythe et al., 2019; Kirwan et al., 2005; McVey et al., 2023). Thus, in the context of this study, PE is essential as it may help uncover exactly those preferences, experiences, and needs regarding self-management that are not included in current literature. Therefore, this study aims to 1) investigate the problems of current practice and needs and wishes regarding self-management support of people with COPD and RMDs in their daily practice, and 2), through a participatory design process, design self-management support from a patient perspective. As research from te Braake et al., (2026) showed that underlying needs surrounding self-management support might be disease-generic rather than disease-specific, this study will focus on more than one chronic condition by involving people with COPD and people with RMDs.

Methods

Study design

This study was set up following a participatory design approach consisting of three phases with seven distinct study rounds. Throughout the different studies, people with COPD and people with RMDs were engaged as patient partners to involve and integrate their perspectives. For being a patient partner, no particular training or skills were required. Most study rounds were offered online and offline to support those without digital skills in joining our offline meetings, and to support those unable to travel to the offline meetings in joining our online meetings. Patient partners were recruited via patient organisations or through their participation in previous projects. To show the researchers' appreciation, each patient partner was provided with a gift voucher after each meeting. Studies were carried out between April 2024 and October 2025. Each study round provided input for and shaped the following steps. To be eligible for participation, participants needed to be 1) 16 years or older and diagnosed with an RMD or COPD. One of the seven studies was an online survey for HCPs to capture their perspectives. All HCPs, regardless of their background, were eligible to complete this survey. All participants received information about the study well in advance and provided their (online) informed consent before participating in the study. The nature of this study does not require formal medical ethical approval, as was assessed by the Medical Research Ethics Committee (MREC) Oost-Nederland in terms of the Medical Research Involving Human Subjects Act (WMO) obligation (File number: 2024-17042). All procedures were in accordance with the Declaration of Helsinki (64th WMA General Assembly, Fortaleza, Brazil, October 2013, and 75th WMA General Assembly, Helsinki, Finland, October 2024) and Good Clinical Practice (GCP) guidelines.

The complete design of the whole participatory design process is depicted in Figure 11 and consists of three phases: 1) Exploration, 2) Iterative Design, and 3) Final Evaluation. During various focus groups, the sticky notes method (Ball et al., 2021; Burgess et al., 2021) was used to facilitate engagement and support design collaboration. Using such a creative method invites participants to think out of the box, which often leads to new ideas (Ball et al., 2021). A detailed explanation of each study round is shown in Multimedia Appendix 6.1.

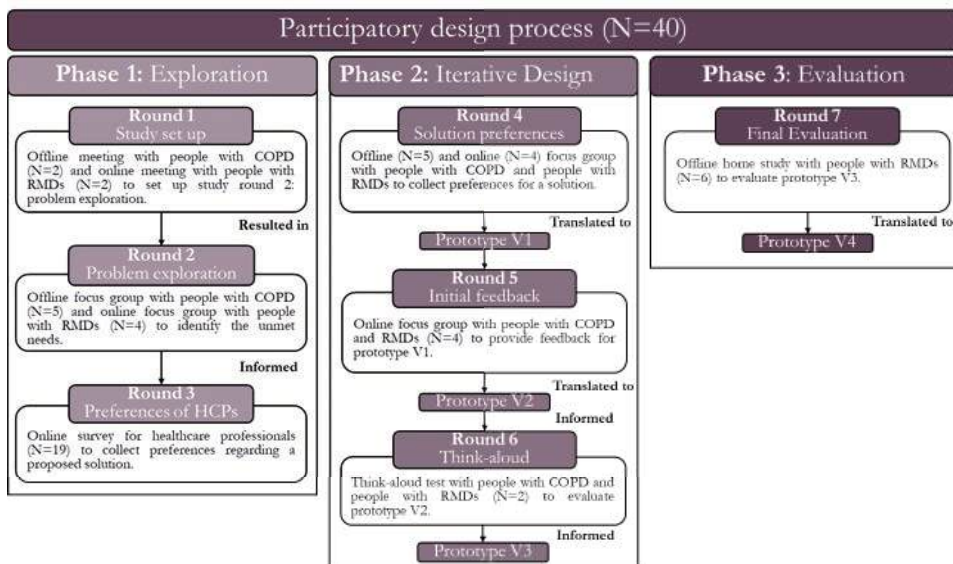


Figure 11. Participatory Design Process.

Phase 1: Exploration

The goal of Phase 1 was to explore the current problem of supporting self-management from a patient perspective. As PE was central throughout the participatory design process, the first study round was organized to shape the subsequent focus groups together with patient partners (Study Round 1). This was done to ensure the right questions were asked to uncover the needs of self-management and to make the content and set-up of the focus groups understandable for the participants. Study Round 1 was performed through two separate meetings: one meeting with people with RMDs (online) and another meeting with people with COPD (offline). The results of this study round are reflected in the study protocol for Round 2. In Study Round 2, two focus groups (one with people with COPD and one with people with RMDs) were conducted to explore the problems of current practice towards self-management. The results of the two focus groups were compared and summarized to identify the current problems. In the Exploration phase, both HCPs and people with chronic conditions were considered as possible end users of the self-management guide. Therefore, in Study Round 3, an online multiple-choice survey was developed in Qualtrics (*Qualtrics*, n.d.) to gather the preferences of HCPs for the self-management guide. HCPs could give more than one answer. As the survey was part of the problem exploration phase, the design, content, and target group of the end product were not completely clear yet. That is why the survey

provided a broad description of the intended goals and the possible elements of the end product.

Phase 2: Iterative Design

Phase 2 aimed to iteratively design the self-management support guide with people with COPD and people with RMDs. The main idea of this guide is to support people with chronic conditions in their self-management, which entails more than the physical aspect of self-management only. To gather inputs for the guide, preferences for the end product were collected in Study Round 4. In this round, aspects that participants felt HCPs or other people do not understand about living with COPD or RMDs were first identified. Thereafter, using the sticky notes method (Ball et al., 2021; Burgess et al., 2021), information was collected about which self-management knowledge was important to share with those people to help them empathize with or understand the lived experience a bit better, and the possible modality of the self-management support guide. The session consisted of offline and online sessions, with mixed groups of people with COPD and RMDs working towards the proposed solution. As the guide aims to support people with chronic conditions, this study round mixed people with RMDs and people with COPD in the focus groups to discuss their preferences with each other without making explicit distinctions between chronic conditions. The results of this Study Round were translated into Prototype Version 1 of the self-management guide. In Study Round 5, the first version of the Prototype (V1) was discussed with people with COPD and RMDs during an online focus group. Again, the group of participants was mixed, and no distinction between chronic conditions was made. This feedback round focused on the content, design, and understandability of the self-management guide. This resulted in several points for improvement. The feedback shared during this round was translated into Prototype Version 2 (V2). In Study Round 6, Prototype Version 2 (V2) was face-to-face tested via the Think-Aloud method with two participants. With the think-aloud method, mostly, (textual) errors and unclear sentences were identified. The results of these two sessions were translated into Version 3 (V3) of the self-management support guide.

Phase 3. Final Evaluation

Phase 3 aimed to evaluate the self-management support guide for people with chronic conditions in the real-life setting. In Study Round 7, this prototype version (V3) was evaluated by participants at home by utilizing the self-management support guide and filling out an evaluation form. As we wanted people to use the guide outside the lab

setting and inside the real-life setting, this final evaluation was performed at their homes. Thereby, trying to recreate the proposed use of the guide once implemented. In addition, by performing this evaluation in their own safe environment, we also wanted people to feel comfortable when filling out this prototype and give them all the time they needed, especially considering that the guide supports reflection about what people consider important in life. In this way, they could decide for themselves when and to what extent they wanted to utilize the self-management guide without feeling pressured by a researcher looking over their shoulders. The evaluation form consisted of several open questions focusing on first impressions, the content of the guide (positive/negative aspects), the layout of the guide (positive/ negative aspects), and ended with three multiple-choice questions focusing on its acceptance. The acceptance of the guide was evaluated using questions inspired by the Technology Acceptance Model (TAM) (Davis, 1985, 1989), which asked participants to rate the perceived usefulness, intention to use, and ease of use. The results of this final evaluation were translated into Version 4 (V4) of the self-management support guide.

Data analysis

The results of each focus group round were analysed by one reviewer (EtB) using an inductive approach. This inductive approach entailed, firstly, thoroughly reading through the transcripts of the focus groups and notes of the researcher(s). Based on this information, themes were created by one researcher (EtB) that covered the information collected in the focus groups. The most important themes (those uncovering unmet needs, informing the following steps, or providing input for the self-management guide) were carefully considered and discussed during meetings with the other authors (CG, MHB, MT) to determine the next steps of the project. This supported the fluidity and iterative nature of the design process, in which results from each round provided input for the following round. All focus groups were audio-recorded. The online survey for HCPs (Round 3) was open from [15-01-2025] to [25-02-2025] (Multimedia Appendix 6.1). Survey responses were collected with Qualtrics (*Qualtrics*, n.d.), and results were exported to a secure Excel file, where they were anonymized and analysed using descriptive statistics (counts for frequency distribution and average). The final evaluation in Round 7 was analysed using the filled-in prototypes and evaluation forms, which were sent to the researcher on paper and were then transferred to a secure Excel file. Here, a deductive approach to identify and categorise common problems and areas for improvement was utilized.

Results

In total, N=40 unique participants (N=13 with COPD, N=8 with RMDs, and N=19 HCPs) participated in this participatory design process. Some people with COPD or RMDs (N=13) participated in more than one study round. Of the people with COPD or RMDs, 11 were male, and 12 were female. The most important results of the various rounds that informed further design are presented below.

Phase 1. Exploration

Round 1. Study set up

The goal of the first study round was to, together with patient partners, set up the protocol for study round 2. In this round, discussions on how to make the focus group understandable and how to best explore the problems of current practice, needs, and wishes took place. This resulted in the protocol consisting of different steps to explore the problem: Investigating the current situation, the patient journey, the desired situation, and the support participants would prefer. The results of the first round are reflected in the focus group protocol, available in Multimedia Appendix 6.1.

Round 2. Problem exploration

Study round 2 identified the problems in the current practice experienced by people with COPD and people with RMDs. Table 21 provides an overview of the recurring topics mentioned by both groups, highlighting the problems of current practice.

Table 21. Problems in current practice experienced by people with COPD and people with RMDs.

Identified problems of current practice
Missing information about their disease and self-management
Receiving self-management support depends on the HCPs
Needing to figure out everything themselves for self-management
Being treated by the protocol in which self-management does not fit
Missing a holistic approach

Both people with COPD and people with RMDs mentioned that they missed information about their disease and self-management, and had to figure everything out on their own. There was no support experienced that helped them get started with self-management. They mentioned retrieving information about self-management depending

on their own search strategy (for example, via flyers, the internet, or other people): *'I was diagnosed [between 20-30] years ago. And for the first [between 10-20] years, I was very ill. I was in a lot of pain and really just muddled through. There was no support whatsoever. . . After [between 10-20] years, I started looking for support myself and found it, which helped me enormously, and that support was online'* (RMD01). Participants noted that this search for information takes effort, and one needs to be willing to explore it oneself. However, this also brings difficulties: *'If you look on the internet and type in COPD, you'll get around 1,000 hits. So, what's the right one? I'm afraid of self-medicating or who knows what else'* (COPD033).

People with COPD and people with RMDs also mentioned the lack of self-management support provided by HCPs as a problem in current practice. Participants noted that it depended on the HCPs whether they received information about self-management: *'At some point, you're confronted and told that you have COPD. And then what? Nothing. Figure it out yourself. . . Sure, the pulmonologist says, "I'll prescribe you some medication, and you'll get an inhaler and stuff". Yeah, great, and then what? . . . I had to search the internet myself to find out what COPD actually is and what it all entails'* (COPD018), and *'You are dependent on the pulmonologist [for information]. Actually, there should be something outside the pulmonologists, a place or something where you can get all kinds of information'* (COPD034). Furthermore, participants missed a holistic approach among physicians, in which patients and their specific situations are considered, and in which attention is given to the psycho-social aspects of the person. For example: *'I often miss doctors and other healthcare providers asking questions such as: What is your home situation like? What do you want to do, what are you capable of, what do you want, what would you like? I really miss that. Look, they often focus on medication . . . But no one asks anything else, like how you feel about life, what you can do yourself, and things like that . . . The overall picture is not quite there'* (RMDs03). People with RMDs added that they experienced being treated according to a specific clinical protocol, and that their specific way of doing self-management (e.g., alternative medicine, nutrition, and supplements) does not align with the protocol being used. This was also considered a problem of current practice.

Round 3. Online survey

Study Round 3 focused on identifying preferences of HCPs for a self-management support guide, considering that at this stage of the project, the target group of the end product would potentially be both people with chronic conditions and HCPs. A total of 19 HCPs filled in the short online survey. HCPs had diverse backgrounds (e.g., physician, rehabilitation physician, nurse, physiotherapist). Table 22 presents the survey results for each answer option. Participants could give more than one answer.

Results about the purpose of using the guide in daily practice were ambiguous. Participants wanted to use it to increase their own knowledge, prepare for their consultations with patients, or utilize it during a consultation. Two participants filled in the ‘other’ category: one mentioned wanting to use it to educate other HCPs, and one mentioned wanting to use it as a reference book. Results about the preferred form of the end product were diverse. An e-learning (N=13), an infographic (N=12), and a video (N=8) were mentioned most often. The end product was preferred to be available online via a website (N=16). When asked about their intention to use the proposed solution (using a 5-point Likert scale from 1 = completely disagree to 5 = completely agree), participants gave an average of 3.7. Finally, the perceived usefulness, using the same Likert scale, scored an average of 3.9. Most HCPs preferred to spend either 5-10 minutes (N=10) or 10-30 minutes (N=7) on the guide. Only 2 participants were willing to spend more than 30 minutes on the guide.

Table 22. Results of a survey about HCPs ‘perspectives on the proposed solution.

Question	Answer possibilities	N
Purpose of using the solution	To increase knowledge	16
	To prepare for a consultation	11
	During a consultation	9
	Other	2
Preferred form of the solution	E-learning	13
	Infographic	12
	Video	8
	Animation	6
	Information folder	5
	Handbook	2
	Poster	2
	Other	0
Preferred availability of the solution	Online via a website	16
	Via my organisation	6
	In my possession	3
	Other	1
Preferred time spent on the solution	5- 10 minutes	10
	10-30 minutes	7
	>30 minutes	2

Phase 2: Iterative Design

Round 4. Solution preferences

Based on the results from the problem exploration, we decided to create a self-management support guide completely from the patient perspective, supporting people with chronic conditions with self-management, and educating HCPs about the patient perspective. Therefore, in Round 4, preferences for the end product were gathered by first exploring what opportunities participants had missed from their HCPs, and what participants wanted to make their HCPs aware of. Thereafter, the sticky notes method was used to look at ways to design the self-management guide.

Participants (N=9) from the two different mixed focus groups mentioned having experienced missed opportunities regarding their contact with HCPs. They noted that HCPs often did not discuss patients' daily living during consults, for example, whether there were problems at home, how people were managing their disease, or how they dealt with the pain: *'There is little communication about problems, such as how to deal with pain, for example, and what that means for you in your daily life. And I don't think I've ever been asked whether I have help at home. . . Well, that is something that is never really talked about, what it means for you'* (RMDs07). Participants experienced that questions about their own context were not asked: *'They ask too few questions, especially the doctor, about what you need in your context. . . the pulmonology nurse [for example] has the main task of doing a bicycle test or something else, or taking a measurement, but not of addressing that context. Such questions are relevant, such as how are things going?' (COPD09)*. One participant even mentioned that the HCPs see the patient as medically treatable, not as a human being. In general, feelings of not being heard and not being understood were commonly shared among participants.

When considering the aspects that HCPs could learn from patients, various points were mentioned. First, participants noted that the knowledge of HCPs about living with the disease from a patient perspective could be improved. Participants had several experiences in which HCPs lacked some knowledge about the disease. This entailed, for example, knowledge about the condition in general, and knowledge about the effect of the condition on the social lives, hobbies, and working lives of the participants. Furthermore, they had some recommendations for their consults; there should be an equal relationship between the HCP and the patient, in which they both take accountability for preparing their consults, so they can strive towards reaching the

best results. One participant mentioned: *'It is not like the doctor is someone who knows everything, and the patient who has to follow. But instead of an equal relationship, to achieve the best result together. The listening [skills] of a doctor is very important in this regard.'* (RMDs03). Thus, to do so, participants mentioned that HCPs should possess empathic competencies, ask questions, take time to listen actively, and pay attention to the person in front of them and their specific context. They also experienced that the conversation often focused on the computer, as HCPs simultaneously typed their answers into the electronic patient file: *'Some HCPs sit in front of the screen during consultations. They look at the screen instead of the patient. This gives the impression that they are not listening, which is often also the case'* (COPD05). To achieve the optimal situation, participants emphasized that preparations on both sides are necessary; HCPs should prepare the consultation and be aware of who is in front of them, while patients should prepare the topics they wish to discuss and formulate their questions. It was also discussed whether the above-mentioned was enough to support patients in their self-management. Participants also mentioned to believe that for HCPs to fully support self-management, a shift in their way of thinking would also be necessary. It was mentioned that the HCP would need to accept that there is much more to self-management than the clinical protocol that they might have learned and are familiar with, and therefore, out-of-the-box thinking (e.g., going beyond the clinical protocol and acknowledging that self-management is more than medication only) was essential. Furthermore, it was discussed that HCPs needed to trust the patient to perform self-management without the HCPs being in control. To do so, participants mentioned that this required a new way of working for HCPs in healthcare and that this would be very hard to change, as HCPs were used to working according to their clinical protocol.

Finally, when developing ways to translate these wishes into the design of the potential solutions, opinions were diverse. Some participants noted that there could be several options for the design (e.g., campaign, podcast, workshops, infographics) and that they did not have a strong preference for the form of the solution; the content was what mattered to them. This content should be short and effective. Another participant mentioned that the solution could contain two different aspects: one focusing on improving the knowledge of HCPs and patients in general, and the other focusing on a solution that could be used individually, for example, during consultations.

Proof-of-Concept Design of prototype V1

Based on the results, prototype V1 was set up as a self-management communication guide for HCPs and patients. The first version of the self-management guide, called 'My

self-management card' (translated from Dutch) focused on guiding people with chronic conditions to self-management (Figure 12). People with chronic conditions can choose how to use the guide; they can use this guide for themselves or for guiding consultations between them and their HCPs. The HCPs should then prepare the filled-in guide before the consultations. In this guide, first, self-management information is provided, followed by information on how to use the guide and a tip on where to find more information. Then, several holistic categories are presented to the participants ('My Pleasure', 'My Mental Health', 'My Body', 'My Daily Activities', 'My Environment', 'My Expectations'). The categories are organized to start with a positive category, 'My Pleasure', instead of immediately focusing on the medical ('My Body'). Participants can check the boxes of the categories that they find important at this moment and want to answer questions for. The categories 'My Self-Management', 'My Goals', 'My Actions', and 'My Retrospective' should always be answered as this invite taking action for self-management and reflection upon efforts. The following pages of the guide contain questions for the specific categories to help people decide how they are doing, what they find important for that category, and what they want to achieve for that category. The full version of this prototype is shown in Multimedia Appendix 6.1.



Figure 12. Some of the screenshots of Design Prototype V1.

Round 5. Initial Feedback

In Round 5, 4 participants provided feedback on the self-management communication guide during an online focus group. The most important point for improvement was that, through discussion, participants agreed it would be better to focus the guide on supporting patients rather than on their communication with HCPs. It should help them

to take a step in the right direction, as HCPs were busy and would not have the time to discuss these holistic categories, or were not open to discussing such matters. Participants agreed that it should not depend on HCPs whether people with chronic conditions can benefit from this guide. Thus, this guide should focus on the people with chronic conditions and help them make steps towards self-management. They would still be able to use it for themselves as a reminder or conversation starter in consultations, but the HCPs do not have an active role in its preparation. Furthermore, it was mentioned that the information contained a lot of text that was hard to follow. Also, self-management should be more central in the guide, and a clear explanation and definition of self-management, along with clear instructions on how to use the prototype, should be added.

Design of prototype V2

The prototype was improved (Figure 13) using the feedback from Study Round 5. Considering the strong sentiment that the guide should focus on guiding the person with a chronic condition and less on guiding the consultation, we decided to change the concept accordingly. This empowers people with chronic conditions in their self-management and makes the guide independent of whether the HCP uses the guide in their daily practice. In the following, the most important changes will be mentioned. Firstly, more information about self-management and how to use the guide is added in the introduction. Secondly, the self-management guide was divided into three different phases: 1) Preparation, 2) Execution, and 3) Reflection. In the first Phase, six holistic categories ('My Pleasure', 'My Mental Health', 'My Body', 'My Environment', 'My Daily Activities', and 'My Self-Management Expectations') are provided. Participants choose the categories for which they want to answer questions. In Phase 2, actions and self-management goals are formulated to prepare to perform self-management strategies. After the participants performed self-management, they can fill in Phase 3, in which they reflect upon their self-management strategies and formulate new actions and goals. The full version of Prototype Version 2 is shown in Multimedia Appendix 6.1.

Round 6. Think-aloud test

Prototype V2 was used as input for the think-aloud test in round 6 to ensure that the changes made improved the self-management guide, its understandability, and ensured that the individual's interpretation is in accordance with how it was intended. The think-aloud test was performed face-to-face with two people (one with COPD, one with RMDs). Here, several textual errors and difficulties were detected. Some of these are

mentioned in the following. Both participants perceived the introduction text as being quite long, which made it difficult to understand the text and to pay attention to what was being said. One participant suggested that the text could be shortened if figures or icons were added. Also, some questions or sentences were not understood as they were too broad, unclearly formulated, or experienced as too difficult (to answer) (e.g., ‘What would I like’, and ‘What can I do differently next time’. Finally, participants mentioned that the name ‘my self-management card’ confused them as it did not reflect the guide adequately, and they preferred another name.



Figure 13. Some of the screenshots of Prototype V2.

Design of prototype V3

The points mentioned during the think-aloud tests were considered and incorporated into the development of prototype V3 (Figure 14). First, the name of the guide was changed to ‘my self-management journey’ to reflect the process that this guide entails. Secondly, the information about self-management and the phases was made shorter, easier, and more appealing by adding a figure. The text was separated over a few pages, creating easy-to-follow pages. Thirdly, more appealing elements (figures, icons, textboxes) were added to make the guide fun and draw the attention of the participants. Thirdly, the names of the phases were changed from 1) ‘Preparation’, 2) ‘Execution’, and 3) ‘Reflection’ to 1) ‘This is me’, 2) ‘This is what I did’, and 3) ‘This is what I’m going to do’. This way the phases would be easier to understand and formulated using an active voice. Fourthly, the category ‘My Mental Health’ was changed to ‘My Feelings’ as the previous name was experienced to be a serious and heavy formulated topic. Fifthly, some

questions were changed, deleted, or clarified to make it more understandable and easier to answer.



Figure 14. Some screenshots of Prototype V3.

Phase 3. Evaluation

Round 7. Final Evaluation

Prototype Version 3 was used for the final evaluation carried out by participants at home at their own pace. In total, N=6 participants evaluated this prototype by using it as it was supposed to be when preparing for a consult and afterwards filling in an evaluation form. Although no thorough analysis of participants' answers in the actual guide was carried out, we did not get any indication that they did not understand the questions asked. Each participant seemed to be able to answer the questions in the manner that we intended, and we did not observe any surprises in their answers. Table 23 outlines some example quotes taken from the evaluation form. In general, participants had a good first impression. For two participants, their first impression was that the size of the guide in terms of pages came across as quite a lot. Furthermore, participants mentioned several positive points: clear explanation, the free choice to what extent to fill in the guide, the usefulness for evaluating one's own situation, and a clear description of the different phases. Several points for improvement were mentioned related to layout (e.g., needing more space to write, correcting the page numbering, and typos), and content (e.g., needing to add details, adding examples to increase understandability, and improving formulation). Two participants mentioned on two occasions in the evaluation form that the length of the guide was too long, while others (N=4) did not explicitly

mention having a problem with its length. It was also suggested by two participants that an online version of this guide should also be available. When asking participants about whether this guide could support self-management, N=5 participants agreed that this indeed would be helpful. One participant did not fill in this question. Finally, questions regarding the acceptance of the guide were asked. These questions could be answered on a 5-point Likert Scale (1= totally disagree to 5= totally agree). The perceived usefulness was scored 4.5 on average. An average of 3.6 was given to the intention to use the prototype, and the ease of use scored a 3.7 on average.

Table 23. Evaluation results with example quotes

Category	Example quotes
First impressions	<i>'Very neat, clear font, pleasant colours, and images. Easy to read. Attractive and inviting. It made me curious about the rest of the content'</i> (RSP14) <i>'First impressions are positive. Makes a serious impression. The whole thing looks inviting'</i> (RSP02) <i>'Quite a lot of pages'</i> (RSP15)
Positive points	<i>'It makes you think. How is my illness or condition? Can I do anything about my illness myself?'</i> (RSP11) <i>'It is great that self-management is explained! The examples on page 1 are also very helpful'</i> (RSP14) <i>'Very good to evaluate the situation, see it on paper, and put it down. Incentive to take control yourself'</i> (RSP10)
Points for improvements	<i>'Page 7.2 Feelings: Prefer: How do I feel? First, it is about feelings, and then about staying balanced. Keep it to one word'</i> (RSP07) <i>'I sometimes lacked sufficient space [to write]'</i> (RSP02) <i>'[Add] a field or location to enter the date. If you want to set goals, you will want to do so within a specific time frame. The date is also useful for looking back'</i> (RSP15)
Supporting self-management	<i>'I think the booklet can help because it makes you think about your illness. Filling it in can be a first step towards self-management'</i> (RSP02) <i>'Yes, definitely. Very pleasant and fairly easy to use and fill out'</i> (RSP14) <i>'Certainly! This may be facilitated with the assistance of an experienced professional who can be assigned to an individual if desired'</i> (RSP10)

Design of Prototype V4: ‘My self-management guide’

Based on the Final Evaluation (Study Round 7), several aspects have changed. First, more space to write down answers was created to allow more elaboration on the questions asked. Second, participants can enter the date they filled in their answers in the first phase of the self-management guide. In this way, participants can easily reflect on the topics they found important during that time. Thirdly, some textual errors and unclear sentences have been corrected, and the definition of self-management has been extended. Finally, the name of ‘my self-management journey’ was changed to ‘my self-management guide’ to match its content. It was mentioned by two participants in the final evaluation whether the guide will also be available to fill in online. However, this was not yet implemented in the final prototype version. As most participants did not perceive the length of the guide as being too long, this has not been changed.

Through various study rounds, ‘My self-management guide’ was developed as personalized self-management support (Figure 15). The goal of this guide is to guide people with chronic conditions in taking the first step in their self-management. It describes self-management and invites people with chronic conditions to reflect on what they find important in life by answering questions across three phases (1: ‘This is me’, 2: ‘This is what I did’, and 3: ‘This is what I’m going to do’). The final version of the self-management guide is shown in Multimedia Appendix 6.2.



Figure 15. Some screenshots of Prototype V4: ‘My self-management guide’.

Discussion

In this study, we first identified the problems of current practice towards self-management support (Study Round 2). Participants mentioned missing information about self-management, missed self-management support from their HCPs, needing to figure everything out themselves, missed a holistic approach, and experienced being treated by a clinical protocol. The resulting guide aims to meet these problems by providing information about self-management and guiding people through three phases to take the first steps towards self-management. The guide encompasses various holistic categories that can be further elaborated upon by filling in the corresponding questions. As it does not depend on the HCPs whether people can start with the guide, the problem of the lack of self-management support from the HCPs is also solved. While research on self-management support tools is available (Adriaans et al., 2021; Parke et al., 2015; te Braake, Vaseur, et al., 2025), these often focus on one chronic condition, on symptom monitoring, lack inclusion of holistic self-management categories, or do not include the patient perspective in their design. To the best of our knowledge, no guide is available considering the various holistic categories and developed from the patient perspective. Although our participatory design process included several feedback rounds and a final evaluation, a part of the problem space remains underexplored. Participants' experiences of being treated by a clinical protocol cannot be changed by the self-management guide created in this study. In the early phase of the design process, education of HCPs was considered as part of the solution; however, later intentionally disregarded, as patient partners voiced a strong preference to be able to make use of the guide on their own and not be dependent on their HCP. As this guide accounts for holistic categories, it goes beyond clinical self-management only and could also lead to changes in the clinical consult, in which topics discussed may be initiated by people with chronic conditions. Future research should explore ways to transform clinical protocols and allow for a broader perspective of self-management within clinical practice.

In line with the definition of self-management te Braake, Vaseur, et al., (2025), the person with the chronic condition has autonomy over how to use the self-management support guide. There are different options for using this guide. First, it can be introduced to people with chronic conditions, who may use it for themselves as a stand-alone guide. They can walk through the different phases and determine the next steps with the help of the guide. An advantage of giving autonomy to people with chronic conditions is that it is not dependent on the HCPs to provide self-management support. Our study showed that people had to search for information about self-management themselves. We aimed

to guide that process by offering them the self-management support guide, which enables them to start taking the first steps in their self-management without waiting for the HCPs to eventually give them information. Some may question this approach, as HCPs, in this way, do not have the full authority and control over their patients anymore. However, we argue that people with chronic conditions already search for self-management support and perform self-management strategies themselves (for example, as shown in the study of te Braake, Schriemer, et al., (2025)). This guide will help inform them about self-management and guide that process while still giving them the autonomy to perform self-management.

Second, people with chronic conditions may also introduce this guide to HCPs who are not aware of its existence. In this way, the guide can be used to facilitate their consultations. However, Franklin et al., (2017) mentioned that HCPs tend to stay in their authoritative role. Thus, HCPs would need to enable the possibility of shared control and be open to developing a shared understanding of the patient's context. Hence, inviting the HCPs to change their way of work and to adapt to what is important for the patient to discuss. Furthermore, it was also mentioned in this study that HCPs lack knowledge of the patient perspective; this knowledge should be built, for example, through studies like this to provide insights, and the self-management guide developed, and should be taught to HCPs. One possibility for teaching HCPs about the patient perspective is by inviting patients to their education. A study of Adam et al., (2021) showed that patients can have different roles in the education of HCPs, for example, they can teach about their expectations, experiences, and perspectives, provide direct feedback, or give advice on new curricula developments. Future research should investigate how the patient perspective of self-management can be integrated within the curricula for HCPs. When HCPs can consider this perspective and allow greater patient autonomy, this guide can be seen as a collaborative effort in which the HCPs.

One aspect that was mentioned multiple times throughout the various study rounds is that each situation is personal. What might work for one person might not work at all for another. That is the main motivation for the solution to be personalized; the self-management journey that people can personalize and adapt according to their personal needs and priorities at a certain point in time. In addition, as with chronic conditions, priorities can change (e.g., what is important now may be different in a year), so we added the possibility of adding the date of filling in the guide. By engaging people in the research, investigating the needs and requirements, and adding a personalized part in this support, we aimed to design a guide that people intend to use and is perceived as useful

and easy to use. Our evaluation results show that this guide scored above average, which is a great starting point. However, this study provides a first step in guiding people in their self-management. Further improvements and specifications of the onboarding (introducing the guide to people with chronic conditions) and dissemination of this guide have not yet been investigated. One way to introduce and disseminate this guide is through campaigns. Such a campaign can target people with chronic conditions but may also target HCPs and teach them about self-management from a patient perspective. Several campaigns in the context of health, aiming to raise awareness, change beliefs, or create behavioural change showing positive results are available in the literature (e.g., Abdo, 2023; Suman et al., 2021; Van Asbroeck et al., 2021). Therefore, future research should investigate the content and the right platform (e.g., social media (Ghahramani et al., 2022), local newspapers (Tunc et al., 2023)) for the campaigns that suit the end users.

Finally, the self-management guide is not a high-tech prototype and is already available for people to use in practice. In this way, each person with a chronic condition, healthcare provider, or healthcare institution can tailor this approach to their personal preferences and existing care structures.

The iterative design process, consisting of various versions of the guide, resulted in a self-management support guide that can already be used in practice. As te Braake et al., (2026) concluded that self-management categories might be disease-generic instead of disease-specific, the self-management support guide developed may apply to more chronic conditions than COPD or RMDs only. Although the participatory design process and PE within this study included people with COPD and RMDs, we encourage people with other conditions to utilize the guide. Furthermore, it is expected that multimorbidity will increase in the coming years (Kingston et al., 2018). Therefore, it is becoming extremely important to develop support guides and tools that account for this multimorbidity. Further developments should focus on testing and continuing to improve this guide, including people with other chronic conditions in the process, to investigate generalizability across conditions and to ensure their perspectives are included as well.

Patient Engagement within Research

Before starting this study, the researchers were unaware of the exact end goal. Although we initially thought that a personalized patient journey would be developed, during focus groups, it became clear that the true need lay elsewhere: supporting self-management that can be used independently from healthcare professionals. This highlights the

importance of involving individuals with chronic conditions in our research. Without their valuable involvement, we would have developed a solution that did not fit their needs, wishes, and preferences. The importance of engaging end users was also reported by others. A review of (Wilson et al., 2021) about the barriers and facilitators of eHealth use of older adults found that active engagement of end users in the design and delivery of e-health programs was a key facilitator.

Throughout the various study rounds, PE was central. As practice still shows that PE goes wrong quite commonly (e.g., unconscious bias towards patient partners, using patient partners as a check mark (Richards et al., 2023), sufficient efforts from researchers are required. There are no golden standards or requirements to perform PE. However, literature about barriers and facilitators of PE is becoming increasingly available to add to the existing knowledge of PE (e.g., Bird et al., 2020; Chegini et al., 2021; Gonzalez et al., 2023). In the following, we share our experiences to add to the existing knowledge of PE in research. Firstly, we experienced that the researcher should invest sufficient time. One should allow sufficient time for the research itself, as processes and additional steps can change continuously. As shown in the Methods section, this study commenced in April 2024 and concluded in October 2025. Reasons were that steps needed to be adapted (e.g., changing the guide from a communication guide to a guide focused on people with COPD/RMDs), which caused a delay in the design process. However, by changing the direction of the research, a more valuable and useful output was created. The study of Gonzalez et al., (2023) also reported on having to extend their timeline a few times, and supporting this extension was experienced as a facilitator of PE. Secondly, the researcher should be flexible. We experienced that flexibility is a key requirement in patient participation research, as the process and direction of the research continuously changed. Besides being flexible in adapting steps within the research, the researchers should also be flexible in their availability to perform research. By adapting the availability of the researchers to the availability of the patient partners, we experienced a higher willingness to partake in the various studies. Thirdly, we experienced it to be beneficial to invest in the relationship with their patient partners. For example, we sent information about the study well in advance, we kept patient partners in the loop of the research when, for example, taking the next steps, and sent summaries of study results to show that their contributions had an impact on the project. In our view, PE is not a check mark for research in which people are asked for their opinions. It goes beyond solely collecting opinions: it is about a collaboration, by showing genuine interest and listening actively to patient partners, involving them in the

project's decision-making, and thereby, allowing them to have a real impact on the project. Finally, the researchers continuously valued the patient partners and their contributions. We tried to make their value explicit not only by words or by showing the impact of their contributions, but also by providing some sort of compensation (e.g., covering travel expenses, time for time, or offering gift vouchers). Although we acknowledge that our efforts with PE may be difficult in funded projects with strict deadlines and might come across as 'a lot of work' to some, researchers should still try to adapt PE approaches to the best of their abilities, as it will provide many benefits for their research projects. The many benefits of PE (capturing patient partners' preferences, experiences, and needs, among others) were also reported by previous research (Belton et al., 2019; Forsythe et al., 2019; Kirwan et al., 2005; McVey et al., 2023).

Strengths and limitations

This study showcased a participatory design process consisting of 7 study rounds within three phases involving 40 participants. To the best of our knowledge, little research contains such an extensive iterative study design with multiple rounds to explore the problem, an iterative design, and a final evaluation.

This study also has some limitations. While the prototypes were designed based on several study rounds with people with COPD and RMDs, the last version of the prototype was only evaluated with people with RMDs, which then led to the final design. Future research should evaluate the final self-management guide with people with COPD and also people with other chronic conditions to ensure the self-management guide can be used by the wider population of people with chronic conditions. Furthermore, future research should also look at ways to provide the self-management guide via online channels.

In addition, the perspectives of HCPs were only captured at the beginning of the study. Due to the iterative nature of the design process, the focus changed towards having a self-management guide that people with chronic conditions can use independently. Future research should evaluate this prototype with HCPs to gather knowledge about its applicability in clinical practice and in what way HCPs can be supported to learn more about the patient perspective, a need that was expressed by patient partners in this study.

Conclusion

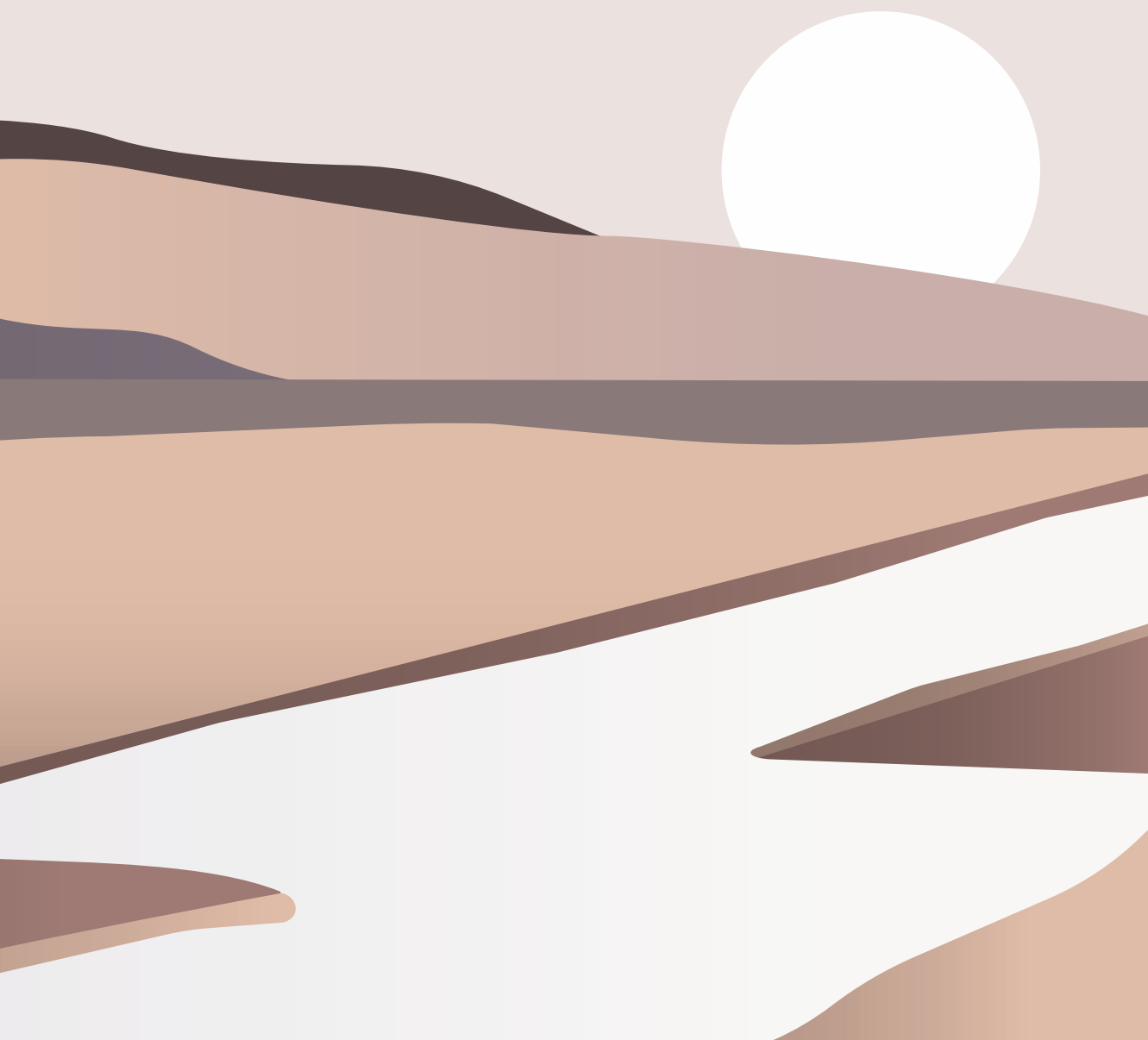
This study showed the iterative design of a self-management support guide. Together with patient partners, we identified the problems of current practice and needs towards self-management support and collaboratively developed self-management support from their perspectives. Given that each chronic situation is personal, a guide was developed that allowed for individual differences and personal needs and goals. Future research should investigate how this support guide could be implemented in practice. Finally, this study experienced much value from PE during the various study rounds. Future researchers should make efforts to focus on PE within their research.

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Chapter 7: General discussion



This dissertation aimed to increase our understanding of self-management and identify how people with chronic conditions can be supported to engage in self-management and create a support tool from a patient perspective, together with patient partners.

We learned that current practice is not fully ready to support self-management (Chapter 2) and that most eHealth self-management interventions support the physical aspect (e.g., self-monitoring) (Chapter 3). Both people with COPD and RMDs already do a lot for their self-management using diverse self-management strategies (Chapter 4 and Chapter 5). Overall, we found a gap between what people are actually doing in their daily lives compared to current literature and what current healthcare practice supports. Finally, we identified the current problems and needs of self-management and iteratively developed self-management support from a patient perspective. These findings were incorporated into our resulting self-management support guide (Chapter 6). In the following, we will discuss and reflect upon our findings by answering the three research questions and sharing our lessons learned about involving people in research.

What is the current body of knowledge of self-management in healthcare practice and literature?

In literature, the body of knowledge currently focuses on the physical part of self-management, while other dimensions are underrepresented (Chapter 3). These findings highlight an important gap in existing research on eHealth self-management interventions for COPD. Other research investigating eHealth self-management interventions for chronic conditions revealed similar results. For example, Seppen et al., (2020) demonstrated in their literature review that the different interventions for people with rheumatoid arthritis focused on, e.g., disease monitoring, medication adherence, and physical activity. Although it was not explicitly stated in the study, the focus on supporting the physical aspect is also present in this review. Furthermore, Lee et al., (2025) found in their review that self-monitoring of symptoms was the most frequently found component of all included studies for people with liver cirrhosis. Although this monitoring covered physical, cognitive, and psychological domains, the physical domain was again most prevalent. These reviews suggest that the focus on the physical aspect of self-management in eHealth self-management interventions might be a common theme in chronic healthcare. This simultaneously suggests the generalizability of our scoping review results. However, we also found that people with COPD and RMDs seem to perform a diverse set of self-management strategies in their daily lives that fall into all domains (Chapter 4 and Chapter 5) and are not limited to the physical domain only, as

discussed in the next section. This gives the impression that the current body of literature is lagging, as the actual people performing self-management are approaching their health more holistically.

One possible explanation for this gap in the literature may be caused by the lack of Patient Engagement (PE) in studies. We found that in most instances, people were not involved in the actual (service) design of the eHealth intervention (Chapter 3). This might imply that different things are needed from a patient perspective than what research is focused on. This leaves us questioning why we keep developing eHealth interventions focusing mainly on the physical aspect when 1) there are already many of such interventions out there, and 2) these do not necessarily reflect what people need, as they are not involved in the development process. Is the current body of literature not undermining the purpose of supporting people in their self-management by allowing technology and a reductionist approach to the self-management definition to push developments rather than designing for patients' needs and wishes?

We also revealed that only a subgroup (those with digital literacy, owning devices) was included in the current literature on eHealth self-management interventions for COPD (Chapter 3). When researchers, developers, and HCPs, for example, are unaware of this, a consequence might be that healthcare becomes even more inaccessible for the people who already have limited access. A recent study from Ding et al., (2025) identified several factors influencing self-management behaviours. They found that individuals with, for example, sufficient social support, high self-efficacy, higher education levels, and higher monthly personal income demonstrate better self-management behaviours. When we keep designing interventions with people already able to self-manage their conditions, we neglect the needs of the group that may actually benefit the most from the support, but do not receive the help they need. There might be a high risk that this leads to eHealth intervention developments that will not fit the needs of the end-users, will not be implemented in practice, and thus will have a limited impact, undermining the aim that eHealth developments had in the first place.

A study of Ellis et al., (2017) defined a 'good' self-manager as taking 'responsibility for their health, is knowledgeable and uses this to manage risks, and is 'active' in using information to make informed decisions regarding health and social well-being'. In practice, the current body of knowledge shows that not all people are immediately ready to self-manage their conditions, and that HCPs tend to stay in their role of authority by not letting go of their responsibility to control and monitor their

patients (Chapter 2). This paternalistic approach is not uncommon in literature, and Franklin et al., (2018) and Grünloh et al. (2018) observed similar results. For example, the systematic review of Franklin et al., (2018) revealed that HCPs tend to stay in their position of authority, which limits the chances for developing a shared understanding of the patient's social context and shared control between HCPs and patients. At the same time, self-management is increasingly advocated as healthcare is under high pressure. This leaves us questioning why self-management approaches in healthcare are recommended when the people who need to perform self-management do not get the responsibility to accomplish it. This shows that current healthcare practice for chronic care is not ready to fully support self-management. However, healthcare practice is dynamic, and concepts such as Shared-Decision Making (SDM) (Charles et al., 1997; Elwyn et al., 2012), are continuously making their introduction. SDM, the collaboration between clinicians and patients, has been increasingly advocated over the last decades. A review of Scholl et al., (2018) identified characteristics influencing the implementation of SDM. They stated that organizational resources such as time (HCPs have for each patient) and space (e.g., the room HCPs receive to carry out such activities within their organization) influenced the implementation of SDM. Thus, organizational change is also needed to adopt such approaches, and the service modelling method (Chapter 2) can, for example, help with identifying the necessary adjustments. However, this is not achieved overnight and might take several years to implement, revealing that it takes time to conceptualize, introduce, and initialize such concepts into healthcare practice. Nevertheless, even though it takes time, SDM has been integrated into the healthcare curriculum (e.g., Durand et al., 2018; Lehane et al., 2023), potentially leading to (future) HCPs adopting this collaborative approach in their daily practice. This shows an opportunity for the concept of self-management to also be adopted within daily practice.

What are the current self-management strategies of people with COPD and RMDs from a patient perspective?

Self-management in daily practice entails more than what is currently known in healthcare practice and literature. Actually, it reveals a mismatch between healthcare practice and literature, and what people actually do in their daily lives for self-management. People already perform many strategies in the physical activity category (Chapters 4 and Chapter 5). This may be explained by the fact that the physical domain

is highly recommended in clinical care and, therefore, well-known to most people. Thus, these might be easier to recall and perform for people with chronic conditions and may be considered as a good starting point in self-management. However, we also found that people with COPD or RMDs performed self-management strategies in other categories (e.g., nutrition and supplements, alternative medicine, energy distribution). If HCPs are unaware of these other strategies, self-management support might only contribute in a limited manner to the patients' well-being, as they may have different needs. The other categories (e.g., energy distribution, nutrition, and supplements) are then underexplored by people with chronic conditions, as they lack the information about their existence and may not come across them in their own search. One may also wonder if the support should therefore focus on the other dimensions instead. If HCPs are educated and align with their patients' self-management needs and what they actually do, they could recognise that there is more to self-management than what they might have learned, and thereby change the focus from the physical part of self-management in current healthcare practice towards what is fitting to the needs of their patients.

The generalizability of the self-management model created for people with RMDs to the COPD population was also investigated (Chapter 5). We showed that self-management might not be disease-specific but rather be disease-generic. However, in the literature, self-management interventions are mostly targeted towards one chronic condition (e.g., Ammerlaan et al., 2016; Chan et al., 2021; Farmer et al., 2014). As it is expected that complex multimorbidity will expand in the coming years (Kingston et al., 2018), it becomes increasingly important to investigate ways to support the self-management of multimorbidity. However, a recent review from Smith et al., (2025) about digital self-management applications for multimorbidity found that there is a lack of evidence on how digital applications can be utilized to address the complexities associated with self-managing multimorbidity. This might mean that healthcare faces an increasing challenge in the future as multimorbidity rises. In our studies, we see that people with COPD and people with RMDs perform self-management strategies that fit within the same categories (e.g., vitamin supplements, pacing, walking). People focus on what feels right for them at that moment in their patient journey and on what makes them feel better, e.g., reducing pain. Some of the participants in our studies also have multimorbidity, indicating that they already self-manage their multimorbidity as a whole. Why should we design self-management interventions for specific conditions, as symptoms are difficult to differentiate, and people already self-manage their condition holistically?

What is the future perspective on supporting self-management?

To move towards a sustainable future and to fully support self-management, structural change is needed. Therefore, based on our findings throughout the different chapters, several recommendations for the future perspective on self-management are formulated. Firstly, it is of utmost importance that people with chronic conditions are engaged in all phases of research, ensuring that the solution focuses on what people truly need. Ideally, this means that we stop letting technology push its development: The current body of literature does not need more (eHealth) interventions that do not match the needs of the people. In this way, meaningful and impactful interventions and support can be developed. Secondly, we identified a tension between the essence of self-management (i.e., the person with a chronic condition is able to take an active role and responsibility) and its current adoption in healthcare today. This tension needs to be considered and dissolved to ensure that people can carry out self-management effectively. Therefore, space must be created for people with chronic conditions to take responsibility for their own health. Shifting these responsibilities, however, requires quite some change management in the current way of working, as this is deeply rooted in existing healthcare structures. This implies that, for example, guidelines on how to give responsibility and support self-management in healthcare should be created, the current and new generation of HCPs should be educated via these guidelines, and these should be promoted organization-wide to support a new way of working. Next to ensuring that the healthcare system is creating space, people with chronic conditions also need to have the resources and capabilities to engage in self-management (e.g., through education and financial and/or social support). Thirdly, our research revealed that certain self-management strategies can be considered disease-generic, which opens up opportunities to investigate how we can support people with chronic conditions on a more general level, instead of focusing narrowly on specific conditions. When considering this, more people can benefit from the possibilities of self-management, as knowledge and experiences between various chronic conditions can be shared. In addition, efforts could be made to add to the current body of knowledge by investigating self-management for multimorbidity. Finally, the future perspective may benefit from a more inclusive approach, accounting for the whole population of people with chronic conditions, including the commonly underrepresented population in research (such as low SES status, migration background, and low (digital/health) literacy). Therefore, exploring opportunities to include them while being transparent about these efforts could be

valuable. In this way, it is clear who the intended and included population is, and it may help to recognise the underrepresented population better. This may help future researchers and developers to have a better understanding of the gaps in the literature and the needs of their target populations. When aiming to reach the underrepresented population, this adds to the existing knowledge, and interventions are created for those who might benefit most from them. Thereby, in the long run, making healthcare innovations more accessible. All recommendations mentioned for the future perspective on self-management are summarized in Textbox 2. These recommendations reflect our perspective (the researchers of these studies). As is known with interpretative qualitative research, our backgrounds and experiences may have impacted the interpretation of study results and the formulation of these recommendations. Others may formulate recommendations differently based on their personal frame of reference. Furthermore, we cannot generalize the recommendations to other chronic conditions, as our studies focused on people with COPD and RMDs. We consider the recommendations a good starting point for investigating their applicability to other chronic conditions.

Textbox 2. Summarized recommendations for the future perspective on self-management.

1. *Engage people with chronic conditions in the different phases of research*
2. *Create space for people with chronic conditions to take responsibility for their own health*
3. *Consider self-management strategies that are disease-generic instead of focusing on disease-specific*
4. *Make self-management strategies inclusive by increasing efforts to reach the underrepresented population*

A first step to incorporating this future perspective for self-management has been made (Chapter 6). As we showed that self-management might not be disease-specific but rather disease-generic (Chapter 5), we combined these two target groups in the different study rounds (Chapter 6). Current literature supports the physical aspect of self-management (Chapter 3) while people perform a diverse range of strategies in their daily lives (Chapter 4 and Chapter 5). For this reason, the self-management support guide was iteratively developed by engaging patient partners. It takes into account more categories than only the physical part and lets people themselves decide what they find important to address in a particular moment of their self-management journey. Given that patient partners already reported that the level of self-management support depends

on HCPs, that adopting a collaborative approach in healthcare is not yet implemented at scale, and that the core of self-management is to empower people to take an active role in their care, we wanted people with chronic conditions to be fully in the lead when using this tool. Thereby, giving them the control and allowing them to decide how and when they want to use this tool (e.g., for themselves in their own time, to discuss it with their HCPs during consultations). In this way, self-management support is created that fits with the needs of the people and enables them to take responsibility for their own health. This complements the shift that healthcare needs to make towards a proactive system and may help in making healthcare sustainable for the future. Future research could build upon our efforts and further develop and evaluate this self-management support guide.

The self-management support guide is a first step towards this future perspective. To facilitate the implementation, we want to share the envisioned use of the self-management support guide in practice. Although no research has been performed yet about its implementation, the vision is nevertheless clear: To support people with chronic conditions in taking steps into self-management that entails more than the physical domain only. We expect that, for healthcare practice, such a guide can be used as a reference book by HCPs for tackling self-management holistically. Furthermore, HCPs could provide this guide to their patients during the initial consultation to already inform them about the existence of self-management early on in their patient journey. During these initial consultations, people should also be informed about the possibility of taking responsibility for their health. For people with chronic conditions, the guide may help them in their search journey. As it was frequently mentioned throughout the studies that people had to figure out everything about self-management themselves, the guide may help them get started in a structured way. This may prevent the years of being unaware of self-management in the first place, and when getting started, not knowing where to begin, and feeling lost and overwhelmed. Instead, the guide could provide them with information about self-management and help them identify what they find important in their journey. Thereby providing the guidance and direction they mentioned to miss for their self-management.

In our research, we invited future researchers to think beyond the scope of an (eHealth) solution, and to consider the processes of changing roles and empowering patients in service design (Chapter 2). That is why we followed our own recommendations and started investigating the practical considerations of implementing the self-management guide. To successfully implement this tool, we should prepare both

people with chronic conditions and HCPs with the concept of self-management from a patient perspective. In our studies, one participant suggested that the solution as a whole should contain different aspects: one focusing on improving the knowledge of HCPs and people with chronic conditions in general, and the other focusing on a solution that could be used individually (see Chapter 6). The individual aspect is covered in the self-management support guide developed with patient partners in Chapter 6. During a meeting with patient partners, a campaign using videos was mentioned as a possible way to improve the knowledge of HCPs and people with chronic conditions in general. This campaign should include two information videos (one for HCPs and people who are recently diagnosed or are not aware of self-management). In this way, the general knowledge of people with chronic conditions will increase, and people can prepare and familiarize themselves with the concepts of self-management. As the people within our studies reported that they feel that HCPs lack the patient perspective, HCPs will also learn about this through the video. In addition, these videos will help in introducing and disseminating the guide, as more people get informed about its existence. We already had a meeting with patient partners to further discuss these plans. In this meeting, patient partners could also provide their feedback on the script for this campaign, leading to an improved version of the script (See Multimedia Appendix 7.1). As the actual filming of these videos was out of scope of the current project, we invite other organisations to use these scripts, already tested with patient partners, to create the videos together with people with chronic conditions. These videos should then be considered the first step in the service design, by providing information and inviting them to use the self-management support guide.

As some people do not have the digital skills or resources to use self-management support, the guide should also be provided offline to lower the threshold of utilizing this support, aiming to guide as many people as possible in their self-management journey. Therefore, when considering options for introducing and disseminating the guide, various platforms should be deliberately considered. For example, though information flyers in libraries or social media messages might be useful for a certain part of the population, videos explaining the self-management guide presented in community (health) centers or information gatherings might be more suitable for those with low literacy or who do not own digital devices. This showcases that different actions are needed to reach the wider population. Future research should investigate how to best implement and disseminate the self-management guide and should describe these various steps and processes within a service model.

Reflecting on involving patient partners in research

Throughout the majority of the studies of this dissertation, efforts have been made to engage people with chronic conditions at various phases in our research. To reflect on the roles of patient partners in this research, we made an assessment using the Involvement Matrix as proposed by Smits et al., (2020), as presented in Figure 16. Chapter 3 of this research is not included in this figure, as this was a scoping review. For this dissertation, we have formulated the roles as follows: a listener is only given information (e.g., a researcher shares information), a co-thinker provides their own opinion (e.g., within interviews, answers surveys), and an advisor gives their opinion while keeping in mind a more collective perspective (e.g., advising on research protocols). Furthermore, one should be considered a partner when they are involved as an equal partner within the project (e.g., determining next steps together). One should be named as the decision-maker if they take initiative and make final decisions, while the researcher(s) remain in the background. It is important to note that the Matrix below reflects our perspective (that of the researcher) on the roles that participants had, which may differ from how patient partners perceived their roles. We did not ask them which role they felt they had. It may be helpful for future projects to fill in this Matrix together with patient partners before the start of the project, and reflect upon it after the project, to improve processes.

		Role in the Research				
		Listener	Co-Thinker	Advisor	Partner	Decision-Maker
Stages of the project	Prepare		Chapter 4	Chapter 4 Chapter 5	Chapter 4 Chapter 6	
	Execute	Chapter 2	Chapter 2 Chapter 4 Chapter 5	Chapter 6	Chapter 4	
	Implement		Chapter 4	Chapter 4 Chapter 6		

Figure 16. Analysis of roles of patient partners in this research using the Involvement Matrix as proposed by Smits et al., (2020).

Our goal was to engage people with chronic conditions in the various phases of our research. However, in practice, we faced challenges such as cancellations (e.g., due to flare-ups/exacerbations of the condition) and time limitations. Reflecting on our efforts, there is still room for improvement. In **Chapter 2**, there was a low level of engagement, although we searched for opportunities to engage patients (e.g., inviting them to focus groups, sending summaries). One explanation is that the topic of service modelling was not something patient partners could relate to and did not spark their interest in participation. Another challenge was that, for certain sessions, it was necessary to be on-site methodologically, but due to the COVID measures, especially the contact with people with COPD, this was not possible. Given that the service model was based on extensive patient involvement during the requirements elicitation phase earlier in the RE-SAMPLE project, the added value of involving patients under the above-mentioned circumstances was unclear, questioning therefore whether their involvement would have balanced out the potential burden of participation. In **Chapter 4**, patient partners were involved throughout different research stages and with different roles in the project. With engaging patient partners throughout these different research stages, the preparation, execution, and implementation of the research took significantly more time than expected. Due to the iterative and participatory design process, we wanted to include patient partners as much as possible, which necessitates accommodating their availability. It is also important to recognise the burden it takes on patient partners, who are already dealing with their disease burden. This reflects the tension as described by Jongsma & Friesen (2019), namely, either demanding too much from our patient partners or not being inclusive enough. That is why we continuously reflected upon the added value of PE for that specific situation. It became quite clear from an early stage in the project that the researchers lacked certain insights crucial for the research that our patient partners did possess (for example, the lived experience with the disease, interpreting the data through their frame of reference, and translating the research in a way that is meaningful to the community). Furthermore, we also learned that keeping patient partners in the loop by sending information about studies well in advance and sending research summaries after each study round (specifying what we did, what we learned from patient partners, and what the next steps were) had positive effects for engagement. Participants could respond to these summaries if they wanted to add things that came to mind later, emphasize certain outcomes, or if we forgot to mention important aspects. In addition, by sending these summaries, including next steps, we simultaneously established a hop-on-hop-off approach, in which people stayed in the loop and could decide whether to join a study or not, and still be able to easily join the

next one, which made the studies highly accessible for our patient partners. We also learned that building relationships and continuously valuing patient partners (with words, showing that their contributions had an impact on the project, and providing compensation) are crucial. In addition, we also continuously searched for opportunities to increase involvement (co-author on the paper, conference participation), which was also very beneficial for the engagement. In **Chapter 5**, we employed an enhanced recruitment strategy compared to **Chapter 4**, as we concluded that by using online surveys, only a subgroup of people was included in our research studies (those with high digital literacy and access to devices). That is why in **Chapter 5**, we aimed to increase response rates and thereby reach the underrepresented COPD population. This implied that the online survey earlier created in **Chapter 4** could also be filled in offline and was disseminated through other online and offline channels. However, these enhanced recruitment efforts were not successful, which might have been due to the passive recruitment approach (e.g., people needed to sign up to participate). An active approach (e.g., the researcher initiating contact with potential participants) might have been more successful. Even though people with COPD were included in the preparation and execution phase of the project, we may have reached the usual participants only (those who are already empowered, engaged in their self-management, and highly educated). This demonstrated the difficulty of including the underrepresented COPD population. Finally, the study in **Chapter 6** engaged people in all stages of the research project and in different roles. Through PE established during previous studies, a community was built in which patient partners stayed in the loop through the course of the project, laying the foundation for PE in this chapter. As mentioned above, we learned from **Chapter 4** that keeping patient partners in the loop, allowing for a hop-on-hop-off approach, searching for opportunities to increase involvement, and building relationships have positive effects for engagement. That is why we employed the same strategy. Moreover, we experienced that organizing meetings around the availability and preferred schedule of the patient partner by offering multiple options for days and times might led to high participation. Although we were aware of working more inclusively (providing online and offline focus groups), we noticed how easily it happens that, when being focused on involving people in all the steps of the project, one forgets to sufficiently check whether the people involved were indeed representative. Overall, we aimed to have high levels of PE throughout every study of this dissertation. The reality, nevertheless, taught us that this is not always feasible. As practice makes perfect, we recommend future research to take into account our attempts to involve people at the different stages of research and build upon our lessons learned, which are summarized in Table 24 below.

Table 24. Lessons Learned from PE throughout the various Chapters of this dissertation.

Lessons Learned	Chapter(s)
Patient Engagement entails balancing the need for inclusivity while keeping the safety, burden, and potential benefits for the patient partners in mind.	2 & 4
Patient Engagement goes beyond collecting relevant and impactful data: It is also about building a community.	4, 5, & 6
Relationship building is crucial for Patient Engagement, and patient partners should be continuously valued.	4, 5, & 6
Approaches for Patient Engagement should be active: They should be organized to be highly accessible and easy to step into at any time.	4, 5, & 6
Flexibility is a key component of Patient Engagement: account for sufficient time for every step, as plans might need to change.	4 & 6
Patient Engagement is not a one-time data collection: It does not stop at the end of your study and entails keeping people in the loop (e.g., by providing information and research summaries).	4 & 6
The researcher should adapt to the availability of the patient partner, not the other way around.	4 & 6
Opportunities must be investigated to increase involvement (e.g., give something back, co-author on papers, participation in conferences).	4 & 6

When we look at the current literature, there are some studies available that focus on identifying barriers and facilitators of PE. Some of these concur with our lessons learned. For example, strong and trustworthy relationships and the provision of information were also mentioned as facilitators for PE by Bird et al., (2020), Chegini et al., (2021), and Gonzalez et al., (2023). The flexibility of time was also mentioned in the review of Bird et al., (2020) and Gonzalez et al., (2023). We also experienced that the flexibility of the researcher to adapt to the scheduling of patient partners was important. Furthermore, when aiming to engage the underrepresented population, we stumbled upon several difficulties. Literature states that, for example, cultural background or

literacy are indicators for identifying the underrepresented population (Long & Renbarger, 2023). In practice, however, it is difficult to determine whether people involved in the research are representative, as the context for these indicators is missing. Also, it is very difficult to recruit and check for specific dimensions of belonging to an underrepresented group, as questions around this are and/or can be perceived as insensitive. Previous research by, for example, Abidi et al., (2024), Heffernan et al., (2023), or Pardhan et al., (2025), already provided insights into barriers and facilitators of inclusive research. By sharing our lessons learned, we want to add to this current body of knowledge. Therefore, we are being transparent about the difficulties we had, and which strategies we applied to maybe reach those who may not usually respond to traditional recruitment approaches, even though we might not have reached the underrepresented population either.

We also observed in the literature that providing compensation to patient partners is important, but it is not specified what is considered sufficient compensation. The study of Richards et al., (2018), for example, formulated five key principles for why compensation should be considered for patient partners: equity, different motivations (of patient partners and professionals), respect for vulnerability, commitment, and barrier removal. In addition, Richards et al., (2018) mentioned that the conversation about compensation should take place early in the project to determine preferences regarding payment. We experienced that the topic of sufficient compensation is an ongoing discussion. While we highly valued our patient partners and wanted to compensate them sufficiently, we frequently encountered several problems. First, when starting the conversation with patient partners, they often dismissed the need for compensation. Second, some patient partners receive government benefits (e.g., sickness benefit, claiming unemployment benefit), making it legally difficult to provide them with sufficient compensation, as they might be cut off from that benefit. Third, although project proposals are (slowly) changing, there is often no room within the budget to provide sufficient compensation. Though we provided our patient partners with gift vouchers to prevent some of the problems, we are still reflecting on whether this is the right manner and are open to learn from others to find the best solution. In conclusion, even though several efforts throughout this dissertation were made for patient engagement, we have not yet found the golden standard for how best to reach and engage people in research. We hope that being transparent about our approaches for PE and formulating our lessons learned will help future researchers in their efforts, and we

invite them to do the same in their research. In this way, we can all learn from each other's efforts and create a strong body of knowledge for PE.

Our research benefited greatly from the PE throughout the different studies, which continuously gave new insights to the researchers. With these findings, we worked towards creating a shared understanding of self-management from the patient perspective. In this light, we incorporated experience-based knowledge. Thereby, we collected patient perspectives through PE instead of evidence-based knowledge. In current research, findings (such as intervention effects) are often deemed true, successful, or implemented only when they are evidence-based. This raises the question of what we value more and for which circumstances we need evidence-based research. One can imagine that evidence-based knowledge will not be built, as many aspects of self-management are missing in current literature, and people are unaware of these gaps. Evidence-based research could then be combined with experience-based participatory research. For example, the self-management strategies people use and find helpful could inform a rigorous study design that produces evidence. This dissertation collected and integrated patient perspectives, with the main aim of supporting people in their self-management. This research is successful if it achieves its aim, namely supporting people with their self-management journey, helping them to reflect on what they find important in life, empowering them in their journey, and informing them about the possibilities of self-management that go beyond the physical aspect. The tangible result of this dissertation is a self-management support guide that has been developed with patient partners and has the potential to create an impact on people with chronic conditions and the scientific community. In our opinion, important and valuable evidence is built over time by incorporating the patient perspective.

Conclusion

This dissertation increased our understanding of self-management from the patient perspective and showed the added value of including patient partners in research. We showed that current literature focuses on the physical aspect of self-management and that current healthcare practice is not ready to fully support self-management. Furthermore, people with RMDs and COPD apply diverse self-management strategies in their daily lives, which are approached more holistically. Thereby, this dissertation revealed a mismatch between what people actually do for their self-management in daily life and what is currently supported by clinical practice. We invite researchers and HCPs to go beyond the physical aspect and account for a more holistic self-management

approach. Furthermore, through a participatory design process, a self-management support guide was iteratively developed from a patient perspective. This guide supports people with chronic conditions in taking the first step in their self-management, and considers holistic self-management categories. It navigates people towards what really matters to them and allows them to take responsibility for their health without being dependent on the HCPs. After all, people with chronic conditions perform their self-management most of their time outside the clinical setting, in their daily life. Our tool could support people in having the control and autonomy over their own self-management journey.

References

Chapter 1

- Abdullah Altassan, W., Mazzy Alharby, S. S., Serhan Alkhalidi, A., Noor Almasoud, A., Nawras Alshanawani, M., Ibrahim Binjudiaan, S., Fahad Alanazi, R., & Jaber Alnassir, M. (2024). From Burnout to Understaffing: The Crisis Facing General Surgery Consultants and General Practice Physicians. *Journal of International Crisis and Risk Communication Research*, 7(3), 801–817. <https://doi.org/DOI:10.63278/jicrcr.vi.1941>
- Adams, M. L., Grandpre, J., Katz, D. L., & Shenson, D. (2019). The impact of key modifiable risk factors on leading chronic conditions. *Preventive Medicine*, 120, 113–118. <https://doi.org/https://doi.org/10.1016/j.ypmed.2019.01.006>
- Ammerlaan, J. W., Mulder, O. K., de Boer-Nijhof, N. C., Maat, B., Kruize, A. A., van Laar, J., van Os-Medendorp, H., & Geenen, R. (2016). Building a Tailored, Patient-Guided, Web-Based Self-Management Intervention ‘ReumaUitgedaagd!’ for Adults With a Rheumatic Disease: Results of a Usability Study and Design for a Randomized Control Trail. *JMIR Research Protocols*, 5(2), e113. <https://doi.org/10.2196/resprot.5735>
- Auduly, Å., Asplund, K., & Norbergh, K. G. (2010). Who’s in charge? The role of responsibility attribution in self-management among people with chronic illness. *Patient Education and Counseling*, 81(1), 94–100. <https://doi.org/10.1016/j.pec.2009.12.007>
- Barakou, I., Seves, B. L., Abonie, U. S., Finch, T., Hackett, K. L., & Hettinga, F. J. (2025). Health-related quality of life associated with fatigue, physical activity and activity pacing in adults with chronic conditions. *BMC Sports Science, Medicine and Rehabilitation*, 17(1). <https://doi.org/10.1186/s13102-025-01057-x>
- Belton, J., Hoens, A., Scott, A., & Ardern, C. L. (2019). Patients as partners in research: It’s the right thing to do. *Journal of Orthopaedic and Sports Physical Therapy*, 49(9), 623–626. <https://doi.org/10.2519/jospt.2019.0106>
- Bird, M., Ouellette, C., Whitmore, C., Li, L., Nair, K., McGillion, M. H., Yost, J., Banfield, L., Campbell, E., & Carroll, S. L. (2020). Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. *Health Expectations*, 23(3), 523–539. Blackwell Publishing Ltd. <https://doi.org/10.1111/hex.13040>
- Bourne, C., Houchen-Wolloff, L., Patel, P., Bankart, J., & Singh, S. (2022). Self-management programme of activity coping and education-SPACE for COPD(C)-In primary care: A pragmatic randomised trial. *BMJ Open Respiratory Research*, 9(1). <https://doi.org/10.1136/bmjresp-2022-001443>
- British Columbia Ministry of Health. (2011). Patients as Partners Nothing About Me Without Me.
- Chudyk, A. M., Stoddard, R., McCleary, N., Duhamel, T. A., Shimmin, C., Hickes, S., & Schultz, A. S. H. (2023). Exploring patient and caregiver perceptions of the meaning of the patient

- partner role: a qualitative study. *Research Involvement and Engagement*, 9(1).
<https://doi.org/10.1186/s40900-023-00511-9>
- Duffett, L. (2017). Patient engagement: What partnering with patient in research is all about. *Thrombosis Research*, 150, 113–120. <https://doi.org/10.1016/j.thromres.2016.10.029>
- Forsythe, L. P., Carman, K. L., Szydowski, V., Fayish, L., Davidson, L., Hickam, D. H., Hall, C., Bhat, G., Neu, D., Stewart, L., Jalowsky, M., Aronson, N., & Anyanwu, C. U. (2019). Patient engagement in research: Early findings from the patient-centered outcomes research institute. *Health Affairs*, 38(3), 359–367. <https://doi.org/10.1377/hlthaff.2018.05067>
- Global Initiative for Chronic Obstructive Lung Disease. (2025). Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease (2025 report).
- Gobat, N., Slack, C., Hannah, S., Salzwedel, J., Bladon, G., Burgos, J. G., Purvis, B., Molony-Oates, B., Siegfried, N., Cheah, P. Y., Conway, M., Kamuya, D., Davies, A., Johnson, T., Tholana, M., Mugamba, S., Mutengu, N. L., Machingaidze, S., Schwartz, L., ... von Harbou, K. (2025). Better engagement, better evidence: working in partnership with patients, the public, and communities in clinical trials with involvement and good participatory practice. *The Lancet Global Health*, 13(4), e716–e731. [https://doi.org/10.1016/S2214-109X\(24\)00521-7](https://doi.org/10.1016/S2214-109X(24)00521-7)
- Grant, P. (2024). The Virtual Hospital. *Springer*. <https://doi.org/https://doi.org/10.1007/978-3-031-69944-3>
- Hacker, K. (2024). The Burden of Chronic Disease. *Mayo Clinic Proceedings: Innovations, Quality and Outcomes*, 8(1), 112–119. <https://doi.org/10.1016/j.mayocpiqo.2023.08.005>
- Hajat, C., & Stein, E. (2018). The global burden of multiple chronic conditions: A narrative review. *Preventive Medicine Reports*, 12, 284–293. <https://doi.org/10.1016/j.pmedr.2018.10.008>
- Harrison, S. L., Janaudis-Ferreira, T., Brooks, D., Desveaux, L., & Goldstein, R. S. (2015). Self-management following an acute exacerbation of COPD: A systematic review. *Chest*, 147(3), 646–661. <https://doi.org/10.1378/chest.14-1658>
- Ivany, C., Hudson, T., Schneider, P., Farrukh, H., Swinton, M., & Ghert, M. (2023). Patient engagement in research; benefits, challenges, importance, and implications. (Pre-print). <https://doi.org/10.1101/2023.03.28.23287870>
- Jones, M. C., MacGillivray, S., Kroll, T., Zohoor, A. R., & Connaghan, J. (2011). A thematic analysis of the conceptualisation of self-care, self-management and self-management support in the long-term conditions management literature. *Journal of Nursing and Healthcare of Chronic Illness*, 3(3), 174–185. <https://doi.org/10.1111/j.1752-9824.2011.01096.x>

- Jonkman, N. H., Schuurmans, M. J., Groenwold, R. H. H., Hoes, A. W., & Trappenburg, J. C. A. (2016). Identifying components of self-management interventions that improve health-related quality of life in chronically ill patients: Systematic review and meta-regression analysis. *Patient Education and Counseling*, *99*(7), 1087–1098. <https://doi.org/10.1016/j.pec.2016.01.022>
- Jonkman, N. H., Schuurmans, M. J., Jaarsma, T., Shortridge-Baggett, L. M., Hoes, A. W., & Trappenburg, J. C. A. (2016). Self-management interventions: Proposal and validation of a new operational definition. *Journal of Clinical Epidemiology*, *80*, 34–42. <https://doi.org/10.1016/j.jclinepi.2016.08.001>
- Khairnar, R., Kamal, K. M., Giannetti, V., Dwibedi, N., & McConaha, J. (2019). Primary care physician perspectives on barriers and facilitators to self-management of type 2 diabetes. *Journal of Pharmaceutical Health Services Research*, *10*(1), 117–123. <https://doi.org/10.1111/jphs.12280>
- Kirwan, J. R., Hewlett, S. E., Heiberg, T., Hughes, R. A., Carr, M., Hehir, M., Kvien, T. K., Minnock, P., Newman, S. P., Quest, E. M., Taal, E., Wale, J., Kirwan, J. R., & Hewlett, S. E. (2005). Incorporating the patient perspective into outcome assessment in rheumatoid arthritis--progress at OMERACT 7. *The Journal of Rheumatology*, *32* (11), 2250-6. PMID: 16265712.
- Koff, P. B., Jones, R. H., Cashman, J. M., Voelkel, N. F., & Vandivier, R. W. (2009). Proactive integrated care improves quality of life in patients with COPD. *European Respiratory Journal*, *33*(5), 1031–1038. <https://doi.org/10.1183/09031936.00063108>
- Kudesia, P., Salimrouny, B., Stanley, M., Fortin, M., Stewart, M., Terry, A., & Ryan, B. L. (2021). The incidence of multimorbidity and patterns in accumulation of chronic conditions: A systematic review. *Journal of Multimorbidity and Comorbidity*, *11*. <https://doi.org/10.1177/26335565211032880>
- Lamontagne, A. J., Peléez, S., Grad, R., Blais, L., Lavoie, K. L., Bacon, S. L., Guay, H., Gauthier, A., McKinney, M. L., Ernst, P., Collin, J., & Ducharme, F. M. (2013). Facilitators and solutions for practicing optimal guided asthma self-management: The physician perspective. *Canadian Respiratory Journal*, *20*(4), 285–293. <https://doi.org/10.1155/2013/146839>
- Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, *26*(1), 1–7. https://doi.org/10.1207/S15324796ABM2601_01
- MacIver, A., Hollinger, H., & Carolan, C. (2021). Tele-health interventions to support self-management in adults with rheumatoid arthritis: a systematic review. *Rheumatology*

- International*, 41(8), 1399–1418. Springer Science and Business Media Deutschland GmbH. <https://doi.org/10.1007/s00296-021-04907-2>
- Mah, H., Dobson, R., & Thomson, A. (2025). The Importance of Lived Experience: A Scoping Review on the Value of Patient and Public Involvement in Health Research. *Health Expectations*, 28(2). <https://doi.org/10.1111/hex.70205>
- McVey, L., Frost, T., Issa, B., Davison, E., Abdulkader, J., Randell, R., Alvarado, N., Zaman, H., Hardiker, N., Cheong, V. L., & Woodcock, D. (2023). Working together: reflections on how to make public involvement in research work. *Research Involvement and Engagement*, 9(1). Ltd. <https://doi.org/10.1186/s40900-023-00427-4>
- Morrissey, E. C., Glynn, L. G., Casey, M., Walsh, J. C., & Molloy, G. J. (2018). New self-management technologies for the treatment of hypertension: general practitioners' perspectives. *Family Practice*, 35(3), 318–322. <https://doi.org/10.1093/fampra/cmz100>
- Newham, J. J., Presseau, J., Heslop-Marshall, K., Russell, S., Ogunbayo, O. J., Netts, P., Hanratty, B., & Kaner, E. (2017). Features of self-management interventions for people with COPD associated with improved health-related quality of life and reduced emergency department visits: A systematic review and meta-analysis. *International Journal of COPD*, 12, 1705–1720. <https://doi.org/10.2147/COPD.S133317>
- Niebuur, J., Vonk, J. M., Du, Y., de Bock, G. H., Lunter, G., Krabbe, P. F. M., Alizadeh, B. Z., Snieder, H., Smidt, N., Boezen, M., & Corpeleijn, E. (2023). Lifestyle factors related to prevalent chronic disease multimorbidity: A population-based cross-sectional study. *PLoS ONE*, 18. <https://doi.org/10.1371/journal.pone.0287263>
- Polanco, B., Oña, A., Gemperli, A., & Pacheco Barzallo, D. (2025). Excess healthcare utilization and costs linked to chronic conditions: a comparative study of nine European countries. *European Journal of Public Health*, 35(2), 216–227. <https://doi.org/10.1093/eurpub/ckaf012>
- RE-SAMPLE. (n.d.). Retrieved November 28, 2022, from <https://www.re-sample.eu/>
- Richards, D. P., Poirier, S., Mohabir, V., Proulx, L., Robins, S., & Smith, J. (2023). Reflections on patient engagement by patient partners: how it can go wrong. *Research Involvement and Engagement*, 9(1). <https://doi.org/10.1186/s40900-023-00454-1>
- Salisbury, L., Baraitser, L., Catty, J., Anucha, K., Davies, S., Flexer, M. J., Moore, M. D., & Osseman, J. (2023). A waiting crisis? *The Lancet*, 401(10375), 428–429. [https://doi.org/10.1016/S0140-6736\(23\)00238-6](https://doi.org/10.1016/S0140-6736(23)00238-6)
- Smits, D. W., Van Meeteren, K., Klem, M., Alsem, M., & Ketelaar, M. (2020). Designing a tool to support patient and public involvement in research projects: The Involvement Matrix. *Research Involvement and Engagement*, 6(1). <https://doi.org/10.1186/s40900-020-00188-4>

- Talukder, A. K., Sanz, J. B., & Samajpati, J. (2020). 'Precision Health': Balancing Reactive Care and Proactive Care Through the Evidence Based Knowledge Graph Constructed from Real-World Electronic Health Records, Disease Trajectories, Disease, and Pathology. *Journée Bases de Données Avancées, 12581*, 113–133. https://doi.org/10.1007/978-3-030-66665-1_9
- te Braake, E., Vaseur, R., Grünloh, C., & Tabak, M. (2025). The State of the Art of eHealth Self-Management Interventions for People With Chronic Obstructive Pulmonary Disease: Scoping Review. *Journal of Medical Internet Research, 27*, e57649. <https://doi.org/10.2196/57649>
- The Canadian Institutes of Health Research. (2014). Strategy for Patient-Oriented Research Patient Engagement Framework 2 Acknowledgements.
- Tumilty, E., Doolan-Noble, F., Latu, A. T. F. A., McAuley, K., Dummer, J., Baxter, J., Hannah, D., Donlevy, S., & Stokes, T. (2020). "A balancing act": Living with severe chronic obstructive pulmonary disease in Southern New Zealand: A qualitative study. *Journal of Primary Health Care, 12*(2), 166–172. <https://doi.org/10.1071/HC20007>
- Van Der Heijde, D., Daikh, D. I., Betteridge, N., Burmester, G. R., Hassett, A. L., Matteson, E. L., Van Vollenhoven, R., & Lakhanpal, S. (2018). Common language description of the term rheumatic and musculoskeletal diseases (RMDs) for use in communication with the lay public, healthcare providers and other stakeholders endorsed by the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR). *Annals of the Rheumatic Diseases, 77*(6), 829–832. <https://doi.org/10.1136/annrheumdis-2017-212565>
- van Hooft, S. M., Dwarswaard, J., Jedeloo, S., Bal, R., & van Staa, A. (2015). Four perspectives on self-management support by nurses for people with chronic conditions: A Q-methodological study. *International Journal of Nursing Studies, 52*(1), 157–166. <https://doi.org/https://doi.org/10.1016/j.ijnurstu.2014.07.004>
- Van Wilder, L., Pype, P., Mertens, F., Rammant, E., Clays, E., Devleeschauwer, B., Boeckxstaens, P., & De Smedt, D. (2021). Living with a chronic disease: insights from patients with a low socioeconomic status. *BMC Family Practice, 22*(1). <https://doi.org/10.1186/s12875-021-01578-7>
- Wiggins, A., & Wilbanks, J. (2019). The Rise of Citizen Science in Health and Biomedical Research. *American Journal of Bioethics, 19*(8), 3–14. <https://doi.org/10.1080/15265161.2019.1619859>
- Zwerink, M., Brusse-Keizer, M., van der Valk, P. D. L. P. M., Zielhuis, G. A., Monninkhof, E. M., van der Palen, J., Frith, P. A., & Effing, T. (2014). Self management for patients with

chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, 2014(3).
<https://doi.org/10.1002/14651858.CD002990.pub3>

Chapter 2

- Adeloye, D., Song, P., Zhu, Y., Campbell, H., Sheikh, A., & Rudan, I. (2022). Global, regional, and national prevalence of, and risk factors for, chronic obstructive pulmonary disease (COPD) in 2019: a systematic review and modelling analysis. *The Lancet Respiratory Medicine*, 10(5), 447–458. [https://doi.org/10.1016/S2213-2600\(21\)00511-7](https://doi.org/10.1016/S2213-2600(21)00511-7)
- Agustí, A., Celli, B. R., Criner, G. J., Halpin, D., Anzueto, A., Barnes, P., Bourbeau, J., Han, M. L. K., Martínez, F. J., de Oca, M. M., Mortimer, K., Papi, A., Pavord, I., Roche, N., Salvi, S., Sin, D. D., Singh, D., Stockley, R., López Varela, M. V., ... Vogelmeier, C. F. (2023). Global Initiative for Chronic Obstructive Lung Disease 2023 Report: GOLD Executive Summary. *European Respiratory Journal*, 61(4). <https://doi.org/10.1183/13993003.00239-2023>
- Ahmed, R. E., Bdaire, I. A., AL-Mugheed, K., Alshahrani, S. H., Alalayani, M. M., Ramaiah, R., Abdelrahman, S. I., Mahmoud, S. A., & Arrab, M. M. (2023). Empowering Self-Efficacy by Using Patient Empowerment among Chronic Obstructive Pulmonary Disease: Pre–Post-Test Study. *Healthcare (Switzerland)*, 11(3). <https://doi.org/10.3390/healthcare11030430>
- Ammenwerth, E., Iller, C., & Mahler, C. (2006). IT-adoption and the interaction of task, technology and individuals: A fit framework and a case study. *BMC Medical Informatics and Decision Making*, 6. <https://doi.org/10.1186/1472-6947-6-3>
- Auduly, Å., Asplund, K., & Norbergh, K. G. (2010). Who’s in charge? The role of responsibility attribution in self-management among people with chronic illness. *Patient Education and Counseling*, 81(1), 94–100. <https://doi.org/10.1016/j.pec.2009.12.007>
- Bitner, M., Ostrom, A., & Morgan, F. (2008). Service Blueprinting: A Practical Technique for Service Innovation. *California Management Review*, 50, 66–94. <https://doi.org/10.2307/41166446>
- Broekhuis, M., Weering, M. D. van, Schuit, C., Schürz, S., & van Velsen, L. (2021). Designing a stakeholder-inclusive service model for an eHealth service to support older adults in an active and social life. *BMC Health Services Research*, 21(1). <https://doi.org/10.1186/s12913-021-06597-9>
- Carr, D., Howells, A., Chang, M., Hirji, N., & English, A. (2009). An Integrated Approach to Stakeholder Engagement. *Healthcare Quarterly*, 12, 62–70. <https://doi.org/10.12927/hcq.2009.20754>

- Charles, C., Gafny, A., & Whelan, T. (1997). Shared Decision-Making in the medical encounter: What does it mean? (or it takes at least two to tango). *In Soc. Sci. Med.*, *44*(5). [https://doi.org/10.1016/s0277-9536\(96\)00221-3](https://doi.org/10.1016/s0277-9536(96)00221-3).
- Chaudhary, M. F. A., Hoffman, E. A., Guo, J., Comellas, A. P., Newell, J. D., Nagpal, P., Fortis, S., Christensen, G. E., Gerard, S. E., Pan, Y., Wang, D., Abtin, F., Barjaktarevic, I. Z., Barr, R. G., Bhatt, S. P., Bodduluri, S., Cooper, C. B., Gravens-Mueller, L., Han, M. K., ... Reinhardt, J. M. (2023). Predicting severe chronic obstructive pulmonary disease exacerbations using quantitative CT: a retrospective model development and external validation study. *The Lancet Digital Health*, *5*(2), e83–e92. [https://doi.org/10.1016/s2589-7500\(22\)00232-1](https://doi.org/10.1016/s2589-7500(22)00232-1)
- Cole, A. C., Adapa, K., Khasawneh, A., Richardson, D. R., & Mazur, L. (2022). Codesign approaches involving older adults in the development of electronic healthcare tools: a systematic review. *BMJ Open*, *12*(7). <https://doi.org/10.1136/bmjopen-2021-058390>
- Corlateanu, A. (2022). COPD and comorbidities in the Republic of Moldova. *Eurasian Journal of Pulmonology*. https://doi.org/10.14744/ejop_78_21
- Cvetanovska, N., Jessup, R. L., Wong Shee, A., Rogers, S., & Beauchamp, A. (2023). Patients' perspectives of factors influencing active participation in healthcare interactions: A qualitative study. *Patient Education and Counseling*, *114*. <https://doi.org/10.1016/j.pec.2023.107808>
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine*, *27*(10), 1361–1367. <https://doi.org/10.1007/s11606-012-2077-6>
- Freeman, R. (2004). The Stakeholder Approach Revisited. *Zeitschrift Für Wirtschafts- Und Unternehmensethik*, *5*. <https://doi.org/10.5771/1439-880X-2004-3-228>
- Funnell, M. M. (2016). Patient empowerment: What does it really mean? *Patient Education and Counseling*, *99*(12), 1921–1922. <https://doi.org/10.1016/j.pec.2016.10.010>
- Funnell, M. M., Anderson, R. M., Arnold, M. S., Barr, P. A., Donnelly, M., Johnson, P. D., Taylor-Moon, D., & White, N. H. (1991). Empowerment: An Idea Whose Time Has Come in Diabetes Education. *The Diabetes Educator*, *17*(1), 37–41. <https://doi.org/10.1177/014572179101700108>
- Gemert-Pijnen, J., Kelders, S., Kip, H., & Sanderman, R. (2018). eHealth Research, Theory and Development: A Multi-Disciplinary Approach.

- GOLD. (2022). Global initiative for chronic obstructive lung disease: global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease (2023 report).
- Greenhalgh, T., Wherton, J., Papoutsi, C., Lynch, J., Hughes, G., A’Court, C., Hinder, S., Fahy, N., Procter, R., & Shaw, S. (2017). Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies. *J Med Internet Res*, *19*(11), e367. <https://doi.org/10.2196/jmir.8775>
- Grünloh, C., Myreteg, G., Cajander, A., & Rexhepi, H. (2018). “why do they need to check me?” patient participation through health and the doctor-patient relationship: Qualitative study. *Journal of Medical Internet Research*, *20*(1). <https://doi.org/10.2196/jmir.8444>
- Hallensleben, C., van Luenen, S., Rolink, E., Ossebaard, H. C., & Chavannes, N. H. (2019). eHealth for people with COPD in the netherlands: A scoping review. *International Journal of COPD*, *14*, 1681–1690. <https://doi.org/10.2147/COPD.S207187>
- Holmes, M. M., Stanescu, S., & Bishop, F. L. (2019). The Use of Measurement Systems to Support Patient Self-Management of Long-Term Conditions: An Overview of Opportunities and Challenges. *Patient Related Outcome Measures*, *10*, 385–394. <https://doi.org/10.2147/prom.s178488>
- Idoughi, D., Seffah, A., & Kolski, C. (2012). Adding user experience into the interactive service design loop: A persona-based approach. *Behaviour and Information Technology*, *31*(3), 287–303. <https://doi.org/10.1080/0144929X.2011.563799>
- Iheanacho, I., Zhang, S., King, D., Rizzo, M., & Ismaila, A. S. (2020). Economic burden of chronic obstructive pulmonary disease (COPD): A systematic literature review. *International Journal of COPD*, *15*, 439–460. <https://doi.org/10.2147/COPD.S234942>
- Jankowska-Polańska, B., Kasprzyk, M., Chudiak, A., & Uchmanowicz, I. (2016). Relation between illness acceptance and quality of life in patients with chronic obstructive pulmonary disease (COPD). *Advances in Respiratory Medicine*, *85*(1), 3–10. <https://doi.org/10.5603/PiAP.a2015.0079>
- Kelly, M., Fullen, B., Martin, D., McMahon, S., & Mcveigh, J. G. (2022). eHealth Interventions to Support Self-Management in People With Musculoskeletal Disorders, “eHealth: It’s TIME” - A Scoping Review. *Physical Therapy*, *102*(4). <https://doi.org/10.1093/ptj/pzab307>
- Kermelley, S. B., & Bourbeau, J. (2022). eHealth in Self-Managing at a Distance Patients with COPD. *Life*, *12*(6), 773.

- Limna, P. (2023). The Digital Transformation of Healthcare in The Digital Economy: A Systematic Review. *International Journal of Advanced Health Science and Technology*, 3(2), 127–132. <https://doi.org/10.35882/ijahst.v3i2.244>
- MacLeod, M., Papi, A., Contoli, M., Begh , B., Celli, B. R., Wedzicha, J. A., & Fabbri, L. M. (2021). Chronic obstructive pulmonary disease exacerbation fundamentals: Diagnosis, treatment, prevention and disease impact. *Respirology*, 26(6), 532–551. <https://doi.org/10.1111/resp.14041>
- Meirte, J., Hellemans, N., Anthonissen, M., Denteneer, L., Maertens, K., Moortgat, P., & Van Daele, U. (2020). Benefits and Disadvantages of Electronic Patient-reported Outcome Measures: Systematic Review. *JMIR Perioperative Medicine*, 3(1), e15588. <https://doi.org/10.2196/15588>
- Mitchell, R. K., Agle, B. R., & Wood, D. J. (1997). Toward a Theory of Stakeholder Identification and Salience: Defining the Principle of Who and What Really Counts. *The Academy of Management Review*, 22(4), 853–886. <https://doi.org/10.2307/259247>
- Mural. (n.d.). Retrieved July 26, 2023, from <https://www.mural.co/>
- Nilsen, E. R., Stendal, K., & Gullslett, M. K. (2020). Implementation of eHealth Technology in Community Health Care: The complexity of stakeholder involvement. *BMC Health Services Research*, 20(1). <https://doi.org/10.1186/s12913-020-05287-2>
- Nyberg, A., Wadell, K., Lindgren, H., & Tistad, M. (2017). Internet-based support for self-management strategies for people with COPD—protocol for a controlled pragmatic pilot trial of effectiveness and a process evaluation in primary healthcare. *BMJ Open*, 7(7). <https://doi.org/10.1136/bmjopen-2017-016851>
- Ossebaard, H. C., & Van Gemert-Pijnen, L. (2016). EHealth and quality in health care: Implementation time. *International Journal for Quality in Health Care*, 28(3), 415–419. <https://doi.org/10.1093/intqhc/mzw032>
- Peters, J. B., Antons, J. C., Koolen, E. H., van Helvoort, H. A. C., van Hees, H. W. H., van den Borst, B., Spruit, M. A., Vercoulen, J. H., & van 't Hul, A. J. (2022). Patient activation is a treatable trait in patients with chronic airway diseases: An observational study. *Frontiers in Psychology*, 13. <https://doi.org/10.3389/fpsyg.2022.947402>
- Pieterse, M., Kip, H., & Cruz-Mart nez, R. R. (2018). The complexity of ehealth implementation: a theoretical and practical perspective. In *eHealth research, theory and development* (pp. 247–270). Routledge.
- Quaderi, S. A., & Hurst, J. R. (2018). The unmet global burden of COPD. *Global Health, Epidemiology and Genomics*, 3. <https://doi.org/10.1017/ghg.2018.1>

- Qualtrics. (n.d.). Retrieved July 26, 2023, from <https://www.qualtrics.com/>
- Raina, R. S., & Thawani, V. (2016). The zest for patient empowerment. *Journal of Clinical and Diagnostic Research*, 10(6), FE01–FE03. <https://doi.org/10.7860/JCDR/2016/16816.7902>
- Redman, B. K. (2007). Responsibility for control; ethics of patient preparation for self-management of chronic disease. *Bioethics*, 21(5), 243–250. <https://doi.org/10.1111/j.1467-8519.2007.00550.x>
- RE-SAMPLE. (n.d.). Retrieved November 28, 2022, from <https://www.re-sample.eu/>
- Richard, A. A., & Shea, K. (2011). Delineation of Self-Care and Associated Concepts. *Journal of Nursing Scholarship*, 43(3), 255–264. <https://doi.org/10.1111/j.1547-5069.2011.01404.x>
- Ross, J., Stevenson, F., Lau, R., & Murray, E. (2016). Factors that influence the implementation of e-health: A systematic review of systematic reviews (an update). *Implementation Science*, 11(1). BioMed Central Ltd. <https://doi.org/10.1186/s13012-016-0510-7>
- Sethi, S., Make, B. J., Robinson, S. B., Kumar, S., Pollack, M., Moretz, C., Dreyfus, J., Xi, A., Powell, D., & Feigler, N. (2022). Relationship of COPD Exacerbation Severity and Frequency on Risks for Future Events and Economic Burden in the Medicare Fee-For-Service Population. *International Journal of COPD*, 17, 593–608. <https://doi.org/10.2147/COPD.S350248>
- Shah, C. H., Onukwugha, E., Zafari, Z., Villalonga-Olives, E., Park, J. eun, & Slejko, J. F. (2022). Economic burden of comorbidities among COPD Patients hospitalized for acute exacerbations: an analysis of a commercially insured population. *Expert Review of Pharmacoeconomics and Outcomes Research*, 22(4), 683–690. <https://doi.org/10.1080/14737167.2021.1981291>
- Sharp, H., Finkelstein, A., & Galal, G. (1999). Stakeholder identification in the requirements engineering process. In DEXA Workshop. <https://doi.org/10.1109/DEXA.1999.795198>
- Shen, H., Van Der Kleij, R. M. J. J., Van Der Boog, P. J. M., Chang, X., & Chavannes, N. H. (2019). Electronic health self-management interventions for patients with chronic kidney disease: Systematic review of quantitative and qualitative evidence. *Journal of Medical Internet Research*, 21(11). <https://doi.org/10.2196/12384>
- Shnaigat, M., Downie, S., & Hosseinzadeh, H. (2022). Effectiveness of patient activation interventions on chronic obstructive pulmonary disease self-management outcomes: A systematic review. *Australian Journal of Rural Health*, 30(1), 8–21. John Wiley and Sons Inc. <https://doi.org/10.1111/ajr.12828>
- Simonse, L., Albayrak, A., & Starre, S. (2019). Patient journey method for integrated service design. *Design for Health*, 3(1), 82–97. <https://doi.org/10.1080/24735132.2019.1582741>

- Small, N., Bower, P., Chew-Graham, C. A., Whalley, D., & Protheroe, J. (2013). Patient empowerment in long-term conditions: Development and preliminary testing of a new measure. *BMC Health Services Research*, *13*(1). <https://doi.org/10.1186/1472-6963-13-263>
- Stefanicka-Wojtas, D., & Kurpas, D. (2022). eHealth and mHealth in Chronic Diseases—Identification of Barriers, Existing Solutions, and Promoters Based on a Survey of EU Stakeholders Involved in Regions4PerMed (H2020). *Journal of Personalized Medicine*, *12*(3). <https://doi.org/10.3390/jpm12030467>
- van Gemert-Pijnen, J. E. W. C., Nijland, N., van Limburg, M., Ossebaard, H. C., Kelders, S. M., Eysenbach, G., & Seydel, E. R. (2011). A holistic framework to improve the uptake and impact of ehealth technologies. *Journal of Medical Internet Research*, *13*(4). <https://doi.org/10.2196/jmir.1672>
- van Gemert-Pijnen, L., Kip, H., Kelders, S. M., & Sanderman, R. (2018). Introducing eHealth. In *eHealth Research, Theory and Development: A multidisciplinary Approach* (1st ed., pp. 1–26). Routledge.
- van Limburg, M., van Gemert-Pijnen, J. E. W. C., Nijland, N., Ossebaard, H. C., Hendrix, R. M. G., & Seydel, E. R. (2011). Why Business Modeling is Crucial in the Development of eHealth Technologies. *Journal of Medical Internet Research*, *13*(4), e124. <https://doi.org/10.2196/jmir.1674>
- Varsi, C., Nes, L. S., Kristjansdottir, O. B., Kelders, S. M., Stenberg, U., Zangi, H. A., Børøsund, E., Weiss, K. E., Stubhaug, A., Asbjørnsen, R. A., Westeng, M., Ødegaard, M., & Eide, H. (2019). Implementation strategies to enhance the implementation of eHealth programs for patients with chronic illnesses: Realist systematic review. *Journal of Medical Internet Research*, *21*(9). <https://doi.org/10.2196/14255>
- Wang, R., Zhou, C., Wu, Y., Sun, M., Yang, L., Ye, X., & Zhang, M. (2022). Patient empowerment and self-management behaviour of chronic disease patients: A moderated mediation model of self-efficacy and health locus of control. *Journal of Advanced Nursing*, *78*(4), 1055–1065. <https://doi.org/10.1111/jan.15077>
- Yadav, U. N., Hosseinzadeh, H., & Baral, K. P. (2018). Self-management and patient activation in COPD patients: An evidence summary of randomized controlled trials. *Clinical Epidemiology and Global Health*, *6*(3), 148–154. <https://doi.org/10.1016/j.cegh.2017.10.004>

Chapter 3

- Alcazar, B., de Lucas, P., Soriano, J. B., Fernández-Nistal, A., Fuster, A., González-Moro, J. M. R., Arnedillo, A., Sidro, P. G., & de los Monteros, M. J. E. (2016). The evaluation of a remote support program on quality of life and evolution of disease in COPD patients with frequent exacerbations. *BMC Pulmonary Medicine*, *16*(1). <https://doi.org/10.1186/s12890-016-0304-3>

- Alharbey, R., & Chatterjee, S. (2019). An mHealth assistive system “mylung” to empower patients with chronic obstructive pulmonary disease: Design science research. *JMIR Formative Research*, 3(1). <https://doi.org/10.2196/12489>
- Ali, L., Wallström, S., Fors, A., Barenfeld, E., Fredholm, E., Fu, M., Goudarzi, M., Gyllensten, H., Kjellberg, I. L., Swedberg, K., Vanfleteren, L. E. G. W., & Ekman, I. (2021). Effects of Person-Centered Care Using a Digital Platform and Structured Telephone Support for People with Chronic Obstructive Pulmonary Disease and Chronic Heart Failure: Randomized Controlled Trial. *Journal of Medical Internet Research*, 23(12). <https://doi.org/10.2196/26794>
- ATLAS.ti Scientific Software Development GmbH. (2021). ATLAS.ti Scientific Software Development GmbH. (Version 9.1.7.0).
- Au, D. H., Macaulay, D. S., Jarvis, J. L., Desai, U. S., & Birnbaum, H. G. (2015). Impact of a telehealth and care management Program for patients with chronic obstructive pulmonary disease. *Annals of the American Thoracic Society*, 12(3), 323–331. <https://doi.org/10.1513/AnnalsATS.201501-042OC>
- Auduly, Å., Asplund, K., & Norbergh, K. G. (2010). Who’s in charge? The role of responsibility attribution in self-management among people with chronic illness. *Patient Education and Counseling*, 81(1), 94–100. <https://doi.org/10.1016/j.pec.2009.12.007>
- Barenfeld, E., Ali, L., Wallström, S., Fors, A., & Ekman, I. (2020). Becoming more of an insider: A grounded theory study on patients’ experience of a person-centred e-health intervention. *PLoS ONE*, 15(11 November). <https://doi.org/10.1371/journal.pone.0241801>
- Barenfeld, E., Fuller, J. M., Wallström, S., Fors, A., Ali, L., & Ekman, I. (2022). Meaningful use of a digital platform and structured telephone support to facilitate remote person-centred care – a mixed-method study on patient perspectives. *BMC Health Services Research*, 22(1). <https://doi.org/10.1186/s12913-022-07831-8>
- Barken, T. L., Thygesen, E., & Söderhamn, U. (2018). Unlocking the limitations: Living with chronic obstructive pulmonary disease and receiving care through telemedicine—A phenomenological study. *Journal of Clinical Nursing*, 27(1), 132–142. ["<http://ezproxy2.utwente.nl/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2017-27984-001&site=ehost-live>"],
- Bednarek, M., Maciejewski, J., Wozniak, M., Kuca, P., & Zielinski, J. (2008). Prevalence, severity and underdiagnosis of COPD in the primary care setting. *Thorax*, 63(5), 402–407. <https://doi.org/10.1136/thx.2007.085456>
- Bentley, C. L., Powell, L., Potter, S., Parker, J., Mountain, G. A., Bartlett, Y. K., Farwer, J., O’Connor, C., Burns, J., Cresswell, R. L., Dunn, H. D., & Hawley, M. S. (2020b). The use of a smartphone app and an activity tracker to promote physical activity in the management

- of chronic obstructive pulmonary disease: Randomized controlled feasibility study. *JMIR MHealth and UHealth*, 8(6). <https://doi.org/10.2196/16203>
- Benzo, R. P., Kramer, K. M., Hoult, J. P., Anderson, P. M., Begue, I. M., & Seifert, S. J. (2018). Development and feasibility of a home pulmonary rehabilitation program with health coaching. *Respiratory Care*, 63(2), 131–140. <https://doi.org/10.4187/respcare.05690>
- Billington, J., Coster, S., Murrells, T., & Norman, I. (2015). Evaluation of a nurse-led educational telephone intervention to support self-management of patients with chronic obstructive pulmonary disease: A randomized feasibility study. *COPD: Journal of Chronic Obstructive Pulmonary Disease*, 12(4), 395–403. <https://doi.org/10.3109/15412555.2014.974735>
- Bødker, M., & Juul Nielsen, A. (2015). Providing rehabilitation online – invisible work and diagnostic agents. *Journal of Health Organization and Management*, 29(7), 948–964. <https://doi.org/10.1108/JHOM-06-2014-0091>
- Boer, L., Bischoff, E., van der Heijden, M., Lucas, P., Akkermans, R., Vercoulen, J., Heijdra, Y., Assendelft, W., & Schermer, T. (2019). A smart mobile health tool versus a paper action plan to support self-management of chronic obstructive pulmonary disease exacerbations: randomized controlled trial. *JMIR MHealth and UHealth*, 7(10), e14408.
- Boer, L. M., van der Heijden, M., van Kuijk, N. M. E., Lucas, P. J. F., Vercoulen, J. H., Assendelft, W. J. J., Bischoff, E. W., & Schermer, T. R. (2018). Validation of ACCESS: An automated tool to support self-management of COPD exacerbations. *International Journal of COPD*, 13, 3255–3267. <https://doi.org/10.2147/COPD.S167272>
- Bourbeau, J., Casan, P., Tognella, S., Haidl, P., Texereau, J. B., & Kessler, R. (2016). An international randomized study of a home-based self-management program for severe COPD: The COMET. *International Journal of COPD*, 11(1), 1447–1451. <https://doi.org/10.2147/COPD.S107151>
- Bourbeau, J., Nault, D., & Dang-Tan, T. (2004). Self-management and behaviour modification in COPD. *Patient Education and Counseling*, 52(3), 271–277. [https://doi.org/https://doi.org/10.1016/S0738-3991\(03\)00102-2](https://doi.org/https://doi.org/10.1016/S0738-3991(03)00102-2)
- Bourbeau, J., & Van Der Palen, J. (2009). Promoting effective self-management programmes to improve COPD. *European Respiratory Journal*, 33(3), 461–463. <https://doi.org/10.1183/09031936.00001309>
- Bourne, C., Houchen-Wolloff, L., Patel, P., Bankart, J., & Singh, S. (2022). Self-management programme of activity coping and education-SPACE for COPD(C)-In primary care: A pragmatic randomised trial. *BMJ Open Respiratory Research*, 9(1). <https://doi.org/10.1136/bmjresp-2022-001443>

- Bugajski, A., Frazier, S. K., Cousin, L., Rechenberg, K., Brown, J., Lengerich, A. J., Moser, D. K., & Lennie, T. A. (2020). Effects of a Digital Self-care Intervention in Adults with COPD: A Pilot Study. *Western Journal of Nursing Research, 42*(9), 736–746. <https://doi.org/10.1177/0193945919892282>
- Burkow, T. M., Vognild, L. K., Johnsen, E., Bratvold, A., & Risberg, M. J. (2018). Promoting exercise training and physical activity in daily life: A feasibility study of a virtual group intervention for behaviour change in COPD. *BMC Medical Informatics and Decision Making, 18*(1). <https://doi.org/10.1186/s12911-018-0721-8>
- Burkow, T. M., Vognild, L. K., Johnsen, E., Risberg, M. J., Bratvold, A., Breivik, E., Krogstad, T., & Hjalmarsen, A. (2015). Comprehensive pulmonary rehabilitation in home-based online groups: A mixed method pilot study in COPD. *BMC Research Notes, 8*(1). <https://doi.org/10.1186/s13104-015-1713-8>
- Burkow, T. M., Vognild, L. K., Ostengen, G., Johnsen, E., Risberg, M. J., Bratvold, A., Hagen, T., Brattvoll, M., Krogstad, T., & Hjalmarsen, A. (2013). Internet-enabled pulmonary rehabilitation and diabetes education in group settings at home: A preliminary study of patient acceptability. *BMC Medical Informatics and Decision Making, 13*(1). <https://doi.org/10.1186/1472-6947-13-33>
- Cameron-Tucker, H. L., Wood-Baker, R., Joseph, L., Walters, J. A., Schüz, N., & Walters, E. H. (2016). A randomized controlled trial of telephone-mentoring with home-based walking preceding rehabilitation in COPD. *International Journal of COPD, 11*(1), 1991–2000. <https://doi.org/10.2147/COPD.S109820>
- Camus-García, E., González-González, A. I., Heijmans, M., de Guzmán, E. N., Valli, C., Beltran, J., Pardo-Hernández, H., Ninov, L., Stramiello, V., Immonen, K., Mavridis, D., Ballester, M., Suñol, R., & Orrego, C. (2021). Self-management interventions for adults living with Chronic Obstructive Pulmonary Disease (COPD): The development of a Core Outcome Set for COMPARE-EU project. *PLoS ONE, 16*(3 March). <https://doi.org/10.1371/journal.pone.0247522>
- Choi, J. Y., George, M., & Yun, S. Y. (2021). Development of a smartphone application for Korean patients with chronic obstructive pulmonary disease: Self-monitoring based action plans. *Applied Nursing Research, 61*, 151475. <https://doi.org/10.1016/j.apnr.2021.151475>
- Cooper, R., Giangreco, A., Duffy, M., Finlayson, E., Hamilton, S., Swanson, M., Colligan, J., Gilliatt, J., McIvor, M., & Sage, E. K. (2022). Evaluation of myCOPD Digital Self-management Technology in a Remote and Rural Population: Real-world Feasibility Study. *JMIR MHealth and UHealth, 10*(2). <https://doi.org/10.2196/30782>
- Coultas, D. B., Jackson, B. E., Russo, R., Peoples, J., Singh, K. P., Sloan, J., Uhm, M., Ashmore, J. A., Blair, S. N., & Bae, S. (2018). Home-based physical activity coaching, physical activity,

- and health care utilization in chronic obstructive pulmonary disease chronic obstructive pulmonary disease self-management activation research trial secondary outcomes. *Annals of the American Thoracic Society*, 15(4), 470–478. <https://doi.org/10.1513/AnnalsATS.201704-308OC>
- Coventry, P. A., Blakemore, A., Baker, E., Sidhu, M., Fitzmaurice, D., & Jolly, K. (2019). The Push and Pull of Self-Managing Mild COPD: An Evaluation of Participant Experiences of a Nurse-Led Telephone Health Coaching Intervention. *Qualitative Health Research*, 29(5), 658–671. <https://doi.org/10.1177/1049732318809679>
- Criner, G. J., Cole, T., Hahn, K. A., Kastango, K., Eudicone, J. M., & Gilbert, I. (2021). Use of a Digital Chronic Obstructive Pulmonary Disease Respiratory Tracker in a Primary Care Setting: A Feasibility Study. *Pulmonary Therapy*, 7(2), 533–547. <https://doi.org/10.1007/s41030-021-00168-3>
- de Bruin, M., Black, N., Javornik, N., Viechtbauer, W., Eisma, M. C., Hartman-Boyce, J., Williams, A. J., West, R., Michie, S., & Johnston, M. (2021). Underreporting of the active content of behavioural interventions: a systematic review and meta-analysis of randomised trials of smoking cessation interventions. *Health Psychology Review*, 15(2), 195–213. <https://doi.org/10.1080/17437199.2019.1709098>
- De San Miguel, K., Smith, J., & Lewin, G. (2013). Telehealth remote monitoring for community-dwelling older adults with chronic obstructive pulmonary disease. *Telemedicine and E-Health*, 19(9), 652–657. <https://doi.org/10.1089/tmj.2012.0244>
- Deng, N., Chen, J., Liu, Y., Wei, S., Sheng, L., Lu, R., Wang, Z., Zhu, J., An, J., Wang, B., Lin, H., Wang, X., Zhou, Y., Duan, H., & Ran, P. (2020). Using mobile health technology to deliver a community-based closed-loop management system for chronic obstructive pulmonary disease patients in remote areas of china: Development and prospective observational study. *JMIR MHealth and UHealth*, 8(11). <https://doi.org/10.2196/15978>
- Dhadge, N., Shevade, M., Kale, N., Narke, G., Pathak, D., Barne, M., Madas, S., & Salvi, S. (2020). Monitoring of inhaler use at home with a smartphone video application in a pilot study. *Npj Primary Care Respiratory Medicine*, 30(1). <https://doi.org/10.1038/s41533-020-00203-x>
- Doyle, J., Murphy, E., Gravin, S., Pascale Alessandra, Depras, S., Tommasi, P., Smith, S., Hannigan, C., Smitt, M. S., van Leeuwen, C., Lastra, J., Galvin, M., McAleer, P., Tompkins, L., Jacobs, A., Marques, M. M., Medina Maestro, J., Boyle, G., & Dinsmore, J. (2021). A Digital Platform to support Self-management of Multiple Chronic Conditions (ProACT): Findings in Relation to Engagement During a One-Year Proof-of-Concept Trial. *Journal of Medical Internet Research*, 23(12). <https://doi.org/10.2196/22672>
- Early, F., Young, J. S., Robinslaw, E., Mi, E. Z., Mi, E. Z., & Fuld, J. P. (2017). A case series of an off-the-shelf online health resource with integrated nurse coaching to support self-

- management in COPD. *International Journal of COPD*, 12, 2955–2967. <https://doi.org/10.2147/COPD.S139532>
- Effing, T. W., Bourbeau, J., Vercoulen, J., Apter, A. J., Coultas, D., Meek, P., Van Der Valk, P., Partridge, M. R., & Van Der Palen, J. (2012). Self-management programmes for COPD: Moving forward. *Chronic Respiratory Disease*, 9(1), 27–35. <https://doi.org/10.1177/1479972311433574>
- Effing, T. W., Vercoulen, J. H., Bourbeau, J., Trappenburg, J., Lenferink, A., Cafarella, P., Coultas, D., Meek, P., Van Der Valk, P., Bischoff, E. W. M. A., Bucknall, C., Dewan, N. A., Early, F., Fan, V., Frith, P., Janssen, D. J. A., Mitchell, K., Morgan, M., Nici, L., ... Van Der Palen, J. (2016). Definition of a COPD self-management intervention: International expert group consensus. *European Respiratory Journal*, 48(1), 46–54. <https://doi.org/10.1183/13993003.00025-2016>
- Farias, R., Sedeno, M., Beaucage, D., Drouin, I., Ouellet, I., Joubert, A., Abimaroun, R., Patel, M., Rjeili, M. A., & Bourbeau, J. (2019). Innovating the treatment of COPD exacerbations: A phone interactive telesystem to increase COPD Action Plan adherence. *BMJ Open Respiratory Research*, 6(1). <https://doi.org/10.1136/bmjresp-2018-000379>
- Farmer, A., Williams, V., Velardo, C., Shah, S. A., Yu, L. M., Rutter, H., Jones, L., Williams, N., Heneghan, C., Price, J., Hardinge, M., & Tarassenko, L. (2017). Self-Management Support Using a Digital Health System Compared With Usual Care for Chronic Obstructive Pulmonary Disease: Randomized Controlled Trial. *Journal of Medical Internet Research*, 19(5). <https://doi.org/10.2196/jmir.7116>
- Fitzsimmons, D. A., Thompson, J., Bentley, C. L., & Mountain, G. A. (2016). Comparison of patient perceptions of Telehealth-supported and specialist nursing interventions for early stage COPD: A qualitative study. *BMC Health Services Research*, 16(1). <https://doi.org/10.1186/s12913-016-1623-z>
- Foreman, K. J., Marquez, N., Dolgert, A., Fukutaki, K., Fullman, N., McGaughey, M., Pletcher, M. A., Smith, A. E., Tang, K., Yuan, C. W., Brown, J. C., Friedman, J., He, J., Heuton, K. R., Holmberg, M., Patel, D. J., Reidy, P., Carter, A., Cercy, K., ... Murray, C. J. L. (2018). Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016–40 for 195 countries and territories. *The Lancet*, 392(10159), 2052–2090. [https://doi.org/10.1016/S0140-6736\(18\)31694-5](https://doi.org/10.1016/S0140-6736(18)31694-5)
- Gershon, A. S., Dolmage, T. E., Stephenson, A., & Jackson, B. (2012). Chronic obstructive pulmonary disease and socioeconomic status: A systematic review. *COPD: Journal of Chronic Obstructive Pulmonary Disease*, 9(3), 216–226. <https://doi.org/10.3109/15412555.2011.648030>

- GOLD. (2024). Global strategy for prevention, diagnosis and management of COPD: 2024 report.
- Haesum, L. K. E., Soerensen, N., Dinesen, B., Nielsen, C., Grann, O., Hejlesen, O., Toft, E., & Ehlers, L. (2012). Cost-utility analysis of a telerehabilitation program: A case study of COPD patients. *Telemedicine and E-Health*, 18(9), 688–692. <https://doi.org/10.1089/tmj.2011.0250>
- Hallensleben, C., van Luenen, S., Rolink, E., Ossebaard, H. C., & Chavannes, N. H. (2019). eHealth for people with COPD in the netherlands: A scoping review. *International Journal of COPD*, 14, 1681–1690. <https://doi.org/10.2147/COPD.S207187>
- Hardeman, W., Michie, S., Fanshawe, T., Prevost, A. T., McLoughlin, K., & Kinmonth, A. L. (2008). Fidelity of delivery of a physical activity intervention: Predictors and consequences. *Psychology and Health*, 23(1), 11–24. <https://doi.org/10.1080/08870440701615948>
- Hardinge, M., Rutter, H., Velardo, C., Shah, S. A., Williams, V., Tarassenko, L., & Farmer, A. (2015). Using a mobile health application to support self-management in chronic obstructive pulmonary disease: A six-month cohort study eHealth/ telehealth/ mobile health systems, ?. *BMC Medical Informatics and Decision Making*, 15(1). <https://doi.org/10.1186/s12911-015-0171-5>
- Heimer, M., Schmitz, S., Teschler, M., Schäfer, H., Douma, E. R., Habibovic, M., Kop, W. J., Meyer, T., Moorden, F. C., & Schmitz, B. (2023). eHealth for maintenance cardiovascular rehabilitation: a systematic review and meta-analysis. *European Journal of Preventive Cardiology*, 30(15), 1634–1651. <https://doi.org/doi:10.1093/eurjpc/zwad145>
- Hoas, H., Andreassen, H. K., Lien, L. A., Hjalmsen, A., & Zanaboni, P. (2016). Adherence and factors affecting satisfaction in long-term telerehabilitation for patients with chronic obstructive pulmonary disease: A mixed methods study eHealth/ telehealth/ mobile health systems. *BMC Medical Informatics and Decision Making*, 16(1). <https://doi.org/10.1186/s12911-016-0264-9>
- Hoas, H., Morseth, B., Holland, A. E., & Zanaboni, P. (2016). Are Physical Activity and Benefits Maintained After Long-Term Telerehabilitation in COPD? *International Journal of Telerehabilitation*, 8(2), 39–48. <https://doi.org/10.5195/ijt.2016.6200>
- Hosseinzadeh, H., & Shnaigat, M. (2019). Effectiveness of chronic obstructive pulmonary disease self-management interventions in primary care settings: A systematic review. *Australian Journal of Primary Health*, 25(3), 195–204. <https://doi.org/10.1071/PY18181>
- Houchen-Wolloff, L., Orme, M., Barradell, A., Clinch, L., Chaplin, E., Gardiner, N., & Singh, S. J. (2021). Web-based self-management program (space for copd) for individuals hospitalized with an acute exacerbation of chronic obstructive pulmonary disease: Nonrandomized feasibility trial of acceptability. *JMIR MHealth and UHealth*, 9(6). <https://doi.org/10.2196/21728>

- Huber, M., André Knottnerus, J., Green, L., Van Der Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., Van Der Meer, J. W. M., Schnabel, P., Smith, R., Van Weel, C., & Smid, H. (2011). How should we define health? *BMJ (Online)*, *343*(7817). <https://doi.org/10.1136/bmj.d4163>
- Huber, M., Van Vliet, M., Giezenberg, M., Winkens, B., Heerkens, Y., Dagnelie, P. C., & Knottnerus, J. A. (2016). Towards a “patient-centred” operationalisation of the new dynamic concept of health: a mixed methods study. *Open*, *5*, 10091. <https://doi.org/10.1136/bmjopen-2015>
- Huniche, L., Dinesen, B., Nielsen, C., Grann, O., & Toft, E. (2013). Patients’ use of self-monitored readings for managing everyday life with COPD: A qualitative study. *Telemedicine and E-Health*, *19*(5), 396–402. <https://doi.org/10.1089/tmj.2012.0135>
- Huygens, M. W. J., Vermeulen, J., Swinkels, I., Friele, R. D., Van Schayck, O. C. P., & De Witte, L. P. (2016). Expectations and needs of patients with a chronic disease toward self-management and eHealth for self-management purposes. *BMC Health Services Research*, *16*(1), 1–11.
- Jankowska-Polańska, B., Kasprzyk, M., Chudiak, A., & Uchmanowicz, I. (2016). Relation between illness acceptance and quality of life in patients with chronic obstructive pulmonary disease (COPD). *Advances in Respiratory Medicine*, *85*(1), 3–10. <https://doi.org/10.5603/PiAP.a2015.0079>
- Jansen-Kosterink, S., Broekhuis, M., & van Velsen, L. (2022). Time to act mature—Gearing eHealth evaluations towards technology readiness levels. *Digital Health*, *8*. <https://doi.org/10.1177/20552076221113396>
- Jolly, K., Sidhu, M. S., Hewitt, C. A., Coventry, P. A., Daley, A., Jordan, R., Heneghan, C., Singh, S., Ives, N., Adab, P., Jowett, S., Varghese, J., Nunan, D., Ahmed, K., Dowson, L., & Fitzmaurice, D. (2018). Self management of patients with mild COPD in primary care: Randomised controlled trial. *BMJ (Online)*, *361*. <https://doi.org/10.1136/bmj.k2241>
- Kale Minal S., Federman, A., Krauskopf, K., Wolf, M., O’Conor, R., Martynenko, M., Leventhal, H., & Wisnivesky, J. (2015). The Association of Health Literacy with Illness and Medication Beliefs among Patients with Chronic Obstructive Pulmonary Disease. *PLOS ONE*, *10*(4), 1–10. <https://doi.org/10.1371/journal.pone.0123937>
- Kaptein, R. J., Helle, T., Kottorp, A., & Patomella, A. H. (2022). Juggling the management of everyday life activities in persons living with chronic obstructive pulmonary disease. *Disability and Rehabilitation*, *44*(14), 3410–3421. <https://doi.org/10.1080/09638288.2020.1862314>
- Kargiannakis, M., Fitzsimmons, D. A., Bentley, C. L., & Mountain, G. A. (2017). Does telehealth monitoring identify exacerbations of chronic obstructive pulmonary disease and reduce

- hospitalisations? an analysis of system data. *JMIR Medical Informatics*, 5(1). <https://doi.org/10.2196/medinform.6359>
- Kaye, L., Gondalia, R., Thompson, A., Stempel, D. A., & Barrett, M. A. (2021). The relationship between objective app engagement and medication adherence in asthma and COPD: a retrospective analysis. *Scientific Reports*, 11(1). <https://doi.org/10.1038/s41598-021-03827-2>
- Kessler, R., Casan-Clara, P., Koehler, D., Tognella, S., Viejo, J. L., Dal Negro, R. W., Díaz-Lobato, S., Reissig, K., González-Moro, J. M. R., Devouassoux, G., Chavaillon, J. M., Botrus, P., Arnal, J. M., Ancochea, J., Bergeron-Lafaurie, A., De Abajo, C., Randerath, W. J., Bastian, A., Cornelissen, C. G., ... Bourbeau, J. (2018). CoMET: A multicomponent home-based disease-management programme versus routine care in severe COPD. *European Respiratory Journal*, 51(1). <https://doi.org/10.1183/13993003.01612-2017>
- Kip, H., & van Gemert-Pijnen, L. (2018). Holistic development of eHealth technology. *EHealth Research, Theory and Development: A Multi-Disciplinary Approach*. London: Routledge, 151–186.
- Kjellsdotter, A., Andersson, S., & Berglund, M. (2021). Together for the future – development of a digital website to support chronic obstructive pulmonary disease self-management: A qualitative study. *Journal of Multidisciplinary Healthcare*, 14, 757–766. <https://doi.org/10.2147/JMDH.S302013>
- Knox, L., Gemine, R., Rees, S., Bowen, S., Groom, P., Taylor, D., Bond, I., & Lewis, K. (2021). Assessing the uptake, engagement, and safety of a self-management app, COPD.Pal, for Chronic Obstructive Pulmonary Disease: a pilot study. *Health and Technology*, 11(3), 557–562. <https://doi.org/10.1007/s12553-021-00534-w>
- Koff, P. B., Min, S. J., Diaz, D. L. P., Freitag, T. J., James, S. S., Voelkel, N. F., Linderman, D. J., Diaz del Valle, F., Zakrajsek, J. K., Albert, R. K., Bull, T. M., Beck, A., Stelzner, T. J., Ritzwoller, D. P., Kveton, C. M., Carwin, S., Ghosh, M., Keith, R. L., Westfall, J. M., & Vandivier, R. W. (2020). Impact of proactive integrated care on chronic obstructive pulmonary disease. *Chronic Obstructive Pulmonary Diseases*, 8(1). <https://doi.org/10.15326/JCOPDF.2020.0139>
- Kooij, L., Vos, P. J. E., Dijkstra, A., & van Harten, W. H. (2021). Effectiveness of a mobile health and self-management app for high-risk patients with chronic obstructive pulmonary disease in daily clinical practice: Mixed methods evaluation study. *JMIR MHealth and UHealth*, 9(2). <https://doi.org/10.2196/21977>
- Korpershoek, Y. J. G., Hermsen, S., Schoonhoven, L., Schuurmans, M. J., & Trappenburg, J. C. A. (2020). User-centered design of a mobile health intervention to enhance exacerbation-related self-management in patients with chronic obstructive pulmonary disease (Copilot):

- Mixed methods study. *Journal of Medical Internet Research*, 22(6).
<https://doi.org/10.2196/15449>
- Korpershoek, Y. J. G., Holtrop, T., Vervoort, S. C. J. M., Schoonhoven, L., Schuurmans, M. J., & Trappenburg, J. C. A. (2020a). Early-stage feasibility of a mobile health intervention (copilot) to enhance exacerbation-related self-management in patients with chronic obstructive pulmonary disease: Multimethods approach. *JMIR Formative Research*, 4(11).
<https://doi.org/10.2196/21577>
- Lee, A. C. K., Oliver, S., Fletcher, K., & Robinson, J. (2012). The impact of telehealth support for patients with diabetes or chronic obstructive pulmonary disease on unscheduled secondary care utilisation: A service evaluation. *Informatics in Primary Care*, 20(4), 263–270.
<https://doi.org/10.14236/jhi.v20i4.16>
- Lenferink, A., Brusse-Keizer, M., van der Valk, P. D. L. P. M., Frith, P. A., Zwerink, M., Monninkhof, E. M., van der Palen, J., & Effing, T. W. (2017). Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, 2017(8).
<https://doi.org/10.1002/14651858.CD011682.pub2>
- Lilholt, P. H., Hæsum, L. K. E., & Hejlesen, O. K. (2015). Exploring User Experience of a Telehealth System for the Danish TeleCare North Trial. *Studies in Health Technology and Informatics*, 210, 301–305. <https://doi.org/10.3233/978-1-61499-512-8-301>
- Lorençatto, F., West, R., Stavri, Z., & Michie, S. (2013). How well is intervention content described in published reports of smoking cessation interventions? *Nicotine and Tobacco Research*, 15(7), 1273–1282. <https://doi.org/10.1093/ntr/nts266>
- Lundell, S., Modig, M., Holmner, Å., & Wadell, K. (2020). Perceptions of home telemonitoring use among patients with chronic obstructive pulmonary disease: Qualitative study. *JMIR MHealth and UHealth*, 8(6). <https://doi.org/10.2196/16343>
- Maathuis, I., Margaret Jones, V., Oudshoorn, N., & Maathuis, I. (2014). Telecare and self-management: A guideline for anticipating future care in scenario-based design MobiGuide View project MyoTel View project Telecare and self-management: a guideline for anticipating future care in scenario-based design. *Interaction Design and Architecture(s) Journal* 23(2014), 142-159. <https://doi.org/10.55612/s-5002-023-009>
- Mannino, D. M., & Buist, S. (2007). Global burden of COPD: risk factors, prevalence, and future trends. *The Lancet*, 370. [https://doi.org/10.1016/S0140-6736\(07\)61380-4](https://doi.org/10.1016/S0140-6736(07)61380-4).
- Mark, D. D., Ikehara, C., Matsuura, C., Hara, K., & Li, D. (2013). Validating the impact of teaching pursed-lips breathing with Skype: A pilot study. *Journal of Hospice and Palliative Nursing*, 15(8), 424–432. <https://doi.org/10.1097/NJH.0000000000000015>

- Marklund, S., Tistad, M., Lundell, S., Östrand, L., Sörlin, A., Boström, C., Wadell, K., & Nyberg, A. (2021). Experiences and factors affecting usage of an ehealth tool for self-management among people with chronic obstructive pulmonary disease: qualitative study. *Journal of Medical Internet Research*, 23(4), e25672.
- Marquis, N., Larivée, P., Dubois, M.-F., & Tousignant, M. (2015). Are Improvements Maintained After In-home Pulmonary Telerehabilitation for Patients with Chronic Obstructive Pulmonary Disease? *International Journal of Telerehabilitation*, 21–30. <https://doi.org/10.5195/ijt.2014.6156>
- Mathar, H., Fastholm, P., & Larsen, N. S. (2015). A qualitative study of televideo consultations for COPD patients. *British Journal of Nursing*, 24(4), 205–209.
- McCabe, C., McCann, M., & Brady, A. M. (2017). Computer and mobile technology interventions for self-management in chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, 5. <https://doi.org/10.12968/bjon.2015.24.4.205>.
- Michie, S., Richardson, M., Johnston, M., Abraham, C., Francis, J., Hardeman, W., Eccles, M. P., Cane, J., & Wood, C. E. (2013). The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus for the reporting of behavior change interventions. *Annals of Behavioral Medicine*, 46(1), 81–95. <https://doi.org/10.1007/s12160-013-9486-6>
- Mierdel, S., & Owen, K. (2015). Telehomecare reduces ER use and hospitalizations at William Osler health system. *Studies in Health Technology and Informatics*, 209, 102–108. <https://doi.org/10.3233/978-1-61499-505-0-102>
- Miller, S., Teufel, R., Nichols, M., Davenport, P., Mueller, M., Silverman, E., Madisetti, M., Pittman, M., Kelechi, T., & Strange, C. (2021). Feasibility of resp-fit: Technology-enhanced self-management intervention for adults with copd. *International Journal of COPD*, 16, 3263–3273. <https://doi.org/10.2147/COPD.S326675>
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18(1). <https://doi.org/10.1186/s12874-018-0611-x>
- Murphy, L. A., Harrington, P., Taylor, S. J. C., Teljeur, C., Smith, S. M., Pinnock, H., & Ryan, M. (2017). Clinical-effectiveness of self-management interventions in chronic obstructive pulmonary disease: An overview of reviews. *Chronic Respiratory Disease*, 14(3), 276–288. SAGE Publications Ltd. <https://doi.org/10.1177/1479972316687208>
- Nederlandse Patiënten Consumenten Federatie (NPCF), de Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (KNMG), & Zorgverzekeraars Nederland (ZN). (2012). Nationale Implementatie Agenda (NIA) eHealth.

- Nguyen, H. Q., Donesky-Cuenco, D. A., Wolpin, S., Reinke, L. F., Benditt, J. O., Paul, S. M., & Carrieri-Kohlman, V. (2008). Randomized controlled trial of an internet-based versus face-to-face dyspnea self-management program for patients with chronic obstructive pulmonary disease: Pilot study. *Journal of Medical Internet Research*, *10*(2). <https://doi.org/10.2196/jmir.990>
- Nield, M., & Hoo, G. W. S. (2012). Real-time telehealth for COPD self-management using skype. *COPD: Journal of Chronic Obstructive Pulmonary Disease*, *9*(6), 611–619. <https://doi.org/10.3109/15412555.2012.708067>
- North, M., Bourne, S., Green, B., Chauhan, A. J., Brown, T., Winter, J., Jones, T., Neville, D., Blythin, A., Watson, A., Johnson, M., Culliford, D., Elkes, J., Cornelius, V., & Wilkinson, T. M. A. (2020). A randomised controlled feasibility trial of E-health application supported care vs usual care after exacerbation of COPD: the RESCUE trial. *Npj Digital Medicine*, *3*(1). <https://doi.org/10.1038/s41746-020-00347-7>
- Nyberg, A., Tistad, M., & Wadell, K. (2019). Can the COPD web be used to promote self-management in patients with COPD in swedish primary care: a controlled pragmatic pilot trial with 3 month- and 12 month follow-up. *Scandinavian Journal of Primary Health Care*, *37*(1), 69–82. <https://doi.org/10.1080/02813432.2019.1569415>
- Orme, M. W., Weedon, A. E., Saukko, P. M., Esliger, D. W., Morgan, M. D., Steiner, M. C., Downey, J. W., Sherar, L. B., & Singh, S. J. (2018). Findings of the chronic obstructive pulmonary disease-sitting and exacerbations trial (COPD-SEAT) in reducing sedentary time using wearable and mobile technologies with educational support: Randomized controlled feasibility trial. *JMIR MHealth and UHealth*, *6*(4). <https://doi.org/10.2196/mhealth.9398>
- Park, S. K., Bang, C. H., & Lee, S. H. (2020). Evaluating the effect of a smartphone app-based self-management program for people with COPD: A randomized controlled trial. *Applied Nursing Research*, *52*. <https://doi.org/10.1016/j.apnr.2020.151231>
- Patel, N., Kinmond, K., Jones, P., Birks, P., & Spiteri, M. A. (2021). Validation of COPDpredict™: Unique combination of remote monitoring and exacerbation prediction to support preventative management of COPD exacerbations. *International Journal of COPD*, *16*, 1887–1899. <https://doi.org/10.2147/COPD.S309372>
- Rassouli, F., Boutellier, D., Duss, J., Huber, S., & Brutsche, M. H. (2018). Digitalizing multidisciplinary pulmonary rehabilitation in COPD with a smartphone application: An international observational pilot study. *International Journal of COPD*, *13*, 3831–3836. <https://doi.org/10.2147/COPD.S182880>
- Rayyan. (2022). Rayyan. <https://www.rayyan.ai/>
- Rixon, L., Hirani, S. P., Cartwright, M., Beynon, M., Doll, H., Steventon, A., Henderson, C., & Newman, S. P. (2017). A RCT of telehealth for COPD patient's quality of life: the whole

- system demonstrator evaluation. *Clinical Respiratory Journal*, 11(4), 459–469. <https://doi.org/10.1111/crj.12359>
- Roberts, N. J., Ghiassi, R., & Partridge, M. R. (2008). Health literacy in COPD. *International Journal of COPD*, 3(4). <https://doi.org/10.2147/copd.s1088>.
- Robinson, S. A., Wan, E. S., Shimada, S. L., Richardson, C. R., & Moy, M. L. (2020). Age and attitudes towards an internet-mediated, pedometer-based physical activity intervention for chronic obstructive pulmonary disease: Secondary analysis. *JMIR Aging*, 3(2). <https://doi.org/10.2196/19527>
- Rodríguez Hermosa, J. L., Fuster Gomila, A., Puente Maestu, L., Amado Diago, C. A., Callejas González, F. J., Malo De Molina Ruiz, R., Fuentes Ferrer, M. E., Álvarez Sala-Walther, J. L., & Calle Rubio, M. (2020). Compliance and Utility of a Smartphone App for the Detection of Exacerbations in Patients With Chronic Obstructive Pulmonary Disease: Cohort Study. *JMIR MHealth and UHealth*, 8(3), e15699. <https://doi.org/10.2196/15699>
- Russell, S., Ogunbayo, O. J., Newham, J. J., Heslop-Marshall, K., Netts, P., Hanratty, B., Beyer, F., & Kaner, E. (2018). Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: Views of patients and healthcare professionals. *npj Primary Care Respiratory Medicine*, 28(1). <https://doi.org/10.1038/s41533-017-0069-z>
- Schnoor, K., Versluis, A., Bakema, R., Van Luenen, S., Kooij, M. J., Maurik van den Heuvel, J., Teichert, M., Honkoop, P. J., Van Boven, J. F. M., Chavannes, N. H., & Aardoom, J. J. (2022). A Pharmacy-Based eHealth Intervention Promoting Correct Use of Medication in Patients With Asthma and COPD: Nonrandomized Pre-Post Study. *Journal of Medical Internet Research*, 24(6). <https://doi.org/10.2196/32396>
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., Mccorkle, R., Redeker, N. S., Reynolds, N., & Whittlemore, R. (2012). Processes of Self-Management in Chronic Illness. *Journal of Nursing Scholarship*, 44(2), 136–144. <https://doi.org/10.1111/j.1547-5069.2012.01444.x>
- Seppen, B. F., Den Boer, P., Wiegel, J., ter Wee, M. M., Van der Leeden, M., De Vries, R., Van der Esch, M., & Bos, W. H. (2020). Asynchronous mhealth interventions in rheumatoid arthritis: Systematic scoping review. *JMIR mHealth and uHealth*, 8(11). <https://doi.org/10.2196/19260>
- Sheridan, A., Jennings, A., Keane, S., Power, A., & Kavanagh, P. (2020). “A breath of fresh air” for tackling chronic disease in Ireland? An evaluation of a self-management support service for people with chronic respiratory diseases. *Irish Journal of Medical Science*, 1971. <https://doi.org/10.1007/s11845-019-02081-w/Published>

- Sieverink, F., Kelders, S., Braakman-Jansen, A., & Van Gemert-Pijnen, J. (2019). Evaluating the implementation of a personal health record for chronic primary and secondary care: A mixed methods approach. *BMC Medical Informatics and Decision Making*, *19*(1). <https://doi.org/10.1186/s12911-019-0969-7>
- Sin, D. D., Doiron, D., Agusti, A., Anzueto, A., Barnes, P. J., Celli, B. R., Criner, G. J., Halpin, D., Han, M. K., Martinez, F. J., Montes de Oca, M., Papi, A., Pavord, I., Roche, N., Singh, D., Stockley, R., Lopez Varlera, M. V., Wedzicha, J., Vogelmeier, C., & Bourbeau, J. (2023). Air pollution and COPD: GOLD 2023 committee report. *European Respiratory Journal*, *61*(5), 2202469. <https://doi.org/10.1183/13993003.02469-2022>
- Sloots, J., Bakker, M., van der Palen, J., Eijsvogel, M., van der Valk, P., Linssen, G., van Ommeren, C., Grinovero, M., Tabak, M., Effing, T., & Lenferink, A. (2021). Adherence to an ehealth self-management intervention for patients with both copd and heart failure: Results of a pilot study. *International Journal of COPD*, *16*, 2089–2103. <https://doi.org/10.2147/COPD.S299598>
- Stamenova, V., Liang, K., Yang, R., Engel, K., van Lieshout, F., Lalingo, E., Cheung, A., Erwood, A., Radina, M., Greenwald, A., Agarwal, P., Sidhu, A., Sacha Bhatia, R., Shaw, J., Shafai, R., & Bhattacharyya, O. (2020). Technology-enabled self-management of chronic obstructive pulmonary disease with or without asynchronous remote monitoring: Randomized controlled trial. *Journal of Medical Internet Research*, *22*(7). <https://doi.org/10.2196/18598>
- Stellefson, M. L., Shuster, J. J., Chaney, B. H., Paige, S. R., Alber, J. M., Chaney, J. D., & Sriram, P. S. (2018). Web-based Health Information Seeking and eHealth Literacy among Patients Living with Chronic Obstructive Pulmonary Disease (COPD). *Health Communication*, *33*(12), 1410–1424. <https://doi.org/10.1080/10410236.2017.1353868>
- Steventon, A., Tunkel, S., Blunt, I., & Bardsley, M. (2013). Effect of telephone health coaching (Birmingham OwnHealth) on hospital use and associated costs: Cohort study with matched controls. *BMJ (Online)*, *347*(7920). <https://doi.org/10.1136/bmj.f4585>
- Tabak, M., Brusse-Keizer, M., van der Valk, P., Hermens, H., & Vollenbroek-Hutten, M. (2014). A telehealth program for self-management of COPD exacerbations and promotion of an active lifestyle: A pilot randomized controlled trial. *International Journal of COPD*, *9*, 935–944. <https://doi.org/10.2147/COPD.S60179>
- Talboom-Kamp, E. P. W. A., Holstege, M. S., Chavannes, N. H., & Kasteleyn, M. J. (2019). Effects of use of an eHealth platform e-Vita for COPD patients on disease specific quality of life domains. *Respiratory Research*, *20*(1), 1–9.
- Talboom-Kamp, E. P. W. A., Verdijk, N. A., Kasteleyn, M. J., Harmans, L. M., Talboom, I. J. S. H., den Akker, I., van Geloven, N., Numans, M. E., & Chavannes, N. H. (2017). The effect of integration of self-management web platforms on health status in chronic obstructive

- pulmonary disease management in primary care (e-Vita Study): interrupted time series design. *Journal of Medical Internet Research*, 19(8), e8262.
- Talboom-Kamp, E. P. W. A., Verdijk, N. A., Kasteleyn, M. J., Harmans, L. M., Talboom, I. J. S. H., Numans, M. E., & Chavannes, N. H. (2017). High level of integration in integrated disease management leads to higher usage in the e-vita study: self-management of chronic obstructive pulmonary disease with web-based platforms in a parallel cohort design. *Journal of Medical Internet Research*, 19(5). <https://doi.org/10.2196/JMIR.7037>
- Ter Stal, S., Sloots, J., Ramlal, A., op den Akker, H., Lenferink, A., & Tabak, M. (2021). An embodied conversational agent in an eHealth self-management intervention for chronic obstructive pulmonary disease and chronic heart failure: Exploratory study in a real-life setting. *JMIR Human Factors*, 8(4), e24110.
- Thomas, R. M., Locke, E. R., Woo, D. M., Nguyen, E. H. K., Press, V. G., Layouni, T. A., Trittschuh, E. H., Reiber, G. E., & Fan, V. S. (2017). Inhaler training delivered by internet-based home videoconferencing improves technique and quality of life. *Respiratory Care*, 62(11), 1412–1422. <https://doi.org/10.4187/respcare.05445>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. <https://doi.org/10.7326/M18-0850>
- Valipour, A., Aisanov, Z., Avdeev, S., Koblizek, V., Kocan, I., Kopitovic, I., Lupkovic, G., Man, M., Bukovskis, M., Tudoric, N., Vukoja, M., Naumnik, W., & Yanev, N. (2022). Recommendations for COPD management in Central and Eastern Europe. *Expert Review of Respiratory Medicine*, 16(2), 221–234. <https://doi.org/10.1080/17476348.2021.2023498>
- Van Buul, A. R., Derksen, C., Hoedemaker, O., Van Dijk, O., Chavannes, N. H., & Kasteleyn, M. J. (2021). eHealth program to reduce hospitalizations due to acute exacerbation of chronic obstructive pulmonary disease: Retrospective study. *JMIR Formative Research*, 5(3). <https://doi.org/10.2196/24726>
- van Buul, A. R., Wildschut, T. S., Bonten, T. N., Kasteleyn, M. J., Slats, A. M., Chavannes, N. H., & Taube, C. (2018). A systematic diagnostic evaluation combined with an internet-based self-management support system for patients with asthma or COPD. *International Journal of COPD*, 13, 3297–3306. <https://doi.org/10.2147/COPD.S175361>
- van der Heijden, M., Lucas, P. J. F., Lijnse, B., Heijdra, Y. F., & Schermer, T. R. J. (2013). An autonomous mobile system for the management of COPD. *Journal of Biomedical Informatics*, 46(3), 458–469. <https://doi.org/10.1016/j.jbi.2013.03.003>

- Van Der Weegen, S., Verwey, R., Spreeuwenberg, M., Tange, H., Van Der Weijden, T., & De Witte, L. (2013). The development of a mobile monitoring and feedback tool to stimulate physical activity of people with a chronic disease in primary care: A user-centered design. *JMIR MHealth and UHealth*, 1(2). <https://doi.org/10.2196/mhealth.2526>
- Van Der Weegen, S., Verwey, R., Spreeuwenberg, M., Tange, H., Van Der Weijden, T., & De Witte, L. (2015). It's LiFe! Mobile and web-based monitoring and feedback tool embedded in primary care increases physical activity: A cluster randomized controlled trial. *Journal of Medical Internet Research*, 17(7). <https://doi.org/10.2196/jmir.4579>
- van Gemert-Pijnen, L., Kip, H., Kelders, S. M., & Sanderman, R. (2018). Introducing eHealth. In *eHealth Research, Theory and Development: A multidisciplinary Approach* (1st ed., pp. 1–26). Routledge.
- Van Lieshout, F., Yang, R., Stamenova, V., Agarwal, P., Palma, D. C., Sidhu, A., Engel, K., Erwood, A., Bhatia, R. S., Bhattacharyya, O., & Shaw, J. (2020). Evaluating the implementation of a remote-monitoring program for chronic obstructive pulmonary disease: Qualitative methods from a service design perspective. *Journal of Medical Internet Research*, 22(10). <https://doi.org/10.2196/18148>
- van Zelst, C. M., Kasteleyn, M. J., van Noort, E. M. J., Rutten-van Molken, M. P. M. H., Braunstahl, G. J., Chavannes, N. H., & in 't Veen, J. C. C. M. (2021). The impact of the involvement of a healthcare professional on the usage of an eHealth platform: a retrospective observational COPD study. *Respiratory Research*, 22(1). <https://doi.org/10.1186/s12931-021-01685-0>
- Vatnøy, T. K., Thygesen, E., & Dale, B. (2017). Telemedicine to support coping resources in home-living patients diagnosed with chronic obstructive pulmonary disease: Patients' experiences. *Journal of Telemedicine and Telecare*, 23(1), 126–132. <https://doi.org/10.1177/1357633X15626854>
- Velardo, C., Shah, S. A., Gibson, O., Clifford, G., Heneghan, C., Rutter, H., Farmer, A., & Tarassenko, L. (2017). Digital health system for personalised COPD long-term management. *BMC Medical Informatics and Decision Making*, 17(1). <https://doi.org/10.1186/s12911-017-0414-8>
- Verwey, R., van der Weegen, S., Spreeuwenberg, M., Tange, H., van der Weijden, T., & de Witte, L. (2014). A pilot study of a tool to stimulate physical activity in patients with COPD or type 2 diabetes in primary care. *Journal of Telemedicine and Telecare*, 20(1), 29–34. <https://doi.org/10.1177/1357633X13519057>
- Voncken-Brewster, V., Amoureux, M., Hein De Vries, M. ; Nagykaldi, Z., Winkens, B., Van Der Weijden, T., & Tange, H. (2017). The Impact of Participant Characteristics on Use and Satisfaction of a Web-Based Computer-Tailored Chronic Obstructive Pulmonary Disease

- Self-Management Intervention: A Process Evaluation. *JMIR formative research*, 1(1), e1. <https://formative.jmir.org/2017/1/e1/>
- Voncken-Brewster, V., Moser, A., van der Weijden, T., Nagykalai, Z., de Vries, H., & Tange, H. (2013). Usability evaluation of an online, tailored self-management intervention for chronic obstructive pulmonary disease patients incorporating behavior change techniques. *JMIR Research Protocols*, 2(1). <https://doi.org/10.2196/resprot.2246>
- Voncken-Brewster, V., Tange, H., de Vries, H., Nagykalai, Z., Winkens, B., & van der Weijden, T. (2015). A randomized controlled trial evaluating the effectiveness of a web-based, computer-tailored self-management intervention for people with or at risk for COPD. *International Journal of COPD*, 10, 1061–1073. <https://doi.org/10.2147/COPD.S81295>
- Voncken-Brewster, V., Tange, H., Moser, A., Nagykalai, Z., de Vries, H., & van der Weijden, T. (2014). Integrating a tailored e-health self-management application for chronic obstructive pulmonary disease patients into primary care: a pilot study. *BMC Family Practice*, 15(1), 1–10. <http://www.biomedcentral.com/1471-2296/15/4>
- Vorriink, S., Huisman, C., Kort, H., Troosters, T., & Lammers, J. W. (2017). Perceptions of patients with chronic obstructive pulmonary disease and their physiotherapists regarding the use of an eHealth intervention. *JMIR Human Factors*, 4(3). <https://doi.org/10.2196/humanfactors.7196>
- Walters, J., Cameron-Tucker, H., Wills, K., Schüz, N., Scott, J., Robinson, A., Nelson, M., Turner, P., Wood-Baker, R., & Walters, E. H. (2013). Effects of telephone health mentoring in community-recruited chronic obstructive pulmonary disease on self-management capacity, quality of life and psychological morbidity: A randomised controlled trial. *BMJ Open*, 3(9). <https://doi.org/10.1136/bmjopen-2013-003097>
- Wang, L. H., Guo, Y. M., Wang, M., & Zhao, Y. (2021). A mobile health application to support self-management in patients with chronic obstructive pulmonary disease: a randomised controlled trial. *Clinical Rehabilitation*, 35(1), 90–101. <https://doi.org/10.1177/0269215520946931>
- Whelan, M. E., Velardo, C., Rutter, H., Tarassenko, L., & Farmer, A. J. (2019). Mood monitoring over one year for people with chronic obstructive pulmonary disease using a mobile health system: Retrospective analysis of a randomized controlled trial. *JMIR MHealth and UHealth*, 7(11). <https://doi.org/10.2196/14946>
- Williams, V., Price, J., Hardinge, M., Tarassenko, L., & Farmer, A. (2014). Using a mobile health application to support self-management in COPD: A qualitative study. *British Journal of General Practice*, 64(624). <https://doi.org/10.3399/bjgp14X680473>

World Health Organization (WHO). (2023, March 16). Chronic Obstructive pulmonary disease (COPD). [https://www.who.int/news-room/fact-sheets/detail/chronic-obstructivepulmonary-disease-\(copd\)](https://www.who.int/news-room/fact-sheets/detail/chronic-obstructivepulmonary-disease-(copd))

Zanaboni, P., Hoaas, H., Aarøen Lien, L., Hjalmarsen, A., & Wootton, R. (2017). Long-term exercise maintenance in COPD via telerehabilitation: a two-year pilot study. *Journal of Telemedicine and Telecare*, 23(1), 74–82. <https://doi.org/10.1177/1357633X15625545>

Zanaboni, P., Lien, L. A., Hjalmarsen, A., & Wootton, R. (2013). Long-term telerehabilitation of COPD patients in their homes: Interim results from a pilot study in Northern Norway. *Journal of Telemedicine and Telecare*, 19(7), 425–429. <https://doi.org/10.1177/1357633X13506514>

Chapter 4

Abdelrahman, M. S. I., Shaddad, A. M., Khaleel, W. G. E., Talaat, E. A., Safwat, S. M., & Farrag, S. (2024). Sleep quality, anxiety, depression, and quality of life in rheumatoid arthritis patients and impact of disease activity. *Egyptian Rheumatology and Rehabilitation*, 51(1). <https://doi.org/10.1186/s43166-024-00242-z>

Antunes, T. P. C., Jardim, F. G., de Oliveira Abreu, C. I. P., de Abreu, L. C., & Bezerra, I. M. P. (2024). Chronic Pain Self-Management Strategies for Older Adults: An Integrative Review. *Life*, 14(6). <https://doi.org/10.3390/life14060707>

Athanasίου, A., Papazachou, O., Rovina, N., Nanas, S., Dimopoulos, S., & Kourek, C. (2024). The Effects of Exercise Training on Functional Capacity and Quality of Life in Patients with Rheumatoid Arthritis: A Systematic Review. *Journal of Cardiovascular Development and Disease*, 11(6). <https://doi.org/10.3390/jcdd11060161>

Auduly, Å., Ghahari, S., Kephart, G., Warner, G., & Packer, T. L. (2019). The Taxonomy of Everyday Self-management Strategies (TEDSS): A framework derived from the literature and refined using empirical data. *Patient Education and Counseling*, 102(2), 367–375. <https://doi.org/10.1016/j.pec.2018.08.034>

Auduly, Å., Hutchinson, S., Warner, G., Kephart, G., Versnel, J., & Packer, T. L. (2021). Managing everyday life: Self-management strategies people use to live well with neurological conditions. *Patient Education and Counseling*, 104(2), 413–421. <https://doi.org/10.1016/j.pec.2020.07.025>

Bannuru, R. R., Osani, M. C., Vaysbrot, E. E., Arden, N. K., Bennell, K., Bierma-Zeinstra, S. M. A., Kraus, V. B., Lohmander, L. S., Abbott, J. H., Bhandari, M., Blanco, F. J., Espinosa, R., Haugen, I. K., Lin, J., Mandl, L. A., Moilanen, E., Nakamura, N., Snyder-Mackler, L., Trojjan, T., ... McAlindon, T. E. (2019). OARSI guidelines for the non-surgical management of knee, hip, and polyarticular osteoarthritis. *Osteoarthritis and Cartilage*, 27(11), 1578–1589. <https://doi.org/10.1016/j.joca.2019.06.011>

- Bartlett, S. J., Lambert, S. D., McCusker, J., Yaffe, M., de Raad, M., Belzile, E., Ciampi, A., Di Carlo, M., & Lyddiatt, A. (2020). Self-management across chronic diseases: Targeting education and support needs. *Patient Education and Counseling*, *103*(2), 398–404. <https://doi.org/10.1016/j.pec.2019.08.038>
- Briggs, A. M., Cross, M. J., Hoy, D. G., Sánchez-Riera, L., Blyth, F. M., Woolf, A. D., & March, L. (2016). Musculoskeletal Health Conditions Represent a Global Threat to Healthy Aging: A Report for the 2015 World Health Organization World Report on Ageing and Health. *The Gerontologist*, *56*(2), S243–S255. <https://doi.org/10.1093/geront/gnw002>
- Cao, F., Xu, Z., Li, X. X., Fu, Z. Y., Han, R. Y., Zhang, J. L., Wang, P., Hou, S., & Pan, H. F. (2024). Trends and cross-country inequalities in the global burden of osteoarthritis, 1990–2019: A population-based study. *Ageing Research Reviews*, *99*. <https://doi.org/10.1016/j.arr.2024.102382>
- Courel-Ibáñez, J., Prieto-Moreno, R., Briones-Vozmediano, E., Ariza-Vega, P., Angevare, S., Anton, J., Bini, I., Clemente, D., Correia, M., Costello, W., De Cock, D., Domján, A., Leon, L., Marques, A., Minden, K., Mourão, A. F., Najm, A., Ozen, S., Pimentel, G., ... Estévez-López, F. (2025). EULAR points to consider for patient education in physical activity and self-management of pain during transitional care. *Annals of the Rheumatic Diseases*. <https://doi.org/10.1136/ard-2024-226448>
- Elefante, E., Tani, C., Stagnaro, C., Ferro, F., Parma, A., Carli, L., Signorini, V., Zucchi, D., Peta, U., Santoni, A., Raffaelli, L., & Mosca, M. (2020). Impact of fatigue on health-related quality of life and illness perception in a monocentric cohort of patients with systemic lupus erythematosus. *BMJ Open Sport and Exercise Medicine*, *6*(1). <https://doi.org/10.1136/rmdopen-2019-001133>
- Flurey, C. A., Hewlett, S., Rodham, K., White, A., Noddings, R., & Kirwan, J. (2015). Men, rheumatoid arthritis, psychosocial impact and self-management: A narrative review. *Journal of Health Psychology*, *21*(10), 2168–2182. <https://doi.org/10.1177/1359105315572452>
- Gwinnutt, J. M., Wiczorek, M., Balanescu, A., Bischoff-Ferrari, H. A., Boonen, A., Cavalli, G., de Souza, S., de Thurah, A., Dorner, T. E., Moe, R. H., Putrik, P., Rodríguez-Carrio, J., Silva-Fernández, L., Stamm, T., Walker-Bone, K., Welling, J., Zlatković-Švenda, M. I., Guillemin, F., & Verstappen, S. M. M. (2023). 2021 EULAR recommendations regarding lifestyle behaviours and work participation to prevent progression of rheumatic and musculoskeletal diseases. *Annals of the Rheumatic Diseases*, *82*(1), 48–56. <https://doi.org/10.1136/annrheumdis-2021-222020>
- Gwinnutt, J. M., Wiczorek, M., Cavalli, G., Balanescu, A., Bischoff-Ferrari, H. A., Boonen, A., De Souza, S., De Thurah, A., Dorner, T. E., Moe, R. H., Putrik, P., Rodríguez-Carrio, J., Silva-Fernández, L., Stamm, T., Walker-Bone, K., Welling, J., Zlatković-Švenda, M. I., Guillemin, F., & Verstappen, S. M. M. (2022). Effects of physical exercise and body weight

- on disease-specific outcomes of people with rheumatic and musculoskeletal diseases (RMDs): systematic reviews and meta-analyses informing the 2021 EULAR recommendations for lifestyle improvements in people with RMDs. *RMD Open*, 8(1). <https://doi.org/10.1136/rmdopen-2021-002168>
- Harmsen, S., Nabuurs, J. A., Lehman de Lehnfeld, L. F., van der Meij, M. G., Broerse, J. E. W., & Pittens, C. A. C. M. (2022). Mapping the complex everyday challenges and needs of people with rheumatic disease and their surroundings using a multi-actor approach. *Musculoskeletal Care*, 20(4), 873–891. <https://doi.org/10.1002/msc.1639>
- Hassen, N., Lacaille, D., Xu, A., Alandejani, A., Sidi, S., Mansourian, M., Butt, Z. A., Cahill, L. E., Iyamu, I. O., Lang, J. J., Rana, J., Somayaji, R., Sarrafzadegan, N., Kopec, J. A., Acharya, D., Adeyinka, D. A., Adibi, A., Alam, S., Artaman, A., ... Yaya, S. (2024). National burden of rheumatoid arthritis in Canada, 1990-2019: findings from the Global Burden of Disease Study 2019 - a GBD collaborator-led study. *RMD Open*, 10(1). <https://doi.org/10.1136/rmdopen-2023-003533>
- Huber, M., Van Vliet, M., Giezenberg, M., Winkens, B., Heerkens, Y., Dagnelie, P. C., & Knottnerus, J. A. (2016). Towards a “patient-centred” operationalisation of the new dynamic concept of health: a mixed methods study. *Open*, 5, 10091. <https://doi.org/10.1136/bmjopen-2015>
- Humphreys, J. H., & Verstappen, S. M. M. (2022). The burden of musculoskeletal disease. *Medicine*, 50(2), 82–84. <https://doi.org/https://doi.org/10.1016/j.mpmed.2021.11.002>
- Institute for Positive Health. (n.d.). Getting started with Positive Health. Retrieved November 12, 2024, from <https://www.iph.nl/en/participate/free-downloads/>
- Jongsma, K., & Friesen, P. (2019). The Challenge of Demandingness in Citizen Science and Participatory Research. *American Journal of Bioethics*, 19(8),33–35. <https://doi.org/10.1080/15265161.2019.1619867>
- Kolasinski, S. L., Neogi, T., Hochberg, M. C., Oatis, C., Guyatt, G., Block, J., Callahan, L., Copenhaver, C., Dodge, C., Felson, D., Gellar, K., Harvey, W. F., Hawker, G., Herzig, E., Kwoh, C. K., Nelson, A. E., Samuels, J., Scanzello, C., White, D., ... Reston, J. (2020). 2019 American College of Rheumatology/Arthritis Foundation Guideline for the Management of Osteoarthritis of the Hand, Hip, and Knee. *Arthritis Care and Research*, 72(2), 149–162. <https://doi.org/10.1002/acr.24131>
- Lee, H., & La, I. S. (2024). Association between health literacy and self-management among middle-aged women: A systematic review. *Patient Education and Counseling*, 123. <https://doi.org/10.1016/j.pec.2024.108188>
- Lindgren, L. H., Hammer, N. M., Flurey, C. A., Jensen, K. V., Andersen, L., & Esbensen, B. A. (2025). Gender differences in illness acceptance and coping strategies among patients with

- rheumatoid arthritis, psoriatic arthritis, and axial spondyloarthritis: a cross-sectional survey study. *Rheumatology International*, 45(3), 52. <https://doi.org/10.1007/s00296-025-05805-7>
- Macfarlane, G. J., Kronisch, C., Dean, L. E., Atzeni, F., Häuser, W., Flub, E., Choy, E., Kosek, E., Amris, K., Branco, J., Dincer, F., Leino-Arjas, P., Longle, K., McCarthy, G. M., Makri, S., Perrot, S., Sarzi-Puttini, P., Taylor, A., & Jones, G. T. (2017). EULAR revised recommendations for the management of fibromyalgia. *Annals of the Rheumatic Diseases*, 76(2), 318–328. <https://doi.org/10.1136/annrheumdis-2016-209724>
- Mancuso, C. A., Sayles, W., & Allegrante, J. P. (2009). Development and testing of the asthma Self- Management questionnaire. *Annals of Allergy, Asthma and Immunology*, 102(4), 294–302. [https://doi.org/10.1016/S1081-1206\(10\)60334-1](https://doi.org/10.1016/S1081-1206(10)60334-1)
- Marques, A., Santos, E., Nikiphorou, E., Bosworth, A., & Carmona, L. (2021). Effectiveness of self-management interventions in inflammatory arthritis: A systematic review informing the 2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis. *RMD Open*, 7(2). <https://doi.org/10.1136/rmdopen-2021-001647>
- Moseng, T., Vliet Vlieland, T. P. M., Battista, S., Beckwée, D., Boyadzhieva, V., Conaghan, P. G., Costa, D., Doherty, M., Finney, A. G., Georgiev, T., Gobbo, M., Kennedy, N., Kjekken, I., Kroon, F. P. B., Lohmander, L. S., Lund, H., Mallen, C. D., Pavelka, K., Pitsillidou, I. A., ... Østerås, N. (2024). EULAR recommendations for the non-pharmacological core management of hip and knee osteoarthritis: 2023 update. *Annals of the Rheumatic Diseases*, 83(6), 730–740. <https://doi.org/10.1136/ard-2023-225041>
- Mundell, A., Amarnani, R., Ainsworth, K., Chihwah, F., Hadjidemetriou, M., Katti, S., Mundell, N., Lester, C., & Metsios, G. S. (2024). The Effects of Exercise and Physical Activity in Inflammatory Rheumatic Diseases – a Narrative Review. *Journal of Science in Sport and Exercise*. <https://doi.org/10.1007/s42978-024-00303-x>
- Nunes, F., & Fitzpatrick, G. (2018). Understanding the mundane nature of self-care: Ethnographic accounts of people living with Parkinson's. *Conference on Human Factors in Computing Systems - Proceedings*, 2018-April. <https://doi.org/10.1145/3173574.3173976>
- Öberg, U., Hörnsten, Å., & Isaksson, U. (2019). The Self-Management Assessment Scale: Development and psychometric testing of a screening instrument for person-centred guidance and self-management support. *Nursing Open*, 6(2), 504–513. <https://doi.org/10.1002/nop2.233>
- Osborne, R. H., Elsworth, G. R., & Whitfield, K. (2007). The Health Education Impact Questionnaire (heiQ): An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient Education and Counseling*, 66(2), 192–201. <https://doi.org/10.1016/j.pec.2006.12.002>

- Parodis, I., Girard-Guyonvarc'H, C., Arnaud, L., Distler, O., Domján, A., Van Den Ende, C. H. M., Fligelstone, K., Kocher, A., Larosa, M., Lau, M., Mitropoulos, A., Ndosí, M., Poole, J. L., Redmond, A., Ritschl, V., Alexanderson, H., Sjöberg, Y., Von Perner, G., Uhlig, T., ... Boström, C. (2024). EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. *Annals of the Rheumatic Diseases*, 83(6), 720–729. <https://doi.org/10.1136/ard-2023-224416>
- Rimmer, B., Balla, M., Dutton, L., Lewis, J., Brown, M. C., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., Menger, F., & Sharp, L. (2023). Identifying and understanding how people living with a lower-grade glioma engage in self-management. *Journal of Cancer Survivorship*. <https://doi.org/10.1007/s11764-023-01425-x>
- Schoemaker, C. G., Richards, D. P., & De Wit, M. (2023). Matching researchers' needs and patients' contributions: Practical tips for meaningful patient engagement from the field of rheumatology. *Annals of the Rheumatic Diseases*, 82(3), 312–315. <https://doi.org/10.1136/ard-2022-223561>
- Sebbag, E., Felten, R., Sagez, F., Sibilia, J., Devilliers, H., & Arnaud, L. (2019). The world-wide burden of musculoskeletal diseases: A systematic analysis of the World Health Organization Burden of Diseases Database. *Annals of the Rheumatic Diseases*, 78(6), 844–848. <https://doi.org/10.1136/annrheumdis-2019-215142>
- Shao, J. H., Yu, K. H., & Chen, S. H. (2021). Effectiveness of a self-management program for joint protection and physical activity in patients with rheumatoid arthritis: A randomized controlled trial. *International Journal of Nursing Studies*, 116. <https://doi.org/10.1016/j.ijnurstu.2020.103752>
- Shirk, J. L., Ballard, H. L., Wilderman, C. C., Phillips, T., Wiggins, A., Jordan, R., McCallie, E., Minarchek, M., Lewenstein, B. V., Krasny, M. E., & Bonney, R. (2012). Public participation in scientific research: A framework for deliberate design. *Ecology and Society*, 17(2). <https://doi.org/10.5751/ES-04705-170229>
- Sieczkowska, S. M., Smaira, F. I., Mazzolani, B. C., Gualano, B., Roschel, H., & Peçanha, T. (2021). Efficacy of home-based physical activity interventions in patients with autoimmune rheumatic diseases: A systematic review and meta-analysis. *Seminars in Arthritis and Rheumatism*, 51(3), 576–587. <https://doi.org/10.1016/j.semarthrit.2021.04.004>
- te Braake, E., E Vaseur, R. M., Grünloh, C., & Tabak Roessingh Research, M. (2025). The state-of-the-art of eHealth self-management interventions for people with Chronic Obstructive Pulmonary Disease: a scoping review. *Journal of Medical Internet Research*, 10(27). E57649. <https://doi.org/10.2196/57649>.
- Van Der Heijde, D., Daikh, D. I., Betteridge, N., Burmester, G. R., Hassett, A. L., Matteson, E. L., Van Vollenhoven, R., & Lakhanpal, S. (2018). Common language description of the term

- rheumatic and musculoskeletal diseases (RMDs) for use in communication with the lay public, healthcare providers and other stakeholders endorsed by the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR). *Annals of the Rheumatic Diseases*, 77(6), 829–832. <https://doi.org/10.1136/annrheumdis-2017-212565>
- Villalobos-Sánchez, L., Blanco-Cáceres, B., Bachiller-Corral, J., Rodríguez-Serrano, M. T., Vázquez-Díaz, M., & Lázaro y de Mercado, P. (2024). Quality of life of patients with rheumatic diseases. *Reumatología Clínica*, 20(2), 59–66. <https://doi.org/10.1016/j.reuma.2023.06.004>
- Wiggins, A., & Wilbanks, J. (2019). The Rise of Citizen Science in Health and Biomedical Research. *American Journal of Bioethics*, 19(8), 3–14. <https://doi.org/10.1080/15265161.2019.1619859>
- Wolkorte, R. (2024). REIS: Reuma En Ik: Self-management. DANS Data Station Life Sciences.
- Woodward, A., Walters, K., Davies, N., Nimmons, D., Protheroe, J., Chew-Graham, C. A., Stevenson, F., & Armstrong, M. (2024). Barriers and facilitators of self-management of diabetes amongst people experiencing socioeconomic deprivation: A systematic review and qualitative synthesis. *Health Expectations*, 27(3). <https://doi.org/10.1111/hex.14070>
- Wu, M. J., Zhao, K., & Fils-Aime, F. (2022). Response rates of online surveys in published research: A meta-analysis. *Computers in Human Behavior Reports*, 7. <https://doi.org/10.1016/j.chbr.2022.100206>
- Yang, L., Xiang, P., Pi, G., Wen, T., Liu, L., & Liu, D. (2025). Effectiveness of nurse-led care in patients with rheumatoid arthritis: a systematic review and meta-analysis. *BMJ Open Quality*, 14(1). <https://doi.org/10.1136/bmjjoq-2024-003037>
- Zhou, J., Wang, W., Gao, W., Xu, Y., & Zang, Y. (2024). Fatigue in rheumatoid arthritis patients: The status, independent risk factors, and consistency of multiple scales. *Immunity, Inflammation and Disease*, 12(6). <https://doi.org/10.1002/iid3.1313>
- Zimba, O., & Gasparyan, A. Y. (2023). Designing, Conducting, and Reporting Survey Studies: A Primer for Researchers. *Journal of Korean Medical Science*, 38 (48). <https://doi.org/10.3346/jkms.2023.38.e403>
- Zuidema, R. M., Repping-Wuts, H., Evers, A. W. M., Van Gaal, B. G. I., & Van Achterberg, T. (2015). What do we know about rheumatoid arthritis patients' support needs for self-management? A scoping review. *International Journal of Nursing Studies*, 52(10), 1617–1624. <https://doi.org/10.1016/j.ijnurstu.2015.05.008>

Chapter 5

- Abdullah Altassan, W., Mazzy Alharby, S. S., Serhan Alkhalidi, A., Noor Almasoud, A., Nawras Alshanawani, M., Ibrahim Binjudiaan, S., Fahad Alanazi, R., & Jaber Alnassir, M. (2024). From Burnout to Understaffing: The Crisis Facing General Surgery Consultants and *General Practice Physicians*. 7(3), 801–817. <https://doi.org/DOI:10.63278/jicrcr.vi.1941>
- Adam, H., Giroux, C., Eady, K., & Moreau, K. (2021). A qualitative study of patients' and caregivers' perspectives on educating healthcare providers. *Canadian Medical Education Journal*. <https://doi.org/10.36834/cmej.71541>
- Ball, L. J., Christensen, B. T., & Halskov, K. (2021). Sticky notes as a kind of design material: How sticky notes support design cognition and design collaboration. *Design Studies*, 76. <https://doi.org/10.1016/j.destud.2021.101034>
- Barakou, I., Seves, B. L., Abonie, U. S., Finch, T., Hackett, K. L., & Hettinga, F. J. (2025). Health-related quality of life associated with fatigue, physical activity and activity pacing in adults with chronic conditions. *BMC Sports Science, Medicine and Rehabilitation*, 17(1). <https://doi.org/10.1186/s13102-025-01057-x>
- Belton, J., Hoens, A., Scott, A., & Ardern, C. L. (2019). Patients as partners in research: It's the right thing to do. *Journal of Orthopaedic and Sports Physical Therapy*, 49(9), 623–626. <https://doi.org/10.2519/jospt.2019.0106>
- Bird, M., Ouellette, C., Whitmore, C., Li, L., Nair, K., McGillion, M. H., Yost, J., Banfield, L., Campbell, E., & Carroll, S. L. (2020). Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. *Health Expectations*, 23(3), 523–539. Blackwell Publishing Ltd. <https://doi.org/10.1111/hex.13040>
- Bitner, M., Ostrom, A., & Morgan, F. (2008). Service Blueprinting: A Practical Technique for Service Innovation. *California Management Review*, 50, 66–94. <https://doi.org/10.2307/41166446>
- Broekhuis, M., Weering, M. D. van, Schuit, C., Schürz, S., & van Velsen, L. (2021). Designing a stakeholder-inclusive service model for an eHealth service to support older adults in an active and social life. *BMC Health Services Research*, 21(1). <https://doi.org/10.1186/s12913-021-06597-9>
- Burgess, H., Jongbloed, K., Vorobyova, A., Grieve, S., Lyndon, S., Wesseling, T., Salters, K., Hogg, R. S., Parashar, S., & Pearce, M. E. (2021). The “Sticky Notes” Method: Adapting Interpretive Description Methodology for Team-Based Qualitative Analysis in Community-Based Participatory Research. *Qualitative Health Research*, 31(7), 1335–1344. <https://doi.org/10.1177/10497323211002489>

- Effing, T., & Lenferink, A. (2020). Self-management: personalized action plans for COPD exacerbations. In: Moy, M., Blackstock, F. Nici, L. (eds) *Enhancing Patient Engagement in Pulmonary Healthcare*. Respiratory Medicine, Humano, Cham. 205–230. https://doi.org/10.1007/978-3-030-44889-9_11.
- Forsythe, L. P., Carman, K. L., Szydowski, V., Fayish, L., Davidson, L., Hickam, D. H., Hall, C., Bhat, G., Neu, D., Stewart, L., Jalowsky, M., Aronson, N., & Anyanwu, C. U. (2019). Patient engagement in research: Early findings from the patient-centered outcomes research institute. *Health Affairs*, *38*(3), 359–367. <https://doi.org/10.1377/hlthaff.2018.05067>
- Franklin, M., Lewis, Sophie, Willis, Karen, Bourke-Taylor, Helen, & Smith, Lorraine. (2017). Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. *Chronic Illness*, *14*(2), 79–103. <https://doi.org/10.1177/1742395317710082>
- Hacker, K. (2024). The Burden of Chronic Disease. *Mayo Clinic Proceedings: Innovations, Quality and Outcomes*, *8*, (1), 112–119. <https://doi.org/10.1016/j.mayocpiqo.2023.08.005>
- Hajat, C., & Stein, E. (2018). The global burden of multiple chronic conditions: A narrative review. *Preventive Medicine Reports*, *12*, 284–293. <https://doi.org/10.1016/j.pmedr.2018.10.008>
- Im, B. A., Oh, H. S., Kim, S. H., Jeong, H. S., & Seo, W. S. (2024). Development and Evaluation of a Blended Self-Management Program for Metabolic Syndrome in Patients With Rheumatic Diseases. *Health Education and Behavior*, *51*(4), 625–635. <https://doi.org/10.1177/10901981231188136>
- Kirwan, J. R., Hewlett, S. E., Heiberg, T., Hughes, R. A., Carr, M., Hehir, M., Kvien, T. K., Minnock, P., Newman, S. P., Quest, E. M., Taal, E., Wale, J., Kirwan, J. R., & Hewlett, S. E. (2005). Personal non-commercial use only. *The Journal of Rheumatology*, *32*(11). PMID: 12672221.
- Kuipers, E., Poot, C., Wensing, M., Chavannes, N. H., De Smet, P. A. G. M., & Teichert, M. (2019). SELF-management maintenance Inhalation therapy with EHealth (SELFIE); a study on eHealth use in patient care and research. *International Journal of Clinical Pharmacy*, *41*(2), 601–602. <https://doi.org/10.2196/13551>
- McVey, L., Frost, T., Issa, B., Davison, E., Abdulkader, J., Randell, R., Alvarado, N., Zaman, H., Hardiker, N., Cheong, V. L., & Woodcock, D. (2023). Working together: reflections on how to make public involvement in research work. *Research Involvement and Engagement*, *9*(1). <https://doi.org/10.1186/s40900-023-00427-4>
- Qualtrics. (n.d.). Retrieved July 26, 2023, from <https://www.qualtrics.com/>

- Richards, D. P., Jordan, I., Strain, K., & Press, Z. (2018). Patient partner compensation in research and health care: the patient perspective on why and how. *Patient Experience Journal*, 5(3), 6–12. <https://doi.org/10.35680/2372-0247.1334>
- Richards, D. P., Poirier, S., Mohabir, V., Proulx, L., Robins, S., & Smith, J. (2023). Reflections on patient engagement by patient partners: how it can go wrong. *Research Involvement and Engagement*, 9(1). <https://doi.org/10.1186/s40900-023-00454-1>
- Salisbury, L., Baraitser, L., Catty, J., Anucha, K., Davies, S., Flexer, M. J., Moore, M. D., & Osseman, J. (2023). A waiting crisis? *The Lancet*, 401(10375), 428–429. [https://doi.org/10.1016/S0140-6736\(23\)00238-6](https://doi.org/10.1016/S0140-6736(23)00238-6)
- te Braake, E., Grünloh, C., & Tabak, M. (2024). Shifting Responsibilities: Developing a Pan-European Service Model for an eHealth Technology Supporting Self-Management of People with Chronic Obstructive Pulmonary Disease and Comorbidities. *International Journal of Chronic Obstructive Pulmonary Disease*, 19, 175–192. <https://doi.org/10.2147/COPD.S432568>
- te Braake, E., Schriemer, R., Grünloh, C., Ahoud, S., Asselberghs, T., Bodelier, V., Hansen, D., Ophuis, C., & Wolkorte, R. (2025). The broad range of self-management strategies that people with rheumatic and musculoskeletal conditions apply: an online survey using a citizen science approach. *Rheumatology International*, 45(5), 135. <https://doi.org/10.1007/s00296-025-05842-2>
- te Braake, E., Vaseur, R., Grünloh, C., & Tabak, M. (2025). The State of the Art of eHealth Self-Management Interventions for People With Chronic Obstructive Pulmonary Disease: Scoping Review. *Journal of Medical Internet Research*, 27, e57649. <https://doi.org/10.2196/57649>
- The Canadian Institutes of Health Research. (2014). Strategy for Patient-Oriented Research Patient Engagement Framework 2 Acknowledgements.
- Tumilty, E., Doolan-Noble, F., Latu, A. T. F. A., McAuley, K., Dummer, J., Baxter, J., Hannah, D., Donlevy, S., & Stokes, T. (2020). “A balancing act”. Living with severe chronic obstructive pulmonary disease in Southern New Zealand: A qualitative study. *Journal of Primary Health Care*, 12(2), 166–172. <https://doi.org/10.1071/HC20007>
- van Hooft, S., Berger, E., van Torenburg, C., & van Staa, A. L. (2025). Daily routines, short-term priorities, and nurses’ role hamper self-management support in a hospital setting: A mixed methods study. *International Journal of Nursing Studies Advances*, 8. <https://doi.org/10.1016/j.ijnsa.2024.100279>
- Van Wilder, L., Pype, P., Mertens, F., Rammant, E., Clays, E., Devleeschauwer, B., Boeckxstaens, P., & De Smedt, D. (2021). Living with a chronic disease: insights from patients with a low

socioeconomic status. *BMC Family Practice*, 22(1). <https://doi.org/10.1186/s12875-021-01578-7>

Wilson, J., Heinsch, M., Betts, D., Booth, D., & Kay-Lambkin, F. (2021). Barriers and facilitators to the use of e-health by older adults: a scoping review. *BMC Public Health*, 21(1). <https://doi.org/10.1186/s12889-021-11623-w>

Chapter 6

Abdo, A. (2023). Health Awareness Campaigns and Their Role in Promoting Awareness of Rare Diseases. *Journal of Design Sciences and Applied Arts*, 4(2), 70–83. <https://doi.org/10.21608/jdsaa.2023.173961.1236>

Abdullah Altassan, W., Mazzy Alharby, S. S., Serhan Alkhalidi, A., Noor Almasoud, A., Nawras Alshanawani, M., Ibrahim Binjudiaan, S., Fahad Alanazi, R., & Jaber Alnassir, M. (2024). From Burnout to Understaffing: The Crisis Facing General Surgery Consultants and *General Practice Physicians*. 7(3), 801–817. <https://doi.org/DOI:10.63278/jicrcr.vi.1941>

Adam, H., Giroux, C., Eady, K., & Moreau, K. (2021). A qualitative study of patients' and caregivers' perspectives on educating healthcare providers. *Canadian Medical Education Journal*. <https://doi.org/10.36834/cmej.71541>

Adriaans, D. J. M., Dierick-Van Daele, A. T. M., Van Bakel, M. J. H. M., Nieuwenhuijzen, G. A. P., Teijink, J. A. W., Heesakkers, F. F. B. M., & Van Laarhoven, H. W. M. (2021). Digital self-management support tools in the care plan of patients with cancer: Review of randomized controlled trials. *Journal of Medical Internet Research*, 23(6). <https://doi.org/10.2196/20861>

Ball, L. J., Christensen, B. T., & Halskov, K. (2021). Sticky notes as a kind of design material: How sticky notes support design cognition and design collaboration. *Design Studies*, 76. <https://doi.org/10.1016/j.destud.2021.101034>

Barakou, I., Seves, B. L., Abonie, U. S., Finch, T., Hackett, K. L., & Hettinga, F. J. (2025). Health-related quality of life associated with fatigue, physical activity and activity pacing in adults with chronic conditions. *BMC Sports Science, Medicine and Rehabilitation*, 17(1). <https://doi.org/10.1186/s13102-025-01057-x>

Belton, J., Hoens, A., Scott, A., & Ardern, C. L. (2019). Patients as partners in research: It's the right thing to do. *Journal of Orthopaedic and Sports Physical Therapy*, 49(9), 623–626. <https://doi.org/10.2519/jospt.2019.0106>

Bird, M., Ouellette, C., Whitmore, C., Li, L., Nair, K., McGillion, M. H., Yost, J., Banfield, L., Campbell, E., & Carroll, S. L. (2020). Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. *Health Expectations*, 23(3), 523–539. <https://doi.org/10.1111/hex.13040>

- Burgess, H., Jongbloed, K., Vorobyova, A., Grieve, S., Lyndon, S., Wesseling, T., Salters, K., Hogg, R. S., Parashar, S., & Pearce, M. E. (2021). The “Sticky Notes” Method: Adapting Interpretive Description Methodology for Team-Based Qualitative Analysis in Community-Based Participatory Research. *Qualitative Health Research, 31*(7), 1335–1344. <https://doi.org/10.1177/10497323211002489>
- Chegini, Z., Arab-Zozani, M., Shariful Islam, S. M., Tobiano, G., & Abbasgholizadeh Rahimi, S. (2021). Barriers and facilitators to patient engagement in patient safety from patients and healthcare professionals’ perspectives: A systematic review and meta-synthesis. *Nursing Forum, 56*(4), 938–949. <https://doi.org/10.1111/nuf.12635>
- Davis, F. (1985). A Technology Acceptance Model for Empirically Testing New End-User Information Systems.
- Davis, F. (1989). Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. *MIS Quarterly, 13*, 319. <https://doi.org/10.2307/249008>
- Effing, T., & Lenferink, A. (2020). Self-management: personalized action plans for COPD exacerbations. In: Moy, M., Blackstock, F., Nici, L. (eds) *Enhancing Patient Engagement in Pulmonary Healthcare*, 205–230. Respiratory Medicine. Humana, Cham. https://doi.org/10.1007/978-3-030-44889-9_11
- Forsythe, L. P., Carman, K. L., Szydłowski, V., Fayish, L., Davidson, L., Hickam, D. H., Hall, C., Bhat, G., Neu, D., Stewart, L., Jalowsky, M., Aronson, N., & Anyanwu, C. U. (2019). Patient engagement in research: Early findings from the patient-centered outcomes research institute. *Health Affairs, 38*(3), 359–367. <https://doi.org/10.1377/hlthaff.2018.05067>
- Franklin, M., Lewis, Sophie, Willis, Karen, Bourke-Taylor, Helen, & Smith, Lorraine. (2017). Patients’ and healthcare professionals’ perceptions of self-management support interactions: Systematic review and qualitative synthesis. *Chronic Illness, 14*(2), 79–103. <https://doi.org/10.1177/1742395317710082>
- Ghahramani, A., de Courten, M., & Prokofieva, M. (2022). “The potential of social media in health promotion beyond creating awareness: an integrative review.” *BMC Public Health, 22*(1). <https://doi.org/10.1186/s12889-022-14885-0>
- Gonzalez, M., Ogourtsova, T., Zerbo, A., Lalonde, C., Spurway, A., Gavin, F., Shikako, K., Weiss, J. A., & Majnemer, A. (2023). Patient engagement in a national research network: barriers, facilitators, and impacts. *Research Involvement and Engagement, 9*(1). <https://doi.org/10.1186/s40900-023-00418-5>
- Hacker, K. (2024). The Burden of Chronic Disease. *Mayo Clinic Proceedings: Innovations, Quality and Outcomes, 8*(1), 112–119. <https://doi.org/10.1016/j.mayocpiqo.2023.08.005>

- Hajat, C., & Stein, E. (2018). The global burden of multiple chronic conditions: A narrative review. *Preventive Medicine Reports, 12*, 284–293. <https://doi.org/10.1016/j.pmedr.2018.10.008>
- Im, B. A., Oh, H. S., Kim, S. H., Jeong, H. S., & Seo, W. S. (2024). Development and Evaluation of a Blended Self-Management Program for Metabolic Syndrome in Patients With Rheumatic Diseases. *Health Education and Behavior, 51*(4), 625–635. <https://doi.org/10.1177/10901981231188136>
- Kingston, A., Robinson, L., Booth, H., Knapp, M., Jagger, C., Adelaja, B., Avendano, M., Bamford, S. M., Banerjee, S., Berwald, S., Bowling, A., Burgon, C., Bustard, E., Comas-Herrera, A., Dangoor, M., Dixon, J., Farina, N., Greengross, S., Grundy, E., ... Wittenberg, R. (2018). Projections of multi-morbidity in the older population in England to 2035: Estimates from the Population Ageing and Care Simulation (PACSim) model. *Age and Ageing, 47*(3), 374–380. <https://doi.org/10.1093/ageing/afx201>
- Kirwan, J. R., Hewlett, S. E., Heiberg, T., Hughes, R. A., Carr, M., Hehir, M., Kvien, T. K., Minnock, P., Newman, S. P., Quest, E. M., Taal, E., Wale, J., Kirwan, J. R., & Hewlett, S. E. (2005). Personal non-commercial use only. *The Journal of Rheumatology, 32*(11). PMID: 12672221
- Kuipers, E., Poot, C., Wensing, M., Chavannes, N. H., De Smet, P. A. G. M., & Teichert, M. (2019). SELF-management maintenance Inhalation therapy with EHealth (SELFIE); a study on eHealth use in patient care and research. *International Journal of Clinical Pharmacy, 41*(2), 601–602. <https://doi.org/10.2196/13551>
- McVey, L., Frost, T., Issa, B., Davison, E., Abdulkader, J., Randell, R., Alvarado, N., Zaman, H., Hardiker, N., Cheong, V. L., & Woodcock, D. (2023). Working together: reflections on how to make public involvement in research work. *Research Involvement and Engagement, 9*(1). <https://doi.org/10.1186/s40900-023-00427-4>
- Parke, H. L., Epiphaniou, E., Pearce, G., Taylor, S. J. C., Sheikh, A., Griffiths, C. J., Greenhalgh, T., & Pinnock, H. (2015). Self-management support interventions for stroke survivors: A systematic meta-review. *PLoS ONE, 10*(7). <https://doi.org/10.1371/journal.pone.0131448>
- Qualtrics. (n.d.). Retrieved July 26, 2023, from <https://www.qualtrics.com/>
- Richards, D. P., Poirier, S., Mohabir, V., Proulx, L., Robins, S., & Smith, J. (2023). Reflections on patient engagement by patient partners: how it can go wrong. *Research Involvement and Engagement, 9*(1). <https://doi.org/10.1186/s40900-023-00454-1>
- Salisbury, L., Baraitser, L., Catty, J., Anucha, K., Davies, S., Flexer, M. J., Moore, M. D., & Osserman, J. (2023). A waiting crisis? *The Lancet, 401*(10375), 428–429. [https://doi.org/10.1016/S0140-6736\(23\)00238-6](https://doi.org/10.1016/S0140-6736(23)00238-6)

- Suman, A., Armijo-Olivo, S., Deshpande, S., Marietta-Vasquez, J., Dennett, L., Miciak, M., Reneman, M., Werner, E. L., Straube, S., Buchbinder, R., & Gross, D. P. (2021). A systematic review of the effectiveness of mass media campaigns for the management of low back pain. *Disability and Rehabilitation*, 43(24), 3523–3551. <https://doi.org/10.1080/09638288.2020.1743777>
- te Braake, E., Grünloh, C., & Tabak, M. (2026). Identifying the self-management strategies of people with chronic obstructive pulmonary disease in their daily lives: A qualitative survey. *Heart & Lung*, 76, 124–131. <https://doi.org/10.1016/j.hrtlng.2025.11.022>
- te Braake, E., Schriemer, R., Grünloh, C., Ahoud, S., Asselberghs, T., Bodelier, V., Hansen, D., Ophuis, C., & Wolkorte, R. (2025). The broad range of self-management strategies that people with rheumatic and musculoskeletal conditions apply: an online survey using a citizen science approach. *Rheumatology International*, 45(5), 135. <https://doi.org/10.1007/s00296-025-05842-2>
- te Braake, E., Vaseur, R., Grünloh, C., & Tabak, M. (2025). The State of the Art of eHealth Self-Management Interventions for People With Chronic Obstructive Pulmonary Disease: Scoping Review. *Journal of Medical Internet Research*, 27, e57649. <https://doi.org/10.2196/57649>
- The Canadian Institutes of Health Research. (2014). Strategy for Patient-Oriented Research Patient Engagement Framework 2 Acknowledgements.
- Tumilty, E., Doolan-Noble, F., Latu, A. T. F. A., McAuley, K., Dummer, J., Baxter, J., Hannah, D., Donlevy, S., & Stokes, T. (2020). “A balancing act”. Living with severe chronic obstructive pulmonary disease in Southern New Zealand: A qualitative study. *Journal of Primary Health Care*, 12(2), 166–172. <https://doi.org/10.1071/HC20007>
- Tunc, S., Nijboer, F., Ludden, G., Velsen, L. van, & Tabak, M. (2023). Scenario-based Co-design with Older Adults: A Design Case on Decreasing Loneliness. *International Journal of Design*, 17(2), 99–113. <https://doi.org/10.57698/v17i2.06>
- Van Asbroeck, S., van Boxtel, M. P. J., Steyaert, J., Köhler, S., Heger, I., de Vugt, M., Verhey, F., & Deckers, K. (2021). Increasing knowledge on dementia risk reduction in the general population: Results of a public awareness campaign. *Preventive Medicine*, 147. <https://doi.org/10.1016/j.ypmed.2021.106522>
- van Hooft, S., Berger, E., van Torenburg, C., & van Staa, A. L. (2025). Daily routines, short-term priorities, and nurses’ role hamper self-management support in a hospital setting: A mixed methods study. *International Journal of Nursing Studies Advances*, 8. <https://doi.org/10.1016/j.ijnsa.2024.100279>
- Van Wilder, L., Pype, P., Mertens, F., Rammant, E., Clays, E., Devleeschauwer, B., Boeckxstaens, P., & De Smedt, D. (2021). Living with a chronic disease: insights from patients with a low

socioeconomic status. *BMC Family Practice*, 22(1). <https://doi.org/10.1186/s12875-021-01578-7>

Wilson, J., Heinsch, M., Betts, D., Booth, D., & Kay-Lambkin, F. (2021). Barriers and facilitators to the use of e-health by older adults: a scoping review. *BMC Public Health*, 21(1). <https://doi.org/10.1186/s12889-021-11623-w>

Chapter 7

Abidi, L., Van Koeveringe, J., Smolka, M., Van Lierop, B., Bosma, H., Alleva, J. M., Poole, N. L., & Nagelhout, G. E. (2024). Perceptions, barriers and facilitating strategies of inclusive research: a qualitative study with expert interviews. *Journal of Underrepresented and Minority Progress*, 8(2), 237–263. <http://ojed.org/jump>

Ammerlaan, J. W., Mulder, O. K., de Boer-Nijhof, N. C., Maat, B., Kruize, A. A., van Laar, J., van Os-Medendorp, H., & Geenen, R. (2016). Building a Tailored, Patient-Guided, Web-Based Self-Management Intervention ‘ReumaUitgedaagd!’ for Adults With a Rheumatic Disease: Results of a Usability Study and Design for a Randomized Control Trial. *JMIR Research Protocols*, 5(2), e113. <https://doi.org/10.2196/resprot.5735>

Bird, M., Ouellette, C., Whitmore, C., Li, L., Nair, K., McGillion, M. H., Yost, J., Banfield, L., Campbell, E., & Carroll, S. L. (2020). Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. *Health Expectations*, 23(3), 523–539. <https://doi.org/10.1111/hex.13040>

Chan, H. Y., Leenen, L. A. M., Wijnen, B. F. M., van der Putten, I. M., Evers, S. M. A. A., HJM Majoie, M., & van Heugten, C. M. (2021). ZMILE, a multicomponent self-management intervention for adults with epilepsy: Rationale and description of the intervention. *Clinical Rehabilitation*, 35(5), 629–638.

Charles, C., Gafnv, A., & Whelan, T. (1997). Shared Decision-Making in the medical encounter: What does it mean? (or it takes at least two to tango). *Soc. Sci. Med*, 44(5). [https://doi.org/10.1016/s0277-9536\(96\)00221-3](https://doi.org/10.1016/s0277-9536(96)00221-3)

Chegini, Z., Arab-Zozani, M., Shariful Islam, S. M., Tobiano, G., & Abbasgholizadeh Rahimi, S. (2021). Barriers and facilitators to patient engagement in patient safety from patients and healthcare professionals’ perspectives: A systematic review and meta-synthesis. *Nursing Forum*, 56(4), 938–949. <https://doi.org/10.1111/nuf.12635>

Durand, M.-A., DiMilia, P. R., Song, J., Yen, R. W., & Barr, P. J. (2018). Shared decision making embedded in the undergraduate medical curriculum: A scoping review. *PLOS ONE*, 13(11), e0207012. <https://doi.org/10.1371/journal.pone.0207012>

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision

- making: A model for clinical practice. *Journal of General Internal Medicine*, 27(10), 1361–1367. <https://doi.org/10.1007/s11606-012-2077-6>
- Farmer, A., Toms, C., Hardinge, M., Williams, V., Rutter, H., & Tarassenko, L. (2014). Self-management support using an Internet-linked tablet computer (the EDGE platform)-based intervention in chronic obstructive pulmonary disease: Protocol for the EDGE-COPD randomised controlled trial. *BMJ Open*, 4(1). <https://doi.org/10.1136/bmjopen-2013-004437>
- Franklin, M., Lewis, S., Willis, K., Bourke-Taylor, H., & Smith, L. (2018). Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. *Chronic Illness*, 14(2), 79–103. <https://doi.org/10.1177/1742395317710082>
- Gonzalez, M., Ogourtsova, T., Zerbo, A., Lalonde, C., Spurway, A., Gavin, F., Shikako, K., Weiss, J. A., & Majnemer, A. (2023). Patient engagement in a national research network: barriers, facilitators, and impacts. *Research Involvement and Engagement*, 9(1). <https://doi.org/10.1186/s40900-023-00418-5>
- Grünloh, C., Myreteg, G., Cajander, A., & Rexhepi, H. (2018). “why do they need to check me?” patient participation through ehealth and the doctor-patient relationship: Qualitative study. *Journal of Medical Internet Research*, 20(1). <https://doi.org/10.2196/jmir.8444>
- Heffernan, M. E., Barrera, L., Guzman, Z. R., Golbeck, E., Jedraszko, A. M., Hays, P. T., Herzog, K. A., D'Aquila, R. T., Ison, M. G., & McColley, S. A. (2023). Barriers and facilitators to recruitment of underrepresented research participants: Perspectives of clinical research coordinators. *Journal of Clinical and Translational Science*, 7(1). <https://doi.org/10.1017/cts.2023.611>
- Jongsma, K., & Friesen, P. (2019). The Challenge of Demandingness in Citizen Science and Participatory Research. *American Journal of Bioethics*, 19(8), 33–35. <https://doi.org/10.1080/15265161.2019.1619867>
- Kingston, A., Robinson, L., Booth, H., Knapp, M., Jagger, C., Adelaja, B., Avendano, M., Bamford, S. M., Banerjee, S., Berwald, S., Bowling, A., Burgon, C., Bustard, E., Comas-Herrera, A., Dangoor, M., Dixon, J., Farina, N., Greengross, S., Grundy, E., ... Wittenberg, R. (2018). Projections of multi-morbidity in the older population in England to 2035: Estimates from the Population Ageing and Care Simulation (PACSim) model. *Age and Ageing*, 47(3), 374–380. <https://doi.org/10.1093/ageing/afx201>
- Lee, S., Joo, Y., & Jang, Y. (2025). eHealth Self-Management Interventions for Patients With Liver Cirrhosis: Scoping Review. *Journal of Medical Internet Research*, 27. <https://doi.org/10.2196/68650>

- Lehane, E., Curtin, C., & Corrigan, M. (2023). Teaching strategies for shared decision-making within the context of evidence-based healthcare practice: A scoping review. *Patient Education and Counseling*, 109. <https://doi.org/10.1016/j.pec.2023.107630>
- Long, K., & Renbarger, R. (2023). Persistence of Poverty: How Measures of Socioeconomic Status Have Changed Over Time. *Educational Researcher*, 52(3), 144–154. <https://doi.org/10.3102/0013189X221141409>
- Pardhan, S., Sehmbi, T., Wijewickrama, R., Onumajuru, H., & Piyasena, M. P. (2025). Barriers and facilitators for engaging underrepresented ethnic minority populations in healthcare research: an umbrella review. *International Journal for Equity in Health*, 24(1). <https://doi.org/10.1186/s12939-025-02431-4>
- Richards, D. P., Jordan, I., Strain, K., & Press, Z. (2018). Patient partner compensation in research and health care: the patient perspective on why and how. *Patient Experience Journal*, 5(3), 6–12. <https://doi.org/10.35680/2372-0247.1334>
- Scholl, I., LaRussa, A., Hahlweg, P., Kobrin, S., & Elwyn, G. (2018). Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them - a scoping review. *Implementation Science*, 13(1). <https://doi.org/10.1186/s13012-018-0731-z>
- Seppen, B. F., Den Boer, P., Wiegel, J., ter Wee, M. M., Van der Leeden, M., De Vries, R., Van der Esch, M., & Bos, W. H. (2020). Asynchronous mhealth interventions in rheumatoid arthritis: Systematic scoping review. *JMIR mHealth and uHealth*, 8(11). <https://doi.org/10.2196/19260>
- Smith, L., Simpson, G., Holt, S., & Dambha-Miller, H. (2025). Digital applications to support self-management of multimorbidity: A scoping review. *International Journal of Medical Informatics*, 202. <https://doi.org/10.1016/j.ijmedinf.2025.105988>
- Smits, D. W., Van Meeteren, K., Klem, M., Alsem, M., & Ketelaar, M. (2020). Designing a tool to support patient and public involvement in research projects: The Involvement Matrix. *Research Involvement and Engagement*, 6(1). <https://doi.org/10.1186/s40900-020-00188-4>

Appendices

Appendix 2.1. Stakeholder Saliency Survey

In the next part, you will see a list of potential individuals or organisations that could be relevant for putting RE-SAMPLE into practice. We will ask you three questions about their potential influence in the implementation process:

- 1) The power and influence of each individual or organisation in this process
- 2) Whether it is correct and justifiable to include each individual or organisation in this process
- 3) How urgent it is to take the needs and wishes of each individual or organisation into account in this process

Some of the individuals or organisations will have less or more power to influence the process of putting RE-SAMPLE into practice. An individual or organisation that has more power will be able to influence other parties to take actions they normally would not take.

To what degree do the following individuals or organisations have **power to influence the success** of putting RE-SAMPLE into practice? Please rate each individual or organisation on a scale of 1 (not at all) to 5 (very much).

It may be the case that some individuals or organisations are not applicable for your country. If so, please indicate this.

Power	1	2	3	4	5	N/a in my country
COPD patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informal caregiver (family members or close people)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General Practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonary nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialised nurses at the outpatient department	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physiotherapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychologist/Psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutritionist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Radiologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nephrologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Other (health specialists in general)	o	o	o	o	o	o
Pharmacist	o	o	o	o	o	o
Head of the pulmonary outpatient department	o	o	o	o	o	o
Hospital board	o	o	o	o	o	o
Innovation manager	o	o	o	o	o	o
Legal department	o	o	o	o	o	o
Management of Laboratory	o	o	o	o	o	o
Hospital purchasing department	o	o	o	o	o	o
Information specialist	o	o	o	o	o	o
ICT department	o	o	o	o	o	o
Insurance company	o	o	o	o	o	o
Region/ State Institution	o	o	o	o	o	o
Social ministry	o	o	o	o	o	o
USCAR (Service to assess whether COVID patients are hospitalised)	o	o	o	o	o	o

Some individuals or organisations have a right to be heard and involved in the process of putting RE-SAMPLE into practice, based on societal norms, values, and beliefs. It is therefore correct and justifiable that we take these individuals or organisations into account when putting RE-SAMPLE into practice.

To what degree is it **correct and justifiable** that we involve the following individuals or organisations when putting RE-SAMPLE into practice? Please rate each individual or organisation on a scale of 1 (not at all) to 5 (very much).

It may be the case that some individuals or organisations are not applicable for your country. If so, please indicate this.

Justifiability	1	2	3	4	5	N/a in my country
COPD patient	o	o	o	o	o	o

Informal caregiver (family members or close people)	o	o	o	o	o	o
General Practitioner	o	o	o	o	o	o
Pulmonologist	o	o	o	o	o	o
Pulmonary nurse	o	o	o	o	o	o
Specialised nurses at outpatient department	o	o	o	o	o	o
Physiotherapist	o	o	o	o	o	o
Psychologist/Psychiat rist	o	o	o	o	o	o
Cardiologist	o	o	o	o	o	o
Diabetologist	o	o	o	o	o	o
Nutritionist	o	o	o	o	o	o
Radiologist	o	o	o	o	o	o
Nephrologist	o	o	o	o	o	o
Other (health) specialists in general	o	o	o	o	o	o
Pharmacist	o	o	o	o	o	o
Head of pulmonary outpatient department	o	o	o	o	o	o
Hospital board	o	o	o	o	o	o
Innovation manager	o	o	o	o	o	o
Legal department	o	o	o	o	o	o
Management of Laboratory	o	o	o	o	o	o
Hospital purchasing department	o	o	o	o	o	o
Information specialist	o	o	o	o	o	o
ICT department	o	o	o	o	o	o
Insurance company	o	o	o	o	o	o
Region/ State Institution	o	o	o	o	o	o
Social ministry	o	o	o	o	o	o
USCAR (Service to assess whether COVID patients are hospitalised)	o	o	o	o	o	o

Some individuals or organisations are considered more urgent than other individuals or organisations when putting RE-SAMPLE into practice. For individuals or organisations that have a high urgency, it is important that their needs require immediate attention or action.

To what degree do the needs of the following individuals or organisations **call for immediate action** when putting RE-SAMPLE into practice? Please rate each individual or organisation on a scale of 1 (not at all) to 5 (very much).

It may be the case that some individuals or organisations are not applicable for your country. If so, please indicate this.

Urgency	1	2	3	4	5	N/a in my country
COPD patient	o	o	o	o	o	o
Informal caregiver (family members or close people)	o	o	o	o	o	o
General Practitioner	o	o	o	o	o	o
Pulmonologist	o	o	o	o	o	o
Pulmonary nurse	o	o	o	o	o	o
Specialised nurses at outpatient department	o	o	o	o	o	o
Physiotherapist	o	o	o	o	o	o
Psychologist/Psychiatrist	o	o	o	o	o	o
Cardiologist	o	o	o	o	o	o
Diabetologist	o	o	o	o	o	o
Nutritionist	o	o	o	o	o	o
Radiologist	o	o	o	o	o	o
Nephrologist	o	o	o	o	o	o
Other (health) specialists in general	o	o	o	o	o	o
Pharmacist	o	o	o	o	o	o
Head of pulmonary outpatient department	o	o	o	o	o	o
Hospital board	o	o	o	o	o	o
Innovation manager	o	o	o	o	o	o
Legal department	o	o	o	o	o	o
Management of Laboratory	o	o	o	o	o	o
Hospital purchasing department	o	o	o	o	o	o
Information specialist	o	o	o	o	o	o
ICT department	o	o	o	o	o	o
Insurance company	o	o	o	o	o	o

Region/ State	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Institution						
Social ministry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
USCAR (Service to assess whether COVID patients are hospitalised)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Are there stakeholder groups not included in this list that are relevant for RE-SAMPLE? If so, could you please indicate which stakeholders are missing in the text field below?



Appendix 3.1. PRISMA-ScR Checklist

Section	Item	PRISMA-ScR Checklist Item	Reported on page #
Title			
Title	1	Identify the report as a scoping review.	1
Abstract			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1-2
Introduction			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2-5
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	5
Methods			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	5, 7
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	5
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	-
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	5-8
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	8-9
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	7
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe	-

Section	Item	PRISMA-ScR Checklist Item	Reported on page #
sources of evidence§ Synthesis of results	13	the methods used and how this information was used in any data synthesis (if appropriate). Describe the methods of handling and summarizing the data that were charted.	7-9
Results			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	9
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	9-10
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	-
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Multi. Appendix 1-5
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	11-19
Discussion			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	19-22
Limitations	20	Discuss the limitations of the scoping review process.	22
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	22-23
Funding			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	1

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix 3.2: Search String

Topic	Search	Query
	#4	#1 AND #2 AND #3
Self-management	#3	“Self-manag*” OR “Self manag*” OR "self-care" OR “Self care” OR "self-guidance" OR "self-control" OR "self-regulation" OR "self-inspection" OR "self-monitor*" OR “Self monitor*” OR "self-supervision" OR "self-government" OR "self-rule"
COPD	#2	"Pulmonary Disease, Chronic Obstructive" OR "COPD" OR "chronic obstructive lung disease" OR "chronic obstructive pulmonary disease" OR "COAD" OR "chronic obstructive airway disease" OR "chronic obstructive pulmonary disease" OR "chronic airflow obstruction"
eHealth	#1	"Telemedicine" OR "eHealth" OR "health technology" OR "mHealth" OR "m-health" OR "e-Health" OR "digital aid" OR "digital care" OR "Mobile Health" OR "Health, mobile" OR "e-mental health" OR "tele-health" OR "Telehealth" OR "Telecare" OR "Telemonitor*" OR "teleconsultation" OR "e-governance" OR "Mobile application*"

Appendix 3.3. Overview of extraction and charting details

Extraction categories	Extracted data	Reference	Way of extracting	Way of charting data
General	a) Year of study b) Type of study c) Definition of self-management	n/a	Directly from data	Data clustered in a bar graph [b], table [c], or presented descriptively [a]
SQ1: What is the 'e' in eHealth self-management	a) Functionality b) Modality c) Technology Readiness (TRL)-level (The maturity of a technology) d) eHealth development details	c) (Jansen-Kosterink et al., 2022)	Both directly from data [a, b, d] and assessed/categorised by the reviewer(s) [b, c]	Counted for separately [a, d], and available information about eHealth development status was categorised into the different TRL-levels [c]. Data is mapped into a bar graph [b, c], a table [d], or presented descriptively [a, d]
SQ2: What is the 'health' in eHealth self-management	a) Positive health dimensions	a) (Huber et al., 2016)	Interpretation and assessed/categorised by reviewer(s)	Each dimension is counted separately and mapped in a radar and a bar chart
SQ3: Who is the 'self' in self-management	a) Intended target population b) Included target population c) Actual target population	n/a	Both directly from data [a, b, c] and assessed/categorised by reviewer(s) [c]	When information on the education of participants is available in the demographics, this is categorised in low, medium, or high education [c] and clustered in a flow chart [a, b, c].
SQ4: What is the 'management' in eHealth self-management?	a) Self-management processes b) Behavioural change techniques (BCTs)	a) (Schulman-Green et al., 2012) b) (Michie et al., 2013)	Both directly from data [b] and assessed/categorised by the reviewer(s) [a, b]	Each process and behavioural change technique is counted for separately and mapped in a bar graph [a, b]



Appendix 3.4. Overview of the functionality and modality of eHealth interventions

1a. Functionality of the eHealth interventions

Authors	(Self-) Monitoring tool	Education/ information tool	Communication tool
Alcazar et al. (2016)	✓	-	✓
Alharbey et al. (2019)	✓	✓	-
Ali et al (2021)	✓	✓	✓
Au et al. (2015)	✓	✓	-
Barenfeld et al. (2020)	✓	✓	✓
Barenfeld et al. (2022)	✓	✓	✓
Barken et al. (2018)	✓	-	-
Bentley et al. (2020)	✓	-	-
Benzo et al. (2018)	✓	✓	-
Billington et al. (2015)	-	✓	✓
Bødker et al. (2015)	-	✓	-
Boer et al. (2018)	✓	✓	-
Boer et al. (2019)	✓	✓	-
Bourbeau et al. (2016)	✓	✓	-
Bugajski et al. (2019)	✓	✓	-
Burkow et al. (2013)	✓	✓	-
Burkow et al. (2015)	✓	✓	-
Burkow et al. (2018)	✓	✓	-
Cameron-Tucker et al. (2016)	-	✓	-
Choi et al. (2021)	✓	✓	-
Cooper et al. (2022)	✓	✓	-
Coultas et al. (2018)	✓	✓	-
Coventry et al. (2019)	✓	✓	-
Criner et al. (2021)	✓	-	-
De San Miguel et al. (2013)	✓	-	-
Deng et al. (2020)	✓	✓	✓
Dhadge et al. (2020)	✓	-	✓
Doyle et al. (2021)	✓	✓	✓
Early et al. (2017)	-	✓	✓
Farias et al. (2019)	✓	-	-
Farmer et al. (2017)	✓	✓	-

Fitzsimmons et al. (2016)	✓	-	-
Haesum et al. (2012)	✓	✓	-
Hardinge et al. (2015)	✓	✓	✓
Hoaas et al. (2016)	✓	-	-
Hoaas et al. (2016)	✓	-	-
Houchen-Wolloff et al. (2021)	✓	✓	✓
Huniche et al. (2013)	✓	-	-
Jolly et al. (2018)	✓	✓	-
Kargiannakis et al. (2017)	✓	✓	-
Kaye et al. (2021)	✓	✓	-
Kessler et al. (2018)	✓	✓	-
Kjellsdotter et al. (2021)	-	✓	-
Knox et al. (2021)	✓	-	-
Koff et al. (2021)	✓	✓	-
Kooij et al. (2021)	✓	✓	✓
Korpershoek et al. (2020)	✓	✓	✓
Korpershoek et al. (2020)	✓	-	✓
Lee et al. (2012)	-	✓	-
Lilholt et al. (2015)	✓	-	-
Lundell et al. (2020)	✓	-	-
Maathuis et al. (2014)	✓	-	-
Mark et al. (2013)	-	✓	-
Marklund et al. (2021)	✓	✓	-
Marquis et al. (2015)	-	✓	-
Mathar et al. (2015)	✓	-	-
Mierdel et al. (2015)	✓	✓	-
Miller et al. (2021)	✓	-	-
Nield et al. (2012)	✓	✓	-
North et al. (2020)	-	✓	-
Nyberg et al. (2019)	✓	✓	-
Orme et al. (2018)	✓	✓	-
Park et al. (2020)	✓	✓	✓
Patel et al. (2021)	✓	-	✓
Rassouli et al. (2018)	✓	✓	✓
Rixon et al. (2017)	✓	✓	✓
Robinson et al. (2020)	✓	✓	✓
Rodriguez Hermosa et al. (2020)	✓	✓	-
Schnoor et al. (2022)	✓	✓	-
Sheridan et al. (2020)	✓	✓	✓
Sieverink et al. (2019)	✓	✓	✓
Sloots et al. (2021)	✓	-	✓
Stamenova et al. (2020)	✓	✓	-

Steventon et al. (2013)	✓	✓	✓
Talboom-Kamp et al. (2017)	✓	✓	-
Talboom-Kamp et al. (2017)	✓	✓	-
Talboom-Kamp et al. (2019)	✓	✓	-
Tabak et al. (2014)	✓	✓	✓
ter Stal et al. (2021)	✓	✓	-
Thomas et al. (2017)	✓	✓	-
van Buul et al. (2018)	✓	✓	✓
van Buul et al. (2021)	✓	-	-
van der Heijden et al. (2013)	✓	-	-
van der Weegen et al. (2013)	✓	-	-
van der Weegen et al. (2015)	✓	-	-
van Lieshout et al. (2020)	✓	-	-
van Zelst et al. (2021)	✓	✓	✓
Vatnøy et al. (2017)	✓	-	-
Velardo et al. (2017)	✓	-	✓
Verwey et al. (2014)	✓	-	-
Voncken-Brewster et al. (2013)	✓	-	-
Voncken-Brewster et al. (2014)	✓	✓	-
Voncken-Brewster et al. (2015)	✓	✓	-
Voncken-Brewster et al. (2017)	✓	✓	-
Vorriink et al. (2017)	✓	-	-
Walters et al. (2013)	✓	-	-
Wang et al., (2021)	-	✓	✓
Whelan et al. (2019)	✓	-	-
Williams et al. (2014)	✓	✓	-
Zanaboni et al. (2013)	✓	✓	-
Zanaboni et al. (2017)	✓	-	-
Total	91	69	27

1b. Modality of the eHealth interventions

Author	(Smart) measurement and monitoring devices	Computer/Laptop/Whiteboard	Normal Phone/Landline	Not mentioned	Other	Smartphone	Tablet	Television (TV)
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Alcazar et al. (2016)	-	✓	-	-	-	-	-	-
Alharbey et al. (2019)	✓	-	-	-	-	✓	-	-
Ali et al (2021)	-	-	✓	-	-	-	-	-
Au et al. (2016)	-	-	-	-	-	-	-	-
Barenfeld et al. (2020)	-	-	✓	✓	-	-	-	-
Barenfeld et al. (2022)	-	-	-	✓	-	-	-	-
Barken et al. (2018)	✓	-	-	-	-	-	✓	-
Bentley et al. (2020)	-	-	-	-	-	✓	-	-
Benzo et al. (2018)	✓	-	-	-	-	-	✓	-
Billington et al. (2015)	-	-	✓	-	-	-	-	-
Bødker et al. (2015)	-	✓	-	-	-	-	-	-
Boer et al. (2018)	-	✓	-	-	-	-	-	-
Boer et al. (2019)	✓	-	-	-	-	✓	-	-
Bourbeau et al. (2016)	-	-	-	-	-	✓	-	-
Bugajski et al. (2019)	-	-	-	-	-	✓	✓	-
Burkow et al. (2013)	-	✓	-	-	-	-	-	✓
Burkow et al. (2015)	-	✓	-	-	-	-	-	✓
Burkow et al. (2018)	✓	-	-	-	-	-	✓	-
Cameron-Tucker et al. (2016)	-	-	✓	-	-	-	-	-
Choi et al. (2021)	-	-	-	-	-	✓	-	-
Cooper et al. (2022)	-	-	-	✓	-	-	-	-
Coultas et al. (2018)	-	-	✓	-	-	-	-	-
Coventry et al. (2019)	-	-	✓	-	-	-	-	-
Criner et al. (2021)	-	-	-	-	-	✓	-	-
De San Miguel et al. (2013)	-	✓	✓	-	-	-	-	-
Deng et al. (2020)	-	-	-	-	-	✓	-	-
Dhadge et al. (2020)	-	-	-	-	-	✓	-	-
Doyle et al. (2021)	✓	-	-	-	-	✓	✓	-
Early et al. (2017)	-	✓	✓	-	-	-	-	-
Farias et al. (2019)	-	-	✓	-	-	-	-	-
Farmer et al. (2017)	✓	-	-	-	-	-	✓	-
Fitzsimmons et al. (2016)	-	-	✓	-	-	-	-	-
Haesum et al. (2012)	-	-	-	-	-	-	-	-
Hardinge et al. (2015)	✓	-	-	-	-	-	✓	-
Hoas et al. (2016)	✓	-	-	-	-	-	✓	-
Hoas et al. (2016)	✓	-	-	-	-	-	✓	-
Houchen-Wolloff et al. (2021)	-	-	-	-	-	-	✓	-
Huniche et al. (2013)	✓	-	-	-	✓	-	-	-
Jolly et al. (2018)	-	-	✓	-	-	-	-	-
Kargiannakis et al. (2017)	✓	-	✓	-	-	-	-	-
Kaye et al. (2021)	✓	-	-	-	-	-	-	-
Kessler et al. (2018)	-	-	-	-	-	✓	-	-
Kjellsdotter et al. (2021)	-	-	-	✓	-	-	-	-
Knox et al. (2021)	-	-	-	-	-	✓	-	-
Koff et al. (2021)	✓	-	-	-	-	-	-	-
Kooij et al. (2021)	-	-	-	-	-	-	✓	-
Korpershoek et al. (2020)	-	-	-	-	-	✓	-	-
Korpershoek et al. (2020)	-	-	-	-	-	✓	-	-



Lee et al. (2012)	-	-	✓	-	-	-	-	-
Lilholt et al. (2015)	✓	-	-	-	-	-	✓	-
Lundell et al. (2020)	✓	-	-	-	-	-	✓	-
Maathuis et al. (2014)	✓	-	-	-	-	-	-	-
Mark et al. (2013)	-	✓	-	-	-	-	-	-
Marklund et al. (2021)	✓	-	-	-	-	-	-	-
Marquis et al. (2015)	-	-	-	-	-	-	-	-
Mathar et al. (2015)	✓	-	-	-	-	-	-	-
Mierdel et al. (2015)	-	-	-	-	-	-	✓	-
Miller et al. (2021)	✓	-	-	-	-	✓	-	-
Nield et al. (2012)	-	✓	-	-	-	-	-	-
North et al. (2020)	-	-	-	✓	-	-	-	-
Nyberg et al. (2019)	✓	-	-	-	-	-	-	-
Orme et al. (2018)	✓	-	-	-	-	-	-	-
Park et al. (2020)	✓	-	-	-	-	✓	-	-
Patel et al. (2021)	✓	-	-	-	-	-	✓	-
Rassouli et al. (2018)	-	-	-	-	-	✓	-	-
Rixon et al. (2017)	✓	-	-	-	-	-	-	✓
Robinson et al. (2020)	✓	-	-	-	-	-	-	-
Rodriguez Hermosa et al. (2020)	-	-	-	-	-	✓	-	-
Schnoor et al. (2022)	-	-	-	✓	-	-	-	-
Sheridan et al. (2020)	-	-	✓	-	-	-	-	-
Sieverink et al. (2019)	✓	-	-	-	-	-	-	-
Sloots et al. (2021)	✓	✓	-	-	-	-	✓	-
Stamenova et al. (2020)	✓	-	-	-	-	-	✓	-
Steventon et al. (2013)	-	-	✓	-	-	-	-	-
Talboom-Kamp et al. (2017)	-	-	-	✓	-	-	-	-
Talboom-Kamp et al. (2017)	-	-	-	✓	-	-	-	-
Talboom-Kamp et al. (2019)	-	-	-	✓	-	-	-	-
Tabak et al. (2014)	✓	-	-	-	-	✓	-	-
ter Stal et al. (2021)	✓	-	-	-	-	-	✓	-
Thomas et al. (2017)	-	✓	-	-	-	-	-	-
van Buul et al. (2018)	-	-	-	-	-	-	-	-
van Buul et al. (2021)	✓	-	-	-	-	✓	-	-
van der Heijden et al. (2013)	✓	-	-	-	-	✓	-	-
van der Weegen et al. (2013)	✓	-	-	-	-	✓	-	-
van der Weegen et al. (2015)	✓	-	-	-	-	-	-	-
van Lieshout et al. (2020)	✓	-	-	-	-	-	✓	-
van Zelst et al. (2021)	-	-	-	-	-	✓	-	-
Vatnøy et al. (2017)	✓	-	-	-	-	-	✓	-
Velardo et al. (2017)	✓	-	-	-	-	-	✓	-
Verwey et al. (2014)	-	-	-	-	-	✓	-	-
Voncken-Brewster et al. (2013)	-	✓	-	-	-	-	-	-
Voncken-Brewster et al. (2014)	-	✓	-	-	-	-	-	-
Voncken-Brewster et al. (2015)	-	✓	-	-	-	-	-	-
Voncken-Brewster et al. (2017)	-	✓	-	-	-	-	-	-
Vorriink et al. (2017)	-	-	-	-	-	✓	-	-
Walters et al. (2013)	-	-	✓	-	-	-	-	-

Wang et al., (2021)	-	-	-	-	-	✓	-	-
Whelan et al. (2019)	✓	-	-	-	-	-	✓	-
Williams et al. (2014)	✓	-	-	-	-	-	✓	-
Zanaboni et al. (2013)	✓	-	-	-	-	-	✓	-
Zanaboni et al. (2017)	✓	-	-	-	-	-	✓	-
Total	45	16	16	9	1	26	15	3

Appendix 3.5. Overview of Positive Health Dimensions

Author	Daily functioning	Meaningfulness	Mental Well-being	Participation	Quality of Life	Bodily functioning
Alcazar et al. (2016)	-	-	-	-	-	✓
Alharbey et al. (2019)	-	-	-	-	-	✓
Ali et al (2021)	✓	-	-	-	-	✓
Au et al. (2016)	-	-	-	-	-	✓
Barenfeld et al. (2020)	-	-	-	-	-	✓
Barenfeld et al. (2022)	-	-	-	-	-	✓
Barken et al. (2018)	-	-	-	-	-	✓
Bentley et al. (2020)	-	-	-	-	-	✓
Benzo et al. (2018)	✓	-	-	✓	-	✓
Billington et al. (2015)	-	-	-	-	-	✓
Bødker et al. (2015)	-	-	-	-	-	✓
Boer et al. (2018)	✓	-	-	-	-	✓
Boer et al. (2019)	-	-	✓	-	-	✓
Bourbeau et al. (2016)	-	-	-	-	-	✓
Bugajski et al. (2019)	-	-	-	-	-	✓
Burkow et al. (2013)	✓	-	-	-	-	✓
Burkow et al. (2015)	✓	-	✓	-	-	✓
Burkow et al. (2018)	-	-	-	-	-	✓
Cameron-Tucker et al. (2016)	✓	-	-	-	-	✓
Choi et al. (2021)	✓	-	-	-	-	✓
Cooper et al. (2022)	-	-	-	-	-	✓
Coultas et al. (2018)	-	-	-	-	-	✓
Coventry et al. (2019)	✓	-	✓	-	-	✓
Criner et al. (2021)	✓	-	✓	-	-	✓
De San Miguel et al. (2013)	✓	-	-	-	-	✓
Deng et al. (2020)	✓	-	-	-	-	✓
Dhadge et al. (2020)	✓	-	-	-	-	✓
Doyle et al. (2021)	-	-	-	-	-	✓
Early et al. (2017)	-	-	-	-	-	✓
Farias et al. (2019)	-	-	-	-	-	✓
Farmer et al. (2017)	✓	-	-	-	-	✓
Fitzsimmons et al. (2016)	✓	-	-	-	-	✓
Haesum et al. (2012)	-	-	-	-	-	✓
Hardinge et al. (2015)	-	-	-	-	-	✓

Hoas et al. (2016)	-	-	-	-	-	✓
Hoas et al. (2016)	-	-	-	-	-	✓
Houchen-Wolloff et al. (2021)	✓	-	-	-	-	✓
Huniche et al. (2013)	-	-	-	-	-	✓
Jolly et al. (2018)	-	-	-	-	-	✓
Kargiannakis et al. (2017)	✓	-	-	-	-	✓
Kaye et al. (2021)	✓	-	-	-	-	✓
Kessler et al. (2018)	✓	-	-	-	-	✓
Kjellsdotter et al. (2021)	-	-	-	-	-	✓
Knox et al. (2021)	-	-	-	-	-	✓
Koff et al. (2021)	-	-	-	-	-	✓
Kooij et al. (2021)	-	-	✓	✓	-	✓
Korpershoek et al. (2020)	-	-	-	-	-	✓
Korpershoek et al. (2020)	-	-	-	-	-	✓
Lee et al. (2012)	✓	-	-	-	-	✓
Lilholt et al. (2015)	✓	-	-	-	-	✓
Lundell et al. (2020)	-	-	-	-	-	✓
Maathuis et al. (2014)	-	-	-	-	-	✓
Mark et al. (2013)	✓	-	-	-	-	✓
Marklund et al. (2021)	✓	-	-	-	-	✓
Marquis et al. (2015)	-	-	-	-	-	✓
Mathar et al. (2015)	✓	-	✓	-	-	✓
Mierdel et al. (2015)	-	-	-	-	-	✓
Miller et al. (2021)	-	-	-	-	-	✓
Nield et al. (2012)	✓	-	-	-	-	✓
North et al. (2020)	✓	-	-	-	-	✓
Nyberg et al. (2019)	✓	-	-	-	-	✓
Orme et al. (2018)	✓	-	✓	✓	-	✓
Park et al. (2020)	✓	-	-	-	-	✓
Patel et al. (2021)	-	-	-	-	-	✓
Rassouli et al. (2018)	✓	-	✓	-	-	✓
Rixon et al. (2017)	✓	-	-	✓	-	✓
Robinson et al. (2020)	-	-	-	-	-	✓
Rodriguez Hermosa et al. (2020)	✓	-	✓	✓	-	✓
Schnoor et al. (2022)	-	-	-	-	-	✓
Sheridan et al. (2020)	✓	-	-	-	-	✓
Sieverink et al. (2019)	✓	-	-	-	-	✓
Sloots et al. (2021)	✓	-	-	-	-	✓
Stamenova et al. (2020)	-	-	-	-	-	✓
Steventon et al. (2013)	-	-	-	-	-	✓
Talboom-Kamp et al. (2017)	-	-	✓	✓	-	✓
Talboom-Kamp et al. (2017)	-	-	-	✓	-	✓

Talboom-Kamp et al. (2019)	✓	-	-	-	-	✓
Tabak et al. (2014)	✓	-	-	-	-	✓
ter Stal et al. (2021)	-	-	-	-	-	✓
Thomas et al. (2017)	-	-	-	-	-	✓
van Buul et al. (2018)	-	-	-	✓	-	✓
van Buul et al. (2021)	-	-	-	-	-	✓
van der Heijden et al. (2013)	-	-	-	-	-	✓
van der Weegen et al. (2013)	-	-	✓	✓	-	✓
van der Weegen et al. (2015)	✓	-	-	-	-	✓
van Lieshout et al. (2020)	✓	-	-	-	-	✓
van Zelst et al. (2021)	✓	-	✓	✓	-	✓
Vatnøy et al. (2017)	-	-	-	-	-	✓
Velardo et al. (2017)	✓	-	-	-	-	✓
Verwey et al. (2014)	✓	-	-	-	-	✓
Voncken-Brewster et al. (2013)	✓	-	-	-	-	✓
Voncken-Brewster et al. (2014)	-	-	-	-	-	✓
Voncken-Brewster et al. (2015)	-	-	-	-	-	✓
Voncken-Brewster et al. (2017)	✓	-	-	-	-	✓
Vorrink et al. (2017)	✓	-	-	-	-	✓
Walters et al. (2013)	-	-	-	✓	-	✓
Wang et al., (2021)	-	-	-	-	-	✓
Whelan et al. (2019)	-	-	-	✓	-	✓
Williams et al. (2014)	✓	-	-	✓	-	✓
Zanaboni et al. (2013)	-	-	-	-	-	✓
Zanaboni et al. (2017)	✓	-	-	-	-	✓
<i>Total</i>	<i>46</i>	<i>0</i>	<i>12</i>	<i>13</i>	<i>0</i>	<i>101</i>

Appendix 3.6. Overview of the Self

3a. Intended target population

Authors	COPD in general	COPD severities	Comorbidities
Alcazar et al. (2016)	-	✓	-
Alharbey et al. (2019)	✓	-	-
Ali et al (2021)	-	-	✓
Au et al. (2016)	✓	-	-
Barenfeld et al. (2020)	-	-	✓
Barenfeld et al. (2022)	-	-	✓
Barken et al. (2018)	✓	-	-
Bentley et al. (2020)	✓	-	-
Benzo et al. (2018)	✓	-	-
Billington et al. (2015)	✓	-	-
Bødker et al. (2015)	-	✓	-
Boer et al. (2018)	✓	-	-
Boer et al. (2019)	✓	-	-
Bourbeau et al. (2016)	-	✓	-
Bugajski et al. (2019)	-	✓	-
Burkow et al. (2013)	-	✓	-
Burkow et al. (2015)	✓	-	-
Burkow et al. (2018)	✓	-	-
Cameron-Tucker et al. (2016)	✓	-	-
Choi et al. (2021)	✓	-	-
Cooper et al. (2022)	✓	-	-
Coultas et al. (2018)	✓	-	-
Coventry et al. (2019)	-	✓	-
Criner et al. (2021)	✓	-	-
De San Miguel et al. (2013)	✓	-	-
Deng et al. (2020)	✓	-	-
Dhadge et al. (2020)	-	-	✓
Doyle et al. (2021)	-	-	✓
Early et al. (2017)	✓	-	-
Farias et al. (2019)	✓	-	-
Farmer et al. (2017)	-	✓	-
Fitzsimmons et al. (2016)	-	✓	-
Haesum et al. (2012)	✓	-	-

Hardinge et al. (2015)	-	✓	-
Hoas et al. (2016)	✓	-	-
Hoas et al. (2016)	✓	-	-
Houchen-Wolloff et al. (2021)	-	✓	-
Huniche et al. (2013)	-	✓	-
Jolly et al. (2018)	-	✓	-
Kargiannakis et al. (2017)	-	✓	-
Kaye et al. (2021)	-	-	✓
Kessler et al. (2018)	-	✓	-
Kjellsdotter et al. (2021)	✓	-	-
Knox et al. (2021)	✓	-	-
Koff et al. (2021)	-	✓	-
Kooij et al. (2021)	✓	-	-
Korpershoek et al. (2020)	✓	-	-
Korpershoek et al. (2020)	✓	-	-
Lee et al. (2012)	-	-	✓
Lilholt et al. (2015)	✓	-	-
Lundell et al. (2020)	✓	-	-
Maathuis et al. (2014)	✓	-	-
Mark et al. (2013)	✓	-	-
Marklund et al. (2021)	✓	-	-
Marquis et al. (2015)	-	✓	-
Mathar et al. (2015)	✓	-	-
Mierdel et al. (2015)	-	-	✓
Miller et al. (2021)	✓	-	-
Nield et al. (2012)	-	✓	-
North et al. (2020)	-	✓	-
Nyberg et al. (2019)	✓	-	-
Orme et al. (2018)	-	✓	-
Park et al. (2020)	✓	-	-
Patel et al. (2021)	✓	-	-
Rassouli et al. (2018)	✓	-	-
Rixon et al. (2017)	✓	-	-
Robinson et al. (2020)	✓	-	-
Rodriguez Hermosa et al. (2020)	✓	-	-
Schnoor et al. (2022)	-	-	✓
Sheridan et al. (2020)	-	-	✓
Sieverink et al. (2019)	-	-	✓
Sloots et al. (2021)	-	-	✓
Stamenova et al. (2020)	✓	-	-
Steventon et al. (2013)	-	-	✓
Talboom-Kamp et al. (2017)	✓	-	-

Talboom-Kamp et al. (2017)	✓	-	-
Talboom-Kamp et al. (2019)	✓	-	-
Tabak et al. (2014)	✓	-	-
ter Stal et al. (2021)	-	-	✓
Thomas et al. (2017)	-	-	✓
van Buul et al. (2018)	-	-	✓
van Buul et al. (2021)	-	✓	-
van der Heijden et al. (2013)	-	✓	-
van der Weegen et al. (2013)	-	-	✓
van der Weegen et al. (2015)	-	-	✓
van Lieshout et al. (2020)	✓	-	-
van Zelst et al. (2021)	✓	-	-
Vatnøy et al. (2017)	-	✓	-
Velardo et al. (2017)	✓	-	-
Verwey et al. (2014)	-	-	✓
Voncken-Brewster et al. (2013)	✓	-	-
Voncken-Brewster et al. (2014)	✓	-	-
Voncken-Brewster et al. (2015)	✓	-	-
Voncken-Brewster et al. (2017)	✓	-	-
Vorrink et al. (2017)	✓	-	-
Walters et al. (2013)	-	✓	-
Wang et al., (2021)	✓	-	-
Whelan et al. (2019)	✓	-	-
Williams et al. (2014)	✓	-	-
Zanaboni et al. (2013)	✓	-	-
Zanaboni et al. (2017)	✓	-	-
Total	59	23	19

3b. Included target population

Authors	Disease specific	Capability	Minimum age	Maximum age	Smoking (history)	Technology
Alcazar et al. (2016)	✓	✓	-	-	✓	-
Alharbey et al. (2019)	-	✓	-	-	-	✓
Ali et al (2021)	-	✓	-	-	-	✓
Au et al. (2016)	-	-	-	-	-	-
Barenfeld et al. (2020)	-	-	-	-	-	-
Barenfeld et al. (2022)	-	-	-	-	-	-
Barken et al. (2018)	-	-	-	-	-	-

Bentley et al. (2020)	-	-	-	-	-	-
Benzo et al. (2018)	✓	-	✓	-	✓	-
Billington et al. (2015)	✓	-	-	-	-	-
Bødker et al. (2015)	-	-	-	-	-	-
Boer et al. (2018)	✓	✓	-	-	-	-
Boer et al. (2019)	✓	✓	✓	-	-	-
Bourbeau et al. (2016)	✓	-	-	-	✓	-
Bugajski et al. (2019)	✓	✓	-	✓	-	✓
Burkow et al. (2013)	-	-	-	-	-	-
Burkow et al. (2015)	-	-	✓	-	-	✓
Burkow et al. (2018)	-	✓	-	-	-	-
Cameron-Tucker et al. (2016)	✓	✓	✓	-	-	-
Choi et al. (2021)	✓	✓	✓	-	-	✓
Cooper et al. (2022)	-	✓	-	-	-	✓
Coultas et al. (2018)	✓	-	-	-	-	-
Coventry et al. (2019)	✓	-	✓	-	-	-
Criner et al. (2021)	✓	-	✓	-	✓	-
De San Miguel et al. (2013)	-	✓	-	-	-	✓
Deng et al. (2020)	-	✓	✓	-	-	✓
Dhadge et al. (2020)	-	-	-	-	-	-
Doyle et al. (2021)	-	-	✓	-	-	-
Early et al. (2017)	✓	-	✓	-	-	-
Farias et al. (2019)	✓	✓	✓	-	✓	-
Farmer et al. (2017)	✓	-	✓	-	✓	-
Fitzsimmons et al. (2016)	-	✓	-	-	-	✓
Haesum et al. (2012)	✓	-	-	-	-	-
Hardinge et al. (2015)	-	-	-	-	-	-
Hoaas et al. (2016)	-	-	-	-	-	-
Hoaas et al. (2016)	-	✓	-	-	-	-
Houchen-Wolloff et al. (2021)	-	✓	-	-	-	✓
Huniche et al. (2013)	✓	✓	✓	-	-	-
Jolly et al. (2018)	✓	✓	✓	-	-	-
Kargiannakis et al. (2017)	-	-	-	-	-	-
Kaye et al. (2021)	✓	-	✓	-	-	✓
Kessler et al. (2018)	✓	-	✓	-	✓	-
Kjellsdotter et al. (2021)	-	-	-	-	-	-
Knox et al. (2021)	✓	✓	✓	-	✓	-
Koff et al. (2021)	✓	✓	-	-	-	✓
Kooij et al. (2021)	✓	✓	✓	-	-	✓
Korpershoek et al. (2020)	-	-	-	-	-	-
Korpershoek et al. (2020)	✓	✓	✓	-	-	-
Lee et al. (2012)	-	-	-	-	-	-

Lilholt et al. (2015)	-	-	-	-	-	-
Lundell et al. (2020)	✓	-	✓	-	-	-
Maathuis et al. (2014)	-	-	-	-	-	-
Mark et al. (2013)	-	✓	✓	-	-	-
Marklund et al. (2021)	-	-	-	-	-	✓
Marquis et al. (2015)	✓	✓	-	-	✓	✓
Mathar et al. (2015)	-	-	-	-	-	-
Mierdel et al. (2015)	-	-	-	-	-	-
Miller et al. (2021)	✓	✓	✓	-	-	✓
Nield et al. (2012)	✓	-	✓	-	-	-
North et al. (2020)	-	-	-	-	-	✓
Nyberg et al. (2019)	-	-	-	-	-	-
Orme et al. (2018)	✓	✓	-	✓	-	-
Park et al. (2020)	✓	✓	✓	-	-	✓
Patel et al. (2021)	✓	✓	-	-	-	-
Rassouli et al. (2018)	-	✓	✓	-	-	✓
Rixon et al. (2017)	-	✓	-	-	-	✓
Robinson et al. (2020)	✓	-	-	-	-	-
Rodriguez Hermosa et al. (2020)	✓	✓	✓	-	✓	✓
Schnoor et al. (2022)	-	-	✓	-	-	-
Sheridan et al. (2020)	-	-	-	-	-	-
Sieverink et al. (2019)	-	-	-	-	-	-
Sloots et al. (2021)	✓	✓	✓	-	-	-
Stamenova et al. (2020)	-	✓	✓	-	-	✓
Steventon et al. (2013)	✓	✓	✓	-	-	✓
Talboom-Kamp et al. (2017)	✓	✓	-	-	-	✓
Talboom-Kamp et al. (2017)	✓	✓	-	-	-	✓
Talboom-Kamp et al. (2019)	✓	✓	-	-	-	✓
Tabak et al. (2014)	✓	-	-	-	-	✓
ter Stal et al. (2021)	✓	✓	✓	-	-	✓
Thomas et al. (2017)	-	✓	✓	-	✓	✓
van Buul et al. (2018)	-	-	-	-	-	-
van Buul et al. (2021)	✓	-	-	-	-	✓
van der Heijden et al. (2013)	-	-	-	-	-	-
van der Weegen et al. (2013)	-	-	-	-	-	-
van der Weegen et al. (2015)	✓	✓	-	✓	-	✓
van Lieshout et al. (2020)	-	-	-	-	-	-
van Zelst et al. (2021)	-	✓	✓	-	-	-
Vatnøy et al. (2017)	✓	✓	-	-	-	-
Velardo et al. (2017)	-	-	-	-	-	-
Verwey et al. (2014)	✓	✓	✓	-	-	✓
Voncken-Brewster et al. (2013)	-	-	-	-	-	-

Voncken-Brewster et al. (2014)	-	✓	-	-	-	✓
Voncken-Brewster et al. (2015)	✓	✓	-	✓	-	✓
Voncken-Brewster et al. (2017)	✓	✓	-	✓	-	✓
Vorriink et al. (2017)	✓	-	✓	-	-	-
Walters et al. (2013)	-	✓	✓	-	-	-
Wang et al., (2021)	-	✓	✓	✓	-	✓
Whelan et al. (2019)	-	-	✓	-	-	-
Williams et al. (2014)	✓	-	-	-	✓	-
Zanaboni et al. (2013)	✓	✓	-	✓	-	✓
Zanaboni et al. (2017)	✓	✓	-	✓	-	✓
Total	50	50	38	8	12	39

3c. Actual population

Author	Disease specific	Capability	Mean age	Gender	Smoking (history)	Technology
Alcazar et al. (2016)	-	-	✓	✓	✓	-
Alharbey et al. (2019)	-	-	-	✓	-	-
Ali et al (2021)	✓	✓	✓	✓	✓	-
Au et al. (2016)	-	-	✓	✓	-	-
Barenfeld et al. (2020)	-	✓	✓	✓	-	-
Barenfeld et al. (2022)	-	✓	✓	✓	-	-
Barken et al. (2018)	-	-	✓	✓	-	-
Bentley et al. (2020)	-	-	-	✓	-	✓
Benzo et al. (2018)	-	-	-	-	-	✓
Billington et al. (2015)	✓	-	✓	✓	✓	-
Bødker et al. (2015)	-	-	-	-	-	-
Boer et al. (2018)	-	-	✓	✓	-	-
Boer et al. (2019)	-	-	✓	✓	✓	-
Bourbeau et al. (2016)	-	-	-	-	-	-
Bugajski et al. (2019)	✓	-	✓	✓	-	-
Burkow et al. (2013)	-	-	-	✓	-	-
Burkow et al. (2015)	✓	-	✓	✓	-	-
Burkow et al. (2018)	✓	-	✓	✓	-	-
Cameron-Tucker et al. (2016)	✓	-	✓	✓	-	-

Choi et al. (2021)	-	-	-	✓	-	-
Cooper et al. (2022)	✓	-	-	✓	-	-
Coultas et al. (2018)	-	-	✓	✓	✓	-
Coventry et al. (2019)	-	-	✓	✓	✓	-
Criner et al. (2021)	-	-	✓	✓	✓	-
De San Miguel et al. (2013)	-	-	✓	✓	-	-
Deng et al. (2020)	✓	✓	✓	✓	✓	-
Dhadge et al. (2020)	-	-	✓	✓	-	-
Doyle et al. (2021)	-	-	✓	✓	-	-
Early et al. (2017)		-	✓	✓	-	✓
Farias et al. (2019)	✓	-	✓	✓	-	-
Farmer et al. (2017)	-	-	✓	✓	✓	-
Fitzsimmons et al. (2016)	-	-	-	-	-	-
Haesum et al. (2012)	-	-	✓	-	-	-
Hardinge et al. (2015)	✓	-	-	✓	-	✓
Hoas et al. (2016)	-	-	✓	✓	-	✓
Hoas et al. (2016)	-	-	✓	✓	-	-
Houchen-Wolloff et al. (2021)	-	-	✓	✓	-	-
Huniche et al. (2013)	-	-	✓	✓	✓	-
Jolly et al. (2018)	-	✓	✓	✓	✓	-
Kargiannakis et al. (2017)	-	-	-	-	-	-
Kaye et al. (2021)	-	-	✓	✓	-	-
Kessler et al. (2018)	-	-	✓	✓	✓	-
Kjellsdotter et al. (2021)	-	-	-	-	-	-
Knox et al. (2021)	-	-	✓	✓		-
Koff et al. (2021)	-	-	✓	✓	✓	-
Kooij et al. (2021)	✓	✓	✓	✓	-	-
Korpershoek et al. (2020)	-	-	-	-	-	-
Korpershoek et al. (2020)	-	-	-	-	-	-
Lee et al. (2012)	-	-	-	✓	-	-
Lilholt et al. (2015)	✓	✓	✓	✓	-	✓
Lundell et al. (2020)	✓	-	-	✓	-	-
Maathuis et al. (2014)	-	-	-	✓	-	-
Mark et al. (2013)	-	-	✓	✓	-	-
Marklund et al. (2021)	-	✓	-	✓	✓	-
Marquis et al. (2015)	✓	✓	✓	✓	-	-
Mathar et al. (2015)	✓	-	-	✓	-	-

Mierdel et al. (2015)	-	-	✓	✓	-	-
Miller et al. (2021)	-	-	✓	-	✓	-
Nield et al. (2012)	-	-	✓	✓	✓	✓
North et al. (2020)	✓	-	✓	✓	✓	-
Nyberg et al. (2019)	-	✓	✓	✓	✓	-
Orme et al. (2018)	-	-	✓	✓	✓	-
Park et al. (2020)	-	-	✓	✓	-	-
Patel et al. (2021)	-	-	✓	✓	✓	-
Rassouli et al. (2018)	-	-	✓	✓	-	-
Rixon et al. (2017)	-	-	✓	✓	-	-
Robinson et al. (2020)	-	-	✓	✓	-	-
Rodriguez Hermosa et al. (2020)	-	-	✓	✓	✓	-
Schnoor et al. (2022)	-	-	✓	✓	-	-
Sheridan et al. (2020)	-	✓	-	✓	-	-
Sieverink et al. (2019)	-	-	-	-	-	-
Sloots et al. (2021)	-	✓	✓	✓	-	✓
Stamenova et al. (2020)	-	-	✓	✓	✓	-
Steventon et al. (2013)	-	-	✓	✓	-	-
Talboom-Kamp et al. (2017)	-	✓	✓	✓	-	-
Talboom-Kamp et al. (2017)	-	✓	✓	✓	-	-
Talboom-Kamp et al. (2019)	-	-	-	✓	-	-
Tabak et al. (2014)	-	-	✓	✓	✓	-
ter Stal et al. (2021)	-	-	-	✓	-	-
Thomas et al. (2017)	-	-	✓	✓	✓	-
van Buul et al. (2018)	-	-	✓	✓	✓	-
van Buul et al. (2021)	-	-	✓	✓	✓	-
van der Heijden et al. (2013)	-	-	-	-	-	-
van der Weegen et al. (2013)	-	-	✓	-	-	-
van der Weegen et al. (2015)	✓	✓	✓	✓	-	-
van Lieshout et al. (2020)	-	-	-	✓	-	-
van Zelst et al. (2021)	-	-	-	✓	-	-
Vatnøy et al. (2017)	-	-	-	✓	-	-
Velardo et al. (2017)	✓	-	-	✓	-	-
Verwey et al. (2014)	-	-	✓	✓	-	✓
Voncken-Brewster et al. (2013)	-	✓	-	✓	-	-
Voncken-Brewster et al. (2014)	✓	✓	-	✓	-	-
Voncken-Brewster et al. (2015)	-	✓	✓	✓	-	-

Voncken-Brewster et al. (2017)	-	✓	✓	✓	✓	-
Vorrink et al. (2017)	-	-	✓	✓	-	-
Walters et al. (2013)	-	-	✓	✓	✓	-
Wang et al., (2021)	✓	-	✓	✓	✓	-
Whelan et al. (2019)	✓	-	✓	✓	✓	-
Williams et al. (2014)	✓	-	✓	✓	-	-
Zanaboni et al. (2013)	✓	-	✓	✓	-	-
Zanaboni et al. (2017)	-	✓	✓	✓	-	✓
<i>Total</i>	<i>23</i>	<i>21</i>	<i>71</i>	<i>88</i>	<i>30</i>	<i>11</i>

Appendix 3.7. Overview of the self-management processes

Author	Adjusting	Community resources	Healthcare resources	Integrating illness into daily life	Learning	Meaning making	Performing health promotion	Processing emotions	Psychological resources	Social resources	Spiritual resources	Taking ownership of health needs
Alcazar et al. (2016)	-	-	-	-	-	-	-	-	-	-	-	✓
Alharbey et al. (2019)	-	-	-	-	✓	-	✓	-	-	-	-	✓
Ali et al (2021)	-	-	✓	-	✓	-	-	-	-	✓	-	✓
Au et al. (2016)	-	-	-	-	✓	-	-	-	-	-	-	✓
Barenfeld et al. (2020)	-	-	✓	-	✓	-	-	-	-	✓	-	✓
Barenfeld et al. (2022)	-	-	✓	-	✓	-	-	-	-	✓	-	✓
Barken et al. (2018)	-	-	-	-	-	-	-	-	-	-	-	✓
Bentley et al. (2020)	-	-	-	-	✓	-	-	-	-	-	-	✓
Benzo et al. (2018)	-	-	-	-	✓	-	✓	-	-	-	-	✓
Billington et al. (2015)	-	-	✓	-	✓	-	-	-	-	-	-	✓
Bødker et al. (2015)	-	-	-	-	✓	-	✓	-	-	-	-	-
Boer et al. (2018)	-	-	-	-	✓	-	-	-	-	-	-	✓
Boer et al. (2019)	-	-	-	-	✓	-	-	-	-	-	-	✓
Bourbeau et al. (2016)	-	-	-	-	✓	-	-	-	-	-	-	✓
Bugajski et al. (2019)	✓	-	-	✓	✓	-	✓	-	-	✓	-	✓
Burkow et al. (2013)	-	-	-	-	✓	-	-	-	-	-	-	✓
Burkow et al. (2015)	-	-	-	-	✓	-	-	-	-	-	-	✓
Burkow et al. (2018)	-	-	-	-	✓	-	-	-	-	✓	-	✓
Cameron-Tucker et al. (2016)	-	-	-	-	✓	-	-	-	-	-	-	✓
Choi et al. (2021)	-	-	-	-	✓	-	-	-	-	-	-	✓
Cooper et al. (2022)	-	-	-	-	✓	-	✓	-	-	-	-	✓
Coultas et al. (2018)	-	-	-	-	✓	-	-	-	-	-	-	✓
Coventry et al. (2019)	-	-	-	-	✓	-	-	-	-	-	-	✓
Criner et al. (2021)	-	-	-	-	-	-	-	-	-	-	-	✓
De San Miguel et al. (2013)	-	-	-	-	-	-	-	-	-	-	-	✓
Deng et al. (2020)	-	-	✓	-	✓	-	-	-	-	-	-	✓
Dhadge et al. (2020)	-	-	✓	-	-	-	-	-	-	-	-	✓
Doyle et al. (2021)	-	-	✓	-	✓	-	-	-	-	✓	-	✓
Early et al. (2017)	-	-	✓	-	✓	-	-	-	-	-	-	✓

Farias et al. (2019)	-	-	-	-	-	-	-	-	-	-	✓
Farmer et al. (2017)	-	-	-	-	✓	-	-	-	-	-	✓
Fitzsimmons et al. (2016)	-	-	-	-	-	-	-	-	-	-	✓
Haesum et al. (2012)	-	-	-	-	✓	-	-	-	✓	-	✓
Hardinge et al. (2015)	-	-	✓	-	✓	-	-	-	-	-	✓
Hoas et al. (2016)	-	-	-	-	-	-	-	-	-	-	✓
Hoas et al. (2016)	-	-	-	-	-	-	-	-	-	-	✓
Houchen-Wolloff et al. (2021)	-	-	✓	-	✓	-	-	-	✓	-	✓
Huniche et al. (2013)	-	-	-	-	-	-	-	-	-	-	✓
Jolly et al. (2018)	-	-	-	-	✓	-	-	-	-	-	✓
Kargiannakis et al. (2017)	-	-	-	-	✓	-	-	-	-	-	✓
Kaye et al. (2021)	-	-	-	-	✓	-	✓	-	-	-	✓
Kessler et al. (2018)	-	-	-	-	✓	-	-	-	-	-	✓
Kjellsdotter et al. (2021)	-	-	-	-	✓	-	-	-	-	-	-
Knox et al. (2021)	-	-	-	-	-	-	-	-	-	-	✓
Koff et al. (2021)	-	-	-	-	✓	-	-	-	-	-	✓
Kooij et al. (2021)	-	-	✓	-	✓	-	-	-	-	-	✓
Korpershoek et al. (2020)	-	-	✓	-	✓	-	✓	-	-	-	✓
Korpershoek et al. (2020)	-	-	-	-	✓	-	-	-	-	-	✓
Lee et al. (2012)	-	-	-	-	✓	-	✓	-	-	-	-
Lilholt et al. (2015)	-	-	-	-	✓	-	-	-	-	-	✓
Lundell et al. (2020)	-	-	-	-	-	-	-	-	-	-	✓
Maathuis et al. (2014)	-	-	-	-	-	-	✓	-	-	-	✓
Mark et al. (2013)	-	-	-	-	✓	-	✓	-	-	-	-
Marklund et al. (2021)	-	-	-	-	✓	-	-	-	-	-	✓
Marquis et al. (2015)	-	-	-	-	✓	-	✓	-	-	-	-
Mathar et al. (2015)	-	-	-	-	-	-	-	-	-	-	✓
Mierdel et al. (2015)	-	-	-	-	✓	-	-	-	-	-	✓
Miller et al. (2021)	-	-	-	-	-	-	✓	-	-	-	✓
Nield et al. (2012)	-	-	-	-	✓	-	✓	-	-	-	✓
North et al. (2020)	-	-	-	-	✓	-	✓	-	-	-	-
Nyberg et al. (2019)	-	-	✓	-	✓	-	✓	-	✓	-	✓
Orme et al. (2018)	-	-	-	-	✓	-	-	-	-	-	✓
Park et al. (2020)	-	-	-	-	✓	-	✓	-	✓	-	✓
Patel et al. (2021)	-	-	✓	-	-	-	-	-	-	-	✓
Rassouli et al. (2018)	-	-	✓	-	✓	-	✓	-	-	-	✓
Rixon et al. (2017)	-	-	-	-	✓	-	-	-	-	-	✓
Robinson et al. (2020)	-	-	-	-	✓	-	-	-	✓	-	✓
Rodriguez Hermosa et al. (2020)	-	-	-	-	✓	-	-	-	-	-	✓
Schnoor et al. (2022)	-	-	✓	-	✓	-	-	-	-	-	✓
Sheridan et al. (2020)	-	-	-	-	✓	-	-	-	✓	-	✓
Sieverink et al. (2019)	-	-	✓	-	✓	-	-	-	-	-	✓



Sloots et al. (2021)	-	-	✓	-	-	-	-	-	-	-	✓	
Stamenova et al. (2020)	-	-	✓	-	✓	-	-	-	-	-	✓	
Steventon et al. (2013)	-	-	✓	-	✓	-	✓	-	-	✓	✓	
Talboom-Kamp et al. (2017)	-	-	-	-	✓	-	-	-	-	-	✓	
Talboom-Kamp et al. (2017)	-	-	✓	-	✓	-	-	-	-	-	✓	
Talboom-Kamp et al. (2019)	-	-	-	-	✓	-	-	-	-	-	✓	
Tabak et al. (2014)	-	-	✓	-	✓	-	✓	-	-	-	✓	
ter Stal et al. (2021)	-	-	✓	-	✓	-	✓	-	-	-	✓	
Thomas et al. (2017)	-	-	-	-	✓	-	-	-	-	-	✓	
van Buul et al. (2018)	-	-	✓	-	✓	-	-	-	-	-	✓	
van Buul et al. (2021)	-	-	-	-	-	-	-	-	✓	-	✓	
van der Heijden et al. (2013)	-	-	-	-	-	-	-	-	-	-	✓	
van der Weegen et al. (2013)	-	-	-	-	-	-	-	-	-	-	✓	
van der Weegen et al. (2015)	-	-	-	-	-	-	-	-	-	-	✓	
van Lieshout et al. (2020)	-	-	-	-	-	-	-	-	-	-	✓	
van Zelst et al. (2021)	-	-	✓	-	✓	-	-	-	-	-	✓	
Vatnøy et al. (2017)	-	-	-	-	-	-	-	-	-	-	✓	
Velardo et al. (2017)	-	-	✓	-	-	-	-	-	-	-	✓	
Verwey et al. (2014)	-	-	-	-	-	-	-	-	-	-	✓	
Voncken-Brewster et al. (2013)	-	-	-	-	-	-	-	-	✓	-	✓	
Voncken-Brewster et al. (2014)	-	-	-	-	✓	-	-	-	-	-	✓	
Voncken-Brewster et al. (2015)	-	-	-	-	✓	-	✓	-	-	-	✓	
Voncken-Brewster et al. (2017)	-	-	-	-	✓	-	-	-	✓	-	✓	
Vorrink et al. (2017)	-	-	-	-	-	-	-	-	-	-	✓	
Walters et al. (2013)	-	-	-	-	-	-	-	-	-	-	✓	
Wang et al., (2021)	-	-	✓	-	✓	-	✓	-	-	✓	-	
Whelan et al. (2019)	-	-	-	-	-	-	✓	-	-	-	✓	
Williams et al. (2014)	-	-	-	-	✓	-	-	-	-	-	✓	
Zanaboni et al. (2013)	-	-	-	-	-	-	-	-	-	-	✓	
Zanaboni et al. (2017)	-	-	-	-	✓	-	-	-	-	-	✓	
Total	1	0	27	1	71	0	23	0	0	17	0	94

Appendix 3.8. Overview of the Behaviour Change Techniques

Author	Antecedents	Associations	Comparison of behaviour	Comparison of outcomes	Covert learning	Feedback and monitoring	Goals and planning	Identity	Natural consequences	Regulation	Repetition and substitution	Rewards and threat	Scheduled consequences	Self-belief	Shaping knowledge	Social support
Alcazar et al. (2016)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Alharbey et al. (2019)	-	-	-	-	-	✓	-	-	-	-	-	✓	-	-	✓	-
Ali et al (2021)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	✓
Au et al. (2016)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Barenfeld et al. (2020)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	✓
Barenfeld et al. (2022)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	✓
Barken et al. (2018)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Bentley et al. (2020)	-	-	-	-	-	✓	✓	-	-	-	-	✓	-	-	✓	-
Benzo et al. (2018)	-	-	-	-	-	✓	✓	-	-	-	✓	-	-	-	✓	-
Billington et al. (2015)	-	-	-	-	-	-	✓	-	-	✓	-	-	-	✓	✓	-
Bødker et al. (2015)	-	-	-	-	-	-	-	-	-	-	✓	-	-	-	-	-
Boer et al. (2018)	-	-	-	-	-	✓	-	-	-	✓	-	-	-	-	✓	-
Boer et al. (2019)	-	-	-	-	-	✓	-	-	-	✓	-	-	-	-	✓	-
Bourbeau et al. (2016)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Bugajski et al. (2019)	-	-	-	-	-	-	✓	-	-	-	-	-	-	-	✓	✓
Burkow et al. (2013)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Burkow et al. (2015)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Burkow et al. (2018)	✓	✓	✓	✓	-	✓	✓	-	✓	-	-	✓	-	-	✓	-
Cameron-Tucker et al. (2016)	-	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-
Choi et al. (2021)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Cooper et al. (2022)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Coultas et al. (2018)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	-
Coventry et al. (2019)	-	-	-	-	-	-	✓	-	-	✓	-	-	-	-	-	-
Criner et al. (2021)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
De San Miguel et al. (2013)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Deng et al. (2020)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Dhadge et al. (2020)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Doyle et al. (2021)	-	✓	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	✓
Early et al. (2017)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	-
Farias et al. (2019)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Farmer et al. (2017)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Fitzsimmons et al. (2016)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-



Haesum et al. (2012)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	
Hardinge et al. (2015)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-
Hoas et al. (2016)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Hoas et al. (2016)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Houchen-Wolloff et al. (2021)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	✓
Huniche et al. (2013)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Jolly et al. (2018)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Kargiannakis et al. (2017)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Kaye et al. (2021)	-	✓	-	-	-	✓	-	-	-	-	✓	-	-	-	-	-	-	-	✓	-
Kessler et al. (2018)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-
Kjellsdotter et al. (2021)	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Knox et al. (2021)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Koff et al. (2021)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Kooij et al. (2021)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-
Korpershoek et al. (2020)	-	✓	-	✓	-	✓	✓	-	✓	-	✓	✓	-	-	-	-	-	-	-	✓
Korpershoek et al. (2020)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Lee et al. (2012)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Lilholt et al. (2015)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Lundell et al. (2020)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Maathuis et al. (2014)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	-	-
Mark et al. (2013)	-	-	-	-	-	-	-	-	-	-	✓	-	-	-	-	-	-	-	✓	-
Marklund et al. (2021)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Marquis et al. (2015)	-	-	-	-	-	-	-	-	-	-	✓	-	-	-	-	-	-	-	✓	-
Mathar et al. (2015)	-	-	-	-	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Mierdel et al. (2015)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-
Miller et al. (2021)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Nield et al. (2012)	-	-	-	-	-	✓	-	-	-	-	✓	-	-	-	-	-	-	-	✓	-
North et al. (2020)	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Nyberg et al. (2019)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Orme et al. (2018)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Park et al. (2020)	-	-	-	-	-	✓	✓	-	-	-	✓	✓	-	-	-	-	-	-	✓	✓
Patel et al. (2021)	-	✓	-	-	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Rassouli et al. (2018)	-	-	-	-	-	✓	-	-	-	-	✓	-	-	-	-	-	-	-	✓	-
Rixon et al. (2017)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Robinson et al. (2020)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	✓
Rodriguez Hermosa et al. (2020)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	✓	-
Schnoor et al. (2022)	-	-	✓	-	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Sheridan et al. (2020)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-
Sieverink et al. (2019)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-
Sloots et al. (2021)	-	✓	-	-	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Stamenova et al. (2020)	-	✓	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-
Steventon et al. (2013)	-	-	-	-	-	-	✓	-	-	✓	-	-	-	-	-	-	-	-	✓	✓

Talboom-Kamp et al. (2017)	-	✓	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	-
Talboom-Kamp et al. (2017)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	-
Talboom-Kamp et al. (2019)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Tabak et al. (2014)	-	✓	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	-
ter Stal et al. (2021)	-	✓	✓	-	-	✓	✓	-	-	-	-	-	-	-	✓	-
Thomas et al. (2017)	-	-	✓	-	-	✓	-	-	-	-	✓	-	-	-	✓	-
van Buul et al. (2018)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	✓	-
van Buul et al. (2021)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	✓
van der Heijden et al. (2013)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
van der Weegen et al. (2013)	-	-	-	-	-	✓	✓	-	-	-	-	✓	-	-	-	-
van der Weegen et al. (2015)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-
van Lieshout et al. (2020)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
van Zelst et al. (2021)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Vatnøy et al. (2017)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Velardo et al. (2017)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Verwey et al. (2014)	-	-	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-
Voncken-Brewster et al. (2013)	-	-	-	-	-	✓	✓	✓	✓	-	-	-	-	-	-	✓
Voncken-Brewster et al. (2014)	-	-	-	-	-	✓	✓	-	-	✓	-	-	-	✓	✓	-
Voncken-Brewster et al. (2015)	-	✓	-	-	-	✓	✓	-	✓	-	-	-	-	✓	✓	-
Voncken-Brewster et al. (2017)	-	-	-	-	-	✓	✓	-	✓	✓	-	-	-	✓	✓	✓
Vorrink et al. (2017)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Walters et al. (2013)	-	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-
Wang et al., (2021)	-	-	✓	-	-	-	-	-	-	-	-	-	-	-	✓	✓
Whelan et al. (2019)	-	✓	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Williams et al. (2014)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	✓	-
Zanaboni et al. (2013)	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-
Zanaboni et al. (2017)	-	-	-	-	-	✓	-	-	-	-	-	-	-	✓	✓	-
Total																
	1	23	5	2	0	88	38	1	5	11	10	6	0	5	66	14



Appendix 4.1. Full Survey [Translated to English] and dissemination channels

REIS questionnaire

**UNIVERSITY
OF TWENTE.**



Dear participant,

You have a form of rheumatism, are over 16 years old, and are interested in participating in research into self-management in rheumatism. For self-management, people use different strategies (think of actions, skills, and use of tools). These are aimed at managing symptoms and consequences of the condition for your well-being and your active participation. Self-management is not just about 'doing it yourself'. It is also about 'self-determination'.

Many people go on self-examination to deal with the consequences of rheumatism. That probably applies to you too. With the knowledge and experiences about what helped you and others with rheumatism – or not! - we help people in their search. Our research is not aimed at determining what works for patients in general. We do want to learn from people, what they do and what their experiences are.

The questionnaire

In the questionnaire we collect your experiences with certain activities, methods, tools, etc. We call these activities, methods, and tools strategies. The questionnaire consists of three parts. First, we ask you to describe some strategies you have tried (up to 10). We ask you for both the positive and negative strategies experienced. This way, we can create an overview of barriers and facilitators. Then, you indicate which of these strategies you want to elaborate upon. We end the questionnaire with some information about yourself. Completing the questionnaire will take about 20-30 minutes.

The questionnaire largely contains open questions. That means that you can type the answers into a text field yourself. This way you can better express what you want to share so we get a better understanding of your considerations and experiences. Your written answers matter!

Tips

We also know that typing can be difficult when you have sore hands. We recommend that you do the research at a time when you have enough time and energy and are in a quiet environment. You can then think quietly and type comfortably. We think that typing on a PC, laptop or tablet is a bit easier than on a phone. You can stop for a while during filling in the questionnaire. Your answers are automatically saved. You can then return to the questionnaire later. Of course, you are not obliged to participate in the study, and you can stop at any time. Only the questionnaires that are completed until the end are included in the analysis.

Personal data

This study has been approved by the Ethical Review Committee of the University of Twente. This means that this research is carried out scientifically carefully and in accordance with your rights as a participant.

The data is stored at the University of Twente. Your data is well protected. We do not ask you for any traceable information. So: no names, no housing details, or data of others. We think it is important to work openly. That is why we place the anonymized data in online storage. This means that other researchers can contact us to view this data and use it for scientific research or education. We only give access if the scientific researchers have a suitable question.

The results of the research will be published in a scientific journal and of course also shared with important organizations that work for and with people with rheumatism. If you want to be kept informed of the research results, you can share your email address with us. This is stored separately from your answers.

If you have any questions about the study, you can contact [name of researcher] at [email researcher]

INFORMED CONSENT

Q1

- Yes, I hereby declare that I have read the information above, and I agree to participate in this study. (1)

Q2 Are you 16 years or older and do you have a form of rheumatism?

Not sure? Then take a look at the site of Rheumatism Netherlands

- Yes, I am 16 years or older and have a form of rheumatism (1)
- No, I am not 16 years or older and/or do not have any form of rheumatism (2)

Display This Question:

*Are you 16 years or older and do you have a form of rheumatism? Not sure? Then take a look at the sit...
= No, I am not 16 years or older and/or do not have a form of rheumatism*

Unfortunately, this questionnaire is not intended for you. This questionnaire is only intended for people who are 16 years or older and have a form of rheumatism.

Skip To: End of Survey If Unfortunately, this questionnaire is not intended for you. This questionnaire is intended for people only... Displayed

Display This Question: Are you 16 years or older and do you have a form of rheumatism? Not sure? Then look at the sit... = Yes, I am 16 years or older and have a form of rheumatism.

SELF-MANAGEMENT GENERAL

Q4 This part of the questionnaire focuses on the self-management of your rheumatism. In the following questions you can name which strategies you want to share.

Self-management strategies are actions that you perform aimed at dealing with rheumatism, complaints, and emotions yourself. Think, for example, of what you have done yourself to move forward, how you deal with the rheumatism, and what methods and solutions you have applied.

After this part, you will be invited to provide more information about one or more of the strategies mentioned.

Q6 What self-management strategies do you use, or have you used in the past? Describe the strategy in no more than two or three words.

These can be strategies that you have had good or bad experiences with. Think, for example, of aids, information, mental health, exercise, and so on.

- (1) _____
- (2) _____
- (3) _____
- (4) _____
- (5) _____

Carry Forward Entered Choices - Entered Text from "What self-management strategies do you use, or have you used in the past? Describe the strategy in no more than two or three words. These can be strategies that you have had good or bad experiences with. Think, for example, of aids, information, mental health, exercise and so on. "

Q7 Was this strategy mainly a good or bad experience?

	Good (1)	Bad (2)
(x1)	<input type="radio"/>	<input type="radio"/>
(x2)	<input type="radio"/>	<input type="radio"/>
(x3)	<input type="radio"/>	<input type="radio"/>
(x4)	<input type="radio"/>	<input type="radio"/>
(x5)	<input type="radio"/>	<input type="radio"/>

Q8 Do you have any other self-management strategies that you haven't mentioned yet?

- Yes, I want to name more strategies (1)
- No, I have mentioned everything (2)

Skip To: End of Block If Do you have any more self-management strategies that you haven't mentioned yet? = No, I have mentioned everything

Display This Question:

Do you have any more self-management strategies that you haven't mentioned yet? = Yes, I want to name more strategies

Q9 What self-management strategies do you use, or have you used in the past? Describe the strategy in no more than two or three words.

These can be strategies that you have had good or bad experiences with. Think, for example, of aids, information, mental health, exercise, and so on.

- (1) _____
- (2) _____
- (3) _____
- (4) _____
- (5) _____

Carry Forward Entered Choices - Entered Text from "What self-management strategies do you use, or have you used in the past? Describe the strategy in no more than two or three words. These can be strategies that you have had good or bad experiences with. Think, for example, of aids, information, mental health, exercise, and so on. "

Q10 Was this strategy mainly a good or bad experience?

	Good (1)	Bad (2)
(x1)	<input type="radio"/>	<input type="radio"/>
(x2)	<input type="radio"/>	<input type="radio"/>
(x3)	<input type="radio"/>	<input type="radio"/>
(x4)	<input type="radio"/>	<input type="radio"/>
(x5)	<input type="radio"/>	<input type="radio"/>



Carry Forward Entered Choices - Entered Text from "What self-management strategies do you use, or have you used in the past? Describe the strategy in no more than two or three words. These can be strategies that you have had good or

bad experiences with. Think, for example, of aids, information, mental health, exercise and so on. "

SELF-MANAGEMENT ELABORATION

Q11 Which of these strategies do you want to elaborate upon?

Choose which one and how much you want to work out. Each elaboration takes about 5 minutes.

- (1)
- (2)
- (3)
- (4)
- (5)

Display This Question:

Do you have any more self-management strategies that you haven't mentioned yet? = Yes, I want to name more strategies

Carry Forward Entered Choices - Entered Text from "What self-management strategies do you use, or have you used in the past? Describe the strategy in no more than two or three words. These can be strategies that you have had good or bad experiences with. Think, for example, of aids, information, mental health, exercise and so on. "

Q12 Which of these strategies do you want to elaborate upon?

Choose which one and how much you want to work out. Each elaboration takes about 5 minutes.

- (1)
- (2)
- (3)
- (4)
- (5)

Q13 You will now work out the chosen strategies.

You don't have to answer all the questions if you don't want to.

Q14 What exactly did you do for $\{\text{lm:}/\text{/Field/1}\}$?

Q15 What was the reason you used this strategy called $\{\text{lm://Field/1}\}$?

Q16 When did you do $\{\text{lm://Field/1}\}$?

Consider, for example, how your personal situation and/or the rheumatism situation was: just diagnosed, children, retirement, travel plans.

Q17 What are your experiences with $\{\text{lm://Field/1}\}$?

- Very negative (1)
- Mainly negative (2)
- Mostly positive (3)
- Very Positive (4)



Q18 What went well with the execution of $\{\text{lm://Field/1}\}$?

Q19 What made it possible to start with this strategy ($\{\text{lm://Field/1}\}$)?

- Money/compensation (*for example: "I had enough money"*), because (1)

- Time, (*for example, "I had plenty of time"*) because: (2)

- Support (*for example: "Someone could help me"*) because: (3)

- Knowledge, (*for example, "I have read information"*) because: (4)

- Condition-related, (*for example: "The rheumatism was/was not active"*) because: (5)

- Otherwise, because: (6) _____

Q20 What went wrong with the execution of $\{\text{lm://Field/1}\}$?

Q21 What made it difficult to start with this strategy ($\{\text{lm://Field/1}\}$)?

- Money/compensation, (*for example: "I had no money"*) because: (1)

- Time, (*for example: "I didn't have enough time off"*) because: (2)

- Support, (*for example, "No one could help me"*) because: (3)

- Knowledge, (*for example, "I didn't understand very well what to do"*) because: (4)

- Condition-related, (*e.g., "The rheumatism was/ was not active"*) because: (5)

- Otherwise, because: (6) _____

Q22 Do you want to say something about the strategy $\{\text{lm://Field/1}\}$?

Q23 What exactly did you do for $\{\text{lm://Field/1}\}$?

Q24 What was the reason you used this strategy called $\{\text{lm://Field/1}\}$?

Q25 When did you do $\{\text{lm://Field/1}\}$?



Consider, for example, how your personal situation and/ or the rheumatism situation was: just diagnosed, children, retirement, travel plans.

Q26 What are your experiences with $\{\text{lm://Field/1}\}$?

- Very negative (1)
- Mainly negative (2)
- Mostly positive (3)
- Very Positive (4)

Q27 What went well with the execution of $\{\text{lm://Field/1}\}$?

Q28 What made it possible to execute this strategy ($\{\text{lm://Field/1}\}$)?

- Money/compensation (*For example: I had enough money*), because (1)

- Time, (*for example, "I had plenty of time"*) because: (2)

- Support (*for example: "Someone could help me"*) because: (3)

- Knowledge, (*for example, "I have read information"*) because: (4)

- Condition-related, (*for example: "The rheumatism was/ was not active"*) because: (5)

- Otherwise, because: (6) _____

Q29 What went wrong with the execution of $\${lm://Field/1}$?

Q30 What made it difficult to start with this strategy ($\${lm://Field/1}$)?

- Money/compensation, (*for example: "I had no money"*) because: (1)

- Time, (*for example: "I didn't have time"*) because: (2)

- Support, (*for example, "No one could help me"*) because: (3)

- Knowledge, (*for example, "I didn't really understand what to do"*) because: (4)

- Condition-related, (*For example: "The rheumatism was/was not active"*) because: (5)

- Otherwise, because: (6) _____

Q31 Do you want to say something about this strategy $\${lm://Field/1}$?

DEMOGRAPHICS

Q32 We now ask for some information about your personal situation.

We do this to get a good view of the participants and whether we have reached a good cross-section of people with rheumatism with our questionnaire.

Q33 What is your year of birth?

▼ 1930 (1) ... 2007 (78)

Q34 What is your gender?

- Male (1)
 - Woman (2)
 - I'd rather not say (3)
 - Other, namely: (4)
-

Q35 Do you live alone?

- Yes (1)
- No (2)

Q36 What applies to you?

There are several possible answers.

- I work for a fee (4)
 - I do volunteer work (5)
 - I am a housewife/househusband/caregiver (6)
 - I have taken (early) retirement (AOW, VUT, FPU) (7)
 - I am unemployed/looking for work (registered with the UWV WERKbedrijf) (8)
 - I am incapacitated for work (WAO, WAZ, WIA, Wajong, sickness benefit) (9)
 - I have a social assistance benefit (10)
 - I am in education/I am studying (11)
 - Other, namely: (12)
-

Q37 What is your highest degree?

- None (1)
 - Primary school / primary education (2)
 - MAVO/ MULO/ domestic science school/ VBO (3)
 - HAVO/ HBS (4)
 - VWO/ Atheneum/ Gymnasium (5)
 - MBO/ MTS (6)
 - HBO (7)
 - WO or doctoral (8)
 - Other, namely: (9)
-

Q38 What is your country of birth?

Q39 What is your mother's country of birth?

Q40 What is your father's country of birth?

Q41 How do you feel about your current financial situation?

This information says something about opportunities to buy or deploy self-management strategies that are not free

Rate this on a scale from 0 ("I'm very worried") to 10 ("I'm not worried at all").

	0	1	2	3	4	5	6	7	8	9	10
	(13)	(16)	(17)	(18)	(19)	(20)	(21)	(22)	(23)	(24)	(25)
(6)	○	○	○	○	○	○	○	○	○	○	○

Q42 What form(s) of rheumatism do you have?

There are several answers to this question.

- Psoriatic Arthritis (1)
- Temporal arteritis (2)



- Osteoarthritis (3)
 - Paget's Bone Disease (4)
 - Chondrocalcinosis (5)
 - Raynaud's Phenomenon (132)
 - Fibromyalgia (133)
 - Hypermobility (134)
 - Juvenile rheumatism (JIA) (135)
 - Gout (136)
 - Lupus Erythematosus (137)
 - MCTD (138)
 - Mono-arthritis (139)
 - Myositis (140)
 - Osteoporosis (141)
 - Palindrome rheumatism (142)
 - Reactive Arthritis (143)
 - Rheumatoid arthritis (144)
 - Sarcoidosis (145)
 - Scleroderma (146)
 - Muscular rheumatism (147)
 - Sjogren's syndrome (148)
 - Ankylosing Spondylitis / Axial Spondyloarthritis (149)
 - Forestier's disease (150)
 - Other, namely: (151)
-

Q43 When were you diagnosed with rheumatism?

- Less than a year ago (1)
- 1-2 years ago (2)
- 3-5 years ago (3)

- 6-10 years ago (4)
- 11-20 years ago (5)
- Over 20 years ago (6)
- I don't know anymore (7)

Q44 When did you get your first rheumatism complaints?

- Well before diagnosis (one year or more) (4)
- Around the diagnosis (5)
- I had no complaints (6)
- I don't know anymore (7)

Q45 Do you have any other chronic diseases?

- Yes (1)
- No (2)

Skip To: End of Block If Do you have any other chronic diseases? = No

Q46 What other chronic disease(s) do you have?

CLOSING

Q47 Are there any additional points about self-management that you would like to share with us?

Q48 This is almost the end of the questionnaire. When you go to the next page, your data will be sent. After that, you will be redirected to another website. Do you want to stay informed about the research? Then leave your details there. If not, you can click away from that page. Thank you for participating!

REIS Dissemination channels

The survey was shared with the websites of the Dutch Arthritis Foundation (ReumaNederland), the University of Twente, The National Association of Rheumatic Care Netherlands, Dutch rheumatic patient magazine (Reuma Magazine), the Dutch online care newspaper (de Zorgkrant), The Dutch national association for people with lupus, antiphospholipid syndrome, scleroderma, and mixed connective tissue disease (NVLE: Dutch patient association for Sjögren's syndrome (NVSP), the Dutch association for psoriasis (Psoriasis Vereniging Nederland), the Dutch association for Juvenile Rheumatism Arthritis (Jeugdreuma Vereniging Nederland), the panel from Sint Maartenskliniek and Radboudumc for patients to structurally participate in scientific research (STAP: Key to active participation policy), among members of the citizen science community Citizenlab, through flyers in the waiting rooms of the Sint Maartenskliniek Nijmegen, on LinkedIn, and on personal social media accounts from the researchers.

Appendix 4.2. Demographics

Category	Subcategory	N
Gender	Female	228 (91.2 %)
	Male	22 (8.8 %)
Age	Mean	60
	Range	1933-1999
Educational level	No formal education	1
	Primary education	3
	Pre-vocational secondary education	29
	Senior general secondary education/pre-university education	20
	Secondary vocational education	49
	Higher professional education	103
	University or doctorate	39
	Other	6
Type(s) of Rheumatic condition(s)	Arthritis Psoriatic	20
	Arteritis Temporalis	2
	Arthrosis	148
	Chondrocalcinosis	1
	Raynaud's phenomenon	26
	Fibromyalgia	40
	Hypermobility	23
	Juvenile Idiopathic Arthritis	7
	Gout	7
	Reactive arthritis	2
	Systematic Lupus Erythematosus	7
	MCTD	1
	Myositis	1
	Osteoporosis	12
	Palindromic rheumatism	2
	Rheumatoid arthritis	94
	Sarcoidosis	1
	SCCH/SAPHO	1
	Scleroderma/Systemic Sclerosis	8
	Muscular rheumatism	11
Sjögren's syndrome	24	
Bekhterev disease/ Axial spondylarthritis	6	
Forestier's disease	1	
Tietze's disease	1	
Other	2	
Year(s) living with Rheumatic condition(s)	Less than a year ago	8
	1-2 years ago	13
	3-5 years ago	42
	6-10 years ago	59
	11-20 years ago	69
	More than 20 years ago	56
	I don't remember	3
Comorbidities	Yes	125
	No	125

Appendix 5.1 Full Survey [Translated to English]

COPD questionnaire-Self management

Dear participant,

Thank you for taking the time to fill in the questionnaire manually. We greatly appreciate the effort you are making to achieve this! Once you have completed everything, you can send the questionnaire in the enclosed return envelope to (this is already on the envelope):

[Name organisation]
attn. [name of researcher]
P.O. Box 310
[Postal code] [City]

You have been diagnosed with COPD, you are over 18 years old, and are interested in participating in this study on self-management in COPD. Self-management means that people use different actions or skills, or, for example, use tools. Consciously choosing not to do something is also a form of self-management. All these ways of acting are called strategies. So they are aimed at dealing with the symptoms and consequences of COPD so that you will feel better. It is your own active participation in how to deal with your illness. These strategies can be general, for example, to prevent deterioration, but also after a sudden increase or worsening of symptoms or problems (flare-up). Self-management is not just about 'doing it yourself'. It is also about 'self-determination'. Many people go on self-examination to deal with the consequences of COPD. That probably applies to you, too. With the knowledge and experiences about what helped you and others with COPD – or not! - we help other people in their search. Our research is not aimed at determining what always works for people with COPD. We do want to learn from people what they do and what their experiences are.

The questionnaire

In the questionnaire, we collect your experiences with certain activities, methods, tools, and so on. So we call these strategies. The questionnaire consists of three parts:

1. First, we ask you to briefly and concisely describe a number of strategies or approaches that you have tried. These may be strategies that have worked, but also those that have not worked. This is how we arrive at an overview of recommenders and discouragers.
2. You then answer a number of in-depth questions for each strategy, making it even clearer what the strategy entails.
3. We end the questionnaire with some information about yourself.

Completing the questionnaire will take about 20-30 minutes, but of course, it depends on several factors. The questionnaire largely contains open questions. This means that you can write down the answers yourself in the space provided. In this way, we gain better insight into your considerations and experiences. So your detailed answers matter!

Tips

We ask for an effort, and this may not always be feasible in your situation. We recommend that you complete the questionnaire at a time when you have enough time and energy and are in a quiet environment. You can then think calmly and fill in comfortably. Of course, you are not obliged to participate. Only the questionnaires that are completed until the end are included in the analysis.

RE-SAMPLE

This questionnaire is part of the European RE-SAMPLE project (No 965315). The goal of RE-SAMPLE is to develop a technology that will support patients and caregivers. This technology will help patients manage their COPD and other chronic conditions.

Personal data

The data is stored at Roessingh Research and Development. Your data is well protected. We do not ask you for any traceable information. So: no names, no housing details, or data of others. We think it is important to work openly. That is why we place the anonymized data in an online repository; the paper versions are destroyed after digitization. This means that other researchers can contact us to view this data and use it for scientific research or education. We only give access if the scientific researchers have a suitable question. The results of the study will be published in a scientific journal and, of course, also shared with important organizations that work for and with people with COPD. If you want to be kept informed of the research results, you can share your email address with us. This is stored separately from your answers. If you have any questions about the research, you can contact [name researcher] via [email address researcher]

To use your answers, we need your permission. Would you like to confirm the following claims?

- I hereby declare that I have read the above information and I agree to participate in this study.
- I am 18 years or older and have a form of COPD

Part 1

This part of the questionnaire focuses on the self-management of your COPD. In the following questions, you can name which strategies you want to share. The reason we ask for short strategies first is to make brainstorming easier for you. In the next part we will go into more detail.

Three possible strategies have been chosen to avoid using excessive paper or burdening you with a thick pack of paper. No doubt you have many more strategies. If you would like to share these with us, please contact us by email or letter, or leave your details at the bottom of this document.

Self-management strategies are actions that you perform aimed at dealing with the COPD, complaints and emotions yourself. Think, for example, of what you have done yourself to move forward, how you deal with the COPD and what approaches you have used for this.

What self-management strategies do you use or have you used in the past? Describe the strategy in no more than two or three words. Also, indicate whether it was a good or bad experience.

These can be strategies that you have had good or bad experiences with. Think, for example, of aids, information, mental health, exercise, and so on.

- 1 _____
(1) This was a good/bad experience (cross out what does not apply)
- 2 _____
(2) This was a good/bad experience (cross out what does not apply)
- 3 _____
(3) This was a good/bad experience (cross out what does not apply)

Part 2

You will now work out the chosen strategies. Write down the strategy from part 1 again. *You don't have to answer all the questions if you don't want to.*

Strategy 1:

Q1: What exactly did you do for strategy 1?

Q2: What was the reason you used strategy 1?

Q3: When did you do strategy 1?

Consider, for example, how your personal situation and/or the situation of the COPD was: just diagnosed, children, retirement, travel plans.

Q4: What are your experiences with strategy 1?

- Very negative
- Mainly negative
- Mostly positive
- Very positive

Q5: What went well with the implementation of strategy 1?

Q6: What made it possible to start with strategy 1? *You only have to give an answer to the options you tick.*

- Money/compensation (*for example: "I had enough money"*), because _____
- Time, (*for example: "I had enough time"*) because: _____
- Support (*for example: "Someone could help me"*) because: _____
- Knowledge (*for example, "I have read information"*) because: _____
- Condition-related (*For example: "The COPD was/was not active"*) because: _____
- Emotional/ Mental (*For example: accepting the new situation*) because: _____
- Otherwise, because: _____

Q7: What went wrong with the implementation of strategy 1?



Q8: What made it difficult to start with strategy 1 with this strategy?

You only have to give an answer to the options you tick.

- Money/compensation, (*for example: "I had no money"*) because:

- Time, (*for example: "I didn't have enough time off"*) because:

- Support, (*for example: "No one could help me"*) because:

- Knowledge, (*for example: "I didn't really understand what to do"*) because:

- Condition-related, (*e.g., "The COPD was/was not active"*) because:

- Emotional/Mental, (*For example: an unexpected event in the family*), because:

- Otherwise, because:

Q9: Is there anything else you would like to say about strategy 1?

Strategy 2:

Q1: What exactly did you do for strategy 2?

Q2: What was the reason you used strategy 2?

Q3: When did you do strategy 2?

Consider, for example, how your personal situation and/or the situation of the COPD was: just diagnosed, children, retirement, travel plans.

Q4: What are your experiences with strategy 2?

- Very negative
- Mainly negative
- Mostly positive
- Very positive

Q 5: What went well with the implementation of strategy 2?

Q6: What made it possible to start with strategy 2?

You only have to give an answer to the options you tick.



- Money/compensation (*for example: "I had enough money"*), because

- Time, (*for example: "I had enough time"*) because:

- Support (*for example: "Someone could help me"*) because:

- Knowledge (*for example, "I have read information"*) because:

- Condition-related (*For example: "The COPD was/was not active"*) because:

- Emotional/Mental (*For example: accepting the new situation*) because:

- Otherwise, because: _____

Q7: What went wrong with the implementation of strategy 2?

Q8: What made it difficult to start with strategy 2 with this strategy?

You only have to give an answer to the options you tick.

- Money/compensation, (*for example: "I had no money"*) because:

- Time, (*for example: "I didn't have enough time off"*) because:

- Support, (*for example: "No one could help me"*) because:

- Knowledge (*for example: "I didn't really understand what to do"*) because:

- Condition-related (*e.g., "The COPD was/was not active"*) because:

- Emotional/Mental (*For example: an unexpected event in the family*), because:

- Otherwise, because:

Q9: Is there anything else you would like to say about strategy 2?

Strategy 3:

Q1: What exactly did you do for strategy 3?

Q2: What was the reason you used strategy 3?

Q3: When did you do strategy 3?

Consider, for example, how your personal situation and/or the situation of the COPD was: just diagnosed, children, retirement, travel plans.

Q4: What are your experiences with strategy 3?

- Very negative
- Mainly negative
- Mostly positive
- Very positive



Q5: What went well with the implementation of strategy 3?

Q 6: What made it possible to start with strategy 3?

You only have to give an answer to the options you tick.

- Money/compensation (*for example: "I had enough money"*), because

- Time, (*for example: "I had enough time"*) because:

- Support (*for example: "Someone could help me"*) because:

- Knowledge (*for example, "I have read information"*) because:

- Condition-related (*For example: "The COPD was/was not active"*) because:

- Emotional/Mental (*For example: accepting the new situation*) because:

- Otherwise, because:

Q7: What went wrong with the implementation of strategy 3?

Q8: What made it difficult to start with strategy 3 with this strategy?

You only have to give an answer to the options you tick.

Money/compensation, (for example: "I had no money") because:

Time, (for example: "I didn't have enough time off") because:

Support, (for example: "No one could help me") because:

Knowledge (for example: "I didn't really understand what to do") because:

Condition-related (e.g., "The COPD was/was not active") because:

Emotional/Mental (For example: an unexpected event in the family), because:

Otherwise, because:

Q9: Is there anything else you would like to say about strategy 3?

Part 3

We now ask for some information about your personal situation.

We do this to get a good picture of the participants and whether we have reached a good cross-section of people with COPD with our questionnaire.

Q1: What is your year of birth? _____

Q2: What is your gender?



- Male
- Female
- I'd rather not say
- Other, namely: _____

The following four questions are asked because it provides an insight into the social context of the person with COPD.

You can imagine that someone who lives alone may have to practice more self-management than if they live together. This is may also the case if you live on the countryside, for example. All of this could have consequences for your self-management.

Q 3: What does your family situation look like?

- I live alone
- I live with a partner
- I live with partner and child(ren)
- I live with my child(ren)
- I'd rather not say
- Other, namely _____

Q4: What does your living environment look like?

- I live in a remote area
- I live in a regular house in a neighbourhood (flat, terraced house, semi-detached house, detached house)
- I live in a complex intended for a specific target group (senior flat, nursing home, 'name nursing home')
- I'd rather not say
- Other, namely _____

Q5: How would you describe your social life?

- I am among people every day
- I'm among people every other day
- I am among people 1 or 2 times a week
- I am mostly on my own
- I'd rather not say
- Other, namely _____

Q 6: What applies to you?

There are several possible answers.

- I work for a fee
- I do volunteer work

- I am a housewife/househusband/caregiver
- I have taken (early) retirement (AOW, VUT, FPU)
- I am unemployed/looking for work (registered with the UWV-WERKbedrijf)
- I am incapacitated for work (WAO, WAZ, WIA, Wajong, sickness benefit)
- I have a social assistance benefit
- I am in education/I am studying
- I'd rather not say
- Other, namely: _____

Q 7: What is your highest diploma?

The answer to this question makes it possible to investigate whether education plays a role in the self-management of COPD.

- No
- Primary school/primary education
- MAVO/ MULO/ domestic science school/ VBO
- HAVO / HBS
- VWO/ Atheneum/ Gymnasium
- MBO/ MTS
- HBO
- WO or doctoral degree
- I'd rather not say
- Other, namely: _____

The following 3 questions may give an insight into cultural differences.

You can imagine that people from countries where, from their culture, always 3 generations live together, deal differently with their self-management. For example, there may also be a difference between how people deal with COPD (or look to a doctor, for example) when someone grew up in a certain country.

Q8: What is your country of birth?

Q9: What is your mother's country of birth?

Q10: What is your father's country of birth?



Q11: How do you feel about your current financial situation?

This information says something about opportunities to buy or deploy self-management strategies that are not free. It does not necessarily refer to the actual situation but to your feelings.

Indicate on a scale from 0 ("I am very worried") to 10 ("I am not worried at all").

	0	1	2	3	4	5	6	7	8	9	10
		○	○	○	○	○	○	○	○	○	○

Q12: What stage of COPD do you have?

- GOLD stage 1
- GOLD stage 2
- GOLD stage 3
- GOLD stage 4
- I don't know

Q 14: When were you diagnosed with COPD?

- Less than a year ago
- 1-2 years ago
- 3-5 years ago
- 6-10 years ago
- 11-20 years ago
- More than 20 years ago
- I don't know anymore

Q15: When did you get your first COPD symptoms?

(For example: Shortness of breath, coughing, coughing up mucus, shortness of breath, fatigue, little muscle strength, weight change, etc.)

- Well before diagnosis (one year or more)
- Around the diagnosis
- I had no complaints
- I don't know anymore

The next two questions can make you feel like they are the same, this is not the intention.

An example: You may have been diagnosed with COPD two years ago. Still, you feel very good at the moment. This is your own opinion, not based on a medical specialist. At the same time, you can worry now about what will happen to you in 10 years.

Q 16: How do you assess your own health at the moment?

Rate this on a scale from 0 ("My health is very bad") to 10 ("My health is very good").

	0	1	2	3	4	5	6	7	8	9	10
		○	○	○	○	○	○	○	○	○	○

Q17: To what extent are you worried about your health at the moment?

Rate this on a scale from 0 ("I'm very worried") to 10 ("I'm not worried at all").

	0	1	2	3	4	5	6	7	8	9	10
		○	○	○	○	○	○	○	○	○	○

Q18: Do you have any other chronic diseases?

- Yes
- No
- I'd rather not say

Q19: If so, what other chronic disease(s) do you have?

- Cardiovascular disease
- Diabetes
- Osteoporosis
- Depression and anxiety
- Gastroesophageal reflux disease (GERD)
- Sleep disorders
- Hypertension (high blood pressure)
- Weight loss and/or nutritional problems
- Muscle weakness and sarcopenia
- Rheumatoid arthritis or other autoimmune diseases
- I'd rather not say
- Other, namely: _____



Q20: Are there any additional points about self-management that you would like to share with us?

This is the end of the questionnaire. Thank you for participating! Would you like to stay informed about the research or participate in follow-up research or if you want to share more strategies with us? If so, leave your details here.

- Yes, I would like a summary of the research results
- Yes, you can contact me for follow-up research
- Yes, I want to share more strategies

Name: _____

Email: _____

Phone number (if you don't have an email): _____

Appendix 5.2. Demographics

Category	Subcategory	N	
Gender	Woman	19	
	Male	13	
	Prefer not to say	1	
Age	Mean	70	
	Range	1938 - 1968	
GOLD	GOLD 2	9	
	GOLD 3	10	
	GOLD 4	11	
	Don't know	5	
Year(s) living with COPD	Less than a year ago	1	
	1-2 years ago	4	
	3-5 years ago	6	
	6-10 years ago	7	
	11-20 years ago	7	
	More than 20 years ago	8	
Comorbidities	Yes	19	
	No	14	
Social life	I'm among people daily	19	
	I'm among people every other day	1	
	I am among people once or twice a week	6	
	I'm mostly on my own	5	
	Prefer not to say	1	
	Other	1	
Concerns about financial status	Mean	6,75	
	Median	7	
	Range	0-10	
Educational level	Pre-vocational secondary education	8	
	Senior general secondary education/pre-university education	4	
	Secondary vocational education	8	
	Higher professional education	8	
	University or doctorate	1	
	Other	3	
	Prefer not to say	1	
Cultural background	Own native country	The Netherlands	33
	Native country father	The Netherlands	30
		Germany	1
		Indonesia	1
		Other	1
	Native country Mother	The Netherlands	31
		Belgium	1
	Other	1	

Appendix 6.1: Detailed Information of the Participatory Design Process

Study round 2: Problem exploration

Time	Subject	Explanation	Supplies
Fill in / Provide (online) IC before the start of the study			
5 min	Introduction	Welcome and discuss today's goal. Briefly explain self-management and self-management support. Then do a short introduction round.	IC, recorders, PowerPoint presentation
<p>Note: After the introduction round, ask for permission to start recording and start recording.</p>			
Start recording			
20 min	Current situation (general)	Participants are asked to think about where and when they received support for self-management, and have them write this down on a sticky note. <ul style="list-style-type: none"> - <i>What support have you received?</i> - <i>When was this support</i> (at what stage of the disease) - <i>Who was involved?</i> <p>Time schedule:</p> <ul style="list-style-type: none"> - 5-minute explanation - 8 minutes to write down - 12 minutes to discuss 	Sticky notes, pens
10 min	Patient journey	Explain that every disease goes through a number of phases that everyone who has this disease recognises. Ask participants which phases they would name for their COPD. Writing these different phases on an A3 (1 phase per A3) <ul style="list-style-type: none"> - <i>Which phases would they categorise?</i> <p><i>Possibly in case of low response:</i> Showing the patient journey and complementing it.</p> <ul style="list-style-type: none"> - <i>What is missing here? Is this recognizable? What needs to change?</i> 	Blank A3 sheets

10 min	Current situation (Patient journey)	Then have the participants place the support (as filled in for the current situation) in the different phases.	A3 with patient journey phases, empty A3 for new/extra phases, sticky notes
20 min	Desired situation (patient journey)	If we now look at the ideal situation for self-management support for COPD/ RMDs in the different phases, what would it look like? Note: Use the newly defined patient journey (rewriting phases on paper) to which the participants can stick sticky notes.	Patient journey phases A3, Empty A3 for new/extra phases, sticky notes
20 min	Support	Let people name how they want to be offered that support. They can place a number of example cards with different shapes on the sticky notes. There are also blank cards available on which they can write something themselves. - <i>In what form would you like to see the support for self-management?</i>	Cards with support forms and actors, blank cards, and tape
5 min	Closing	Closing the session, naming next steps, and thanking people for participating.	PowerPoint, gifts



Study round 3: Online survey- Translated to English

Dear healthcare provider, for a study into the self-management of chronic conditions, we are looking for your opinion! *With self-management, we mean all actions, actions, or behaviours aimed at dealing with symptoms and consequences of the condition for the well-being and active participation of someone with a chronic condition.* Self-management is not just about 'doing it yourself'. It is also about 'self-determination'. This concept is not always known to everyone, and people with chronic conditions often do their own research to see which self-management strategies suit them. As a result, people often spend a very long time on their search before they can benefit from the positive effects of self-management. We would like to support this process a little more.

After several studies on self-management from the patient's perspective, the next step is to develop a solution from the patient to the healthcare provider, together with people with chronic conditions. This includes sharing the insights and self-management strategies obtained from the patients themselves, the experiences of the different phases during the patient journey, moments in which they have needed self-management support, and more. The next step is to give concrete shape to this solution. To be able to do this, we created a **short questionnaire** so that we can also include your perspective, that of the healthcare provider, in the development of this solution.

This is an anonymous questionnaire, and we do not ask you for any traceable information. So: no names, no housing details, or data of others. Your data is well protected and is stored at Roessingh Research and Development. The results of the study will be published in a scientific journal.

If you have any questions about the study, please contact [name of researcher] at [email researcher]

Q1

- Yes, I hereby declare that I have read the above information and I agree to participate in this study

Q2 Are you 18 years of age or older and working as a caregiver

- Yes, I am 18 years or older and working as a caregiver
- No, I am not 18 years of age or older and not a healthcare provider

Q3 What kind of caregiver are you?

Q4 In which target group do you work?

Q5 *The content of 'the solution' includes: sharing the insights and self-management strategies obtained from the patients themselves, the experiences of the different phases during the patient journey, and moments in which people with a chronic condition have needed self-management support.*

Q6 What form would you prefer for the solution?

- Information leaflet
- Handbook
- Video
- Animation
- Poster
- Infographic
- e-learning module
- Other, namely _____

Q7 Where should this solution be available?

- My organization's intranet
- Online via a website
- In my own possession
- Other, namely _____

Q8 How much time do you want to spend going through the solution?

- 5 to 10 minutes
- 10 to 30 minutes
- 30 minutes or more
- Other, namely _____

Q9 What would you use this solution for?

- To increase my knowledge
- Preparing for a consultation
- During a consultation
- Other, namely _____

QPerceived usefulness I find this solution useful

- Totally agree (1)
- Agree (2)
- Neutral (3)
- Disagree (4)
- Strongly disagree (5)

QIntention-to-use If this solution is available I would use this

- Totally agree (1)
- Agree (2)
- Neutral (3)
- Disagree (4)
- Strongly disagree (5)

Study round 4: Solution preferences

Time	Subject	Explanation	Supplies
<i>Fill in / Provide (online) IC before the start of the study</i>			
5 min	Introduction	Welcome and discuss today's goal. Briefly explain about self-management and self-management support. Then do a short introduction round. Note: After the introduction round, ask for permission to start recording and start recording.	IC, recorders, PowerPoint presentation
<i>Start recording</i>			
5 min	Retrospect	Brief reflection of previous focus groups, explaining what came out of them and what the next steps are. Discuss today's goal: 'Today's goal is to come up with concrete input for 'the solution' that we are going to develop. In the following, we will first talk about the content of the solution and then discuss the form. Ask if people agree with this. <i>Invite participants to name crazy ideas as well; video, hologram.</i>	PowerPoint presentation
20 min	Content-conveying something	Give everyone Sticky notes. Answer the following questions: 1. What are the signs that the doctor does not understand/does not know what it is like to live with COPD/RMDs <i>(for example, something you had to repeat a lot)</i> 2. What do people not understand/know because they do not have the disease? 3. What should we teach doctors/caregivers? 4. Is that enough to help you do self-management or is more needed?	Sticky notes, pens
20 min	Content-Knowledge studies	What knowledge is important from our previous studies to share? <i>Create an accessible overview of the most important results of:</i> - Scoping review results	PowerPoint Presentation

		<ul style="list-style-type: none"> - Qualitative study survey results - Focus groups, phases, themes, etc. 	
10 min	Form- Open	<p>What is the best form for the solution? [Open-ended question]</p> <ul style="list-style-type: none"> - <i>Invite participants to be as creative as possible; all ideas are welcome. Giving people time to come up with ideas for themselves first. Then grab a big flipchart and write down all the ideas.</i> 	PowerPoint presentation Flipchart or A3 form
		<p>Participants can: Name, write, draw, 'be creative'</p>	
	Form examples HCPs	<p>Then several examples of forms that come from the questionnaire of HCPs, and which were mentioned the most:</p> <ul style="list-style-type: none"> - Video message, campaign, flyers, booklet, manual, storytelling, etc. <p>Is there anything missing from the list we have written down so far?</p>	PowerPoint, cards with HCP ideas
10 min	Form- prioritization	<p>After the first ideas have been formed, the ideas must be sorted. In other words, there must be a concrete idea from this focus group that we can work with. That's why it's important to prioritize ideas during this next step.</p> <p>The possible forms that are mentioned in the first assignment need to be prioritized</p> <ul style="list-style-type: none"> - What will this idea look like in concrete terms? - How long should a healthcare provider take to do it? - When to use this with a healthcare provider? - What can be an advantage/disadvantage of this idea? - What is needed for this? 	PowerPoint, cards with ideas
5 min	Closing	<p>Room for other comments/questions, closing the session, naming next steps, and thanking people for participating.</p>	PowerPoint, presents

Screenshots of Prototype V1



DE ZOEKTOCHT NAAR ZELFMANAGEMENT

Zelfmanagement
Zelfmanagement is het omgaan met symptomen, behandelingen, fysieke, sociale en emotionele gevolgen en veranderingen in iemand's levensstijl. Het is jouw eigen actieve deelname aan jouw gezondheid. Het gaat niet alleen over het 'zelf doen', maar ook over het 'zelf begrijpen'.

Mensen kunnen met zelfmanagement verschillende acties of vaardigheden gebruiken of bijvoorbeeld gebruik maken van hulpmiddelen. Het bewust kiezen om iets niet te doen, is ook een vorm van zelfmanagement. Al deze manieren van handelen, noemen we aanpakken. Ze zijn dus gericht op het omgaan met symptomen en gevolgen van jouw aandoening zodat jij je beter gaat voelen. Zelfmanagement is een breed begrip en veel voorbeelden van aanpakken zijn te bedenken: sporten, wandelen, gezonde voeding, hulpmiddelen, en energie balans.

Zelfmanagement is heel persoonlijk: wat voor de een helpt kan voor de andere juist niet werken. Zelfmanagement doe je niet binnen één dag, het is een zoektocht en door het uitproberen van verschillende aanpakken ervaar je wat wel of niet voor je werkt. Deze zelfmanagement kaart helpt je in dat proces. Het is een eerste stap richting zelfmanagement. Het helpt je, door het beantwoorden van een aantal vragen, stil te staan bij de dingen die jij belangrijk vindt in je leven. Daarnaast helpt het een stap te maken om zelfmanagement uit te voeren door doelen en acties op te stellen.

Hoe te gebruiken?
Kruis eerst op pagina 2 de onderwerpen aan die je op dit moment wilt vullen. Vul vervolgens op de pagina's 3 t/m 5 de vragen in bij de onderwerpen die je hebt aangekruist. Deze vragen helpen je om te bepalen wat op dit moment belangrijk voor je is. Vervolgens kijk je op pagina's 6 en 7 naar zelfmanagement en stel je doelen en acties op om de komende periode aan te werken. Na het uitproberen van deze doelen kijk je op een later moment terug, en vul je de terugblik vragen in.

Het is aan jou hoe je deze kaart wilt toepassen: Je kunt het voor jezelf gebruiken door stil te staan wat voor jou belangrijk is en waar je aan kan werken. Je kunt ook overwegen deze kaart te gebruiken tijdens je volgende consult met je zorgverlener. Deze kaart kan dan een uitgangspunt zijn voor waar zij het over wilt hebben. Hoe je deze kaart ook gebruikt, dit is jouw proces naar zelfmanagement, en de keuze ligt dus bij jou!

Tip: leren van anderen
Ben je nieuwsgierig over wat andere mensen uitprobeerde hebben voor hun zelfmanagement? Ga dan naar www.XXXX.nl en lees hier de resultaten van twee onderzoeken naar zelfmanagement strategieën in het dagelijkse leven van mensen met COPD en Reuma. Let op: deze pagina geeft inzicht in wat mensen zelf hebben geprobeerd, we kunnen geen claims doen over de effectiviteit van deze strategieën.

Wil je meer informatie over zelfmanagement? Kijk dan de video op www.XXXX.nl

1

MIJN ZELFMANAGEMENT KAART

Instructie: Kruis allereerst de onderwerpen aan die je in wilt vullen. De categorieën mijn zelfmanagement, mijn doelen, mijn acties en mijn terugblik vul je altijd in.

<input type="checkbox"/>	Mijn plezier	<input type="checkbox"/>	Mijn mentale gezondheid
<input type="checkbox"/>	Mijn lichaam	<input type="checkbox"/>	Mijn omgeving
<input type="checkbox"/>	Mijn dagelijkse bezigheden	<input type="checkbox"/>	Mijn verwachtingen
<input type="checkbox"/> Mijn zelfmanagement <input type="checkbox"/> Mijn doelen <input type="checkbox"/> Mijn acties <input type="checkbox"/> Mijn terugblik			

2



Mijn plezier

- Wat geeft mij energie of plezier?

- Ik vind het belangrijk om de volgende dingen te (blijven) doen:

- Dit wil ik graag:

Mijn lichaam

- Hoe gaat het lichamelijk met mij?

- Dit heb ik nodig om in balans te blijven:

- Dit vind ik belangrijk:

Mijn mentale gezondheid

- Hoe gaat het mentaal met mij?

- Dit vraagt op dit moment mijn aandacht:

- Dit vind ik belangrijk:

Mijn omgeving

- Hoe is mijn sociale leven?

- Op welke manieren voel ik mij gesteund door mijn omgeving?

- Dit heb ik nodig:

3

4

Mijn dagelijkse bezigheden

- Wat doe ik dagelijks?

- Zijn er onderdelen van mijn dagelijks leven die ik beter aan kan pakken:

- Dit heb ik nodig:

Mijn zelfmanagement

- Wat doe ik al aan zelfmanagement?

- Wat wil ik graag de komende periode uitproberen?

- Welke kennis en hulpmiddelen heb ik nodig om dit te doen?

Mijn verwachtingen

- Hoe verwacht ik dat anderen omgaan met mijn aandoening?

- Hoe kunnen anderen mij het beste ondersteunen in dit proces?

- Dit moet ik communiceren aan (bijvoorbeeld zorgverlener, omgeving):

Mijn doelen

- Ik wil de komende periode graag werken aan het volgende zelfmanagement doel:

- Wanneer is dit doel behaald?

- De onderwerpen die ik hierboven heb ingevuld passen bij dit doel omdat:

5

6

Study round 5: Initial feedback

Time	Subject	Explanation	Supplies
Fill in / Provide (online) IC before the start of the study			
5 min	Introduction	<p>Welcome and discuss today's goal. Then do a short introduction round.</p> <p>Note: After the introduction round, ask for permission to start recording and start recording.</p>	IC, recorders, PowerPoint presentation
<i>Start recording</i>			
5 min	Retrospect	<p>Brief reflection of previous focus groups, explaining what came out of them.</p> <p>Discuss today's goal: Today's goal is to give feedback on the tool we developed. We will use this feedback to design another version of the prototype.</p>	PowerPoint presentation
10 min	<i>Show the tool and explain its different parts</i>		
10 min	Feedback-Content-	<p>Explain that participant get a few minutes to write their feedback about the content on sticky notes. After a few minutes, the feedback will be discussed plenary. (In case of online, let them think first, use a slide with different notes on it. The researcher will write down the feedback on the sticky notes in the slide when discussing the feedback plenary.)</p> <p>Questions to ask: What do you think about the content of the tool? <i>Think, for example, about whether something is missing, what you like, what you dislike</i></p>	PowerPoint Presentation
10 min	Feedback-Form	<p>Explain that participant get a few minutes to write their feedback about the form on sticky notes. After a few minutes, the feedback will be discussed plenary. (In case of online, let them think first, use a slide with different notes on it. The researcher will write down the feedback on the sticky notes in the slide when discussing the feedback plenary.)</p> <p>Questions to ask: What do you think about the form of the tool? <i>Think, for example, about the use of colour, space to write down things, looks, etcetera.</i></p>	PowerPoint presentation Flipchart or A3 form

5 min General Are there any other comments about the tool that PowerPoint, we haven't discussed so far?

Screenshots of Prototype V2



DE ZOEKTOCHT NAAR ZELFMANAGEMENT

Zelfmanagement
Zelfmanagement is het omgaan met symptomen, behandelingen, fysieke, sociale en emotionele gevolgen en veranderingen in iemand's levensstijl. Het is jouw eigen actieve deelname aan jouw gezondheid. Het gaat niet alleen over het 'zelf doen', maar ook over het 'zelf bepalen'.

Mensen kunnen met zelfmanagement verschillende acties of vaardigheden gebruiken of bijvoorbeeld gebruik maken van hulpmiddelen. Het bewust kiezen om iets niet te doen, is ook een vorm van zelfmanagement. Al deze manieren van handelen, noemen we aanpakken. Ze zijn dus gericht op het omgaan met symptomen en gevolgen van jouw aandoening zodat jij je beter gaat voelen. Zelfmanagement is een breed begrip en veel voorbeelden van aanpakken zijn te bedenken: sporten, wandelen, gezonde voeding, hulpmiddelen, en energie balans.

Zelfmanagement is heel persoonlijk: wat voor de een helpt kan voor de andere juist niet werken. Zelfmanagement doe je niet binnen één dag, het is een zoektocht en door het uitproberen van verschillende aanpakken ervaar je wat wel of niet voor je werkt. Deze zelfmanagement kaart helpt je in dat proces. Het is een eerste stap richting zelfmanagement. Het helpt je, door het beantwoorden van een aantal vragen, stil te staan bij de dingen die jij belangrijk vindt in je leven. Daarnaast helpt het een stap te maken om zelfmanagement uit te voeren door doelen en acties op te stellen.

Hoe te gebruiken?
Deze kaart bestaat uit drie verschillende fases. In **Fase 1** kruis je eerst onderwerpen aan die je op dit moment in wilt vullen. Vervolgens vul je de vragen in bij de onderwerpen die je het meest aankruist. Deze vragen helpen je om te bepalen wat op dit moment belangrijk voor je is. In **Fase 2** stel je zelfmanagement doelen en acties op om de komende periode aan te werken. Na het uitproberen van deze doelen kijk je hier in **Fase 3** op terug, en vul je de terugblik vragen in. Na het doorlopen van de fases kun je weer starten met Fase 1 of doorgaan naar Fase 2. Deze kaart kun je zien als een proces en kan je continue gebruiken.

Het is aan jou hoe je deze kaart wilt toepassen: je kunt het voor jezelf gebruiken door stil te staan wat voor jou belangrijk is en waar je aan kan werken. Je kunt ook overwegen deze kaart te gebruiken tijdens je volgende consult met je zorgverlener. De ingevulde kaart kan dan een uitgangspunt zijn voor waar jij het over wilt hebben. Hoe je deze kaart ook gebruikt, dit is jouw proces naar zelfmanagement, en de keuze ligt dus bij jou!

Tip: leren van anderen
Ben je nieuwsgierig over wat andere mensen uitgeprobeerd hebben voor hun zelfmanagement? Ga dan naar www.xxxx.nl en lees hier de resultaten van twee onderzoeken naar zelfmanagement strategieën in het dagelijkse leven van mensen met COPD en Ruma. Let op: deze pagina geeft inzichten in wat mensen zelf hebben geprobeerd, we kunnen geen claims doen over de effectiviteit van deze strategieën.

Wil je meer informatie over zelfmanagement? Kijk dan de video op www.xxxx.nl.



Doorlopende fases

Fase 1: Voorbereiding

Tijdens de eerste fase (**Voorbereiding**) kijk je naar wat belangrijk voor je is. Allereerst kruis je de onderwerpen aan op **pagina 4** die je graag wilt uitwerken. Je mag zelf weten hoeveel onderwerpen je aankruist. Vervolgens vul je de vragen die bij de aangekruiste onderwerpen op **pagina's 5 t/m 7**. Deze vragen zullen je helpen na te denken over wat er momenteel speelt in je leven, wat je belangrijk vindt en wat je nodig hebt.

Fase 2: Uitvoering

Tijdens de tweede fase (**Uitvoering**) ga je acties en doelen opstellen zodat je daadwerkelijk een zelfmanagement aanpak kunt uitvoeren. Je kunt er voor kiezen om deze opgestelde doelen bespreekbaar te maken met je zorgverlener zodat jullie samen concreet kunnen kijken hoe je de uitvoering aan kan pakken. Je kunt er ook voor kiezen om zelf, bijvoorbeeld met behulp van geverfideerde bronnen (zoals Longfonds, reumaNederland), de opgestelde doelen uit te voeren.

Fase 3: Terugblik

Tot slot ga je, na een zelf bepaalde tijd, in de laatste fase (**Terugblik**) kijken naar je opgestelde doelen. Door de vragen in deze fase in te vullen op **pagina 11** kijk je terug op wat er goed ging, wat er niet zo goed ging, en wat je de volgende keer anders kan doen. Dit geeft een mogelijkheid om nieuwe acties en doelen op te stellen en te leren van je uitgevoerde zelfmanagement aanpak. Je kunt aan de hand van je terugblik weer nieuwe doelen en acties opstellen.

Zie 'mijn zelfmanagement kaart' als een proces. Je kan deze kaart dus ook zo vaak gebruiken als je wilt. Onderwerpen die bijvoorbeeld nu belangrijk voor je zijn kunnen veranderen over tijd, en ook doelen en acties kunnen veranderen naar mate je ervaring op doet met een bepaalde zelfmanagement aanpak. Zo kun je dus meerdere keren door de verschillende fases heen lopen.





Fase 1: Vorbereiding

Instructie: Kruis allereerst de onderwerpen aan die je in wilt vullen. Kies bijvoorbeeld onderwerpen die nu belangrijk voor je zijn of waar je aan wilt werken. Je kunt zoveel onderwerpen aankruisen als je zelf wilt. Vul vervolgens op pagina's 5 t/m 7 de vragen in die bij de aangekruiste onderwerpen horen.

3

MIJN ONDERWERPEN

<input type="checkbox"/> Mijn plezier	<input type="checkbox"/> Mijn mentale gezondheid
<input type="checkbox"/> Mijn lichaam	<input type="checkbox"/> Mijn omgeving
<input type="checkbox"/> Mijn dagelijkse bezigheden	<input type="checkbox"/> Mijn zelf-management verwachtingen

Mijn plezier

- Wat geeft mij energie of plezier?

- Ik vind het belangrijk om de volgende dingen te (blijven) doen:

- Dit wil ik graag:

Mijn mentale gezondheid

- Hoe gaat het mentaal met mij?

- Dit vraagt op dit moment mijn aandacht:

- Dit vind ik belangrijk voor mijn mentale gezondheid:

4

5

Mijn lichaam

- Hoe gaat het lichamelijk met mij?

- Dit heb ik nodig om in balans te blijven:

- Dit vind ik belangrijk voor mijn lichaam:

6

Mijn dagelijkse bezigheden

- Wat doe ik dagelijks?

- Zijn er onderdelen van mijn dagelijks leven die ik beter aan kan pakken:

- Dit heb ik nodig voor mijn dagelijkse bezigheden:

7

Mijn omgeving

- Hoe is mijn sociale leven?

- Op welke manieren voel ik mij gesteund door mijn omgeving?

- Hoe kunnen anderen mij ondersteunen?

Mijn zelfmanagement verwachtingen

- Wat doe ik al aan zelfmanagement?

- Hoe verwacht ik dat zelfmanagement mij gaat helpen?

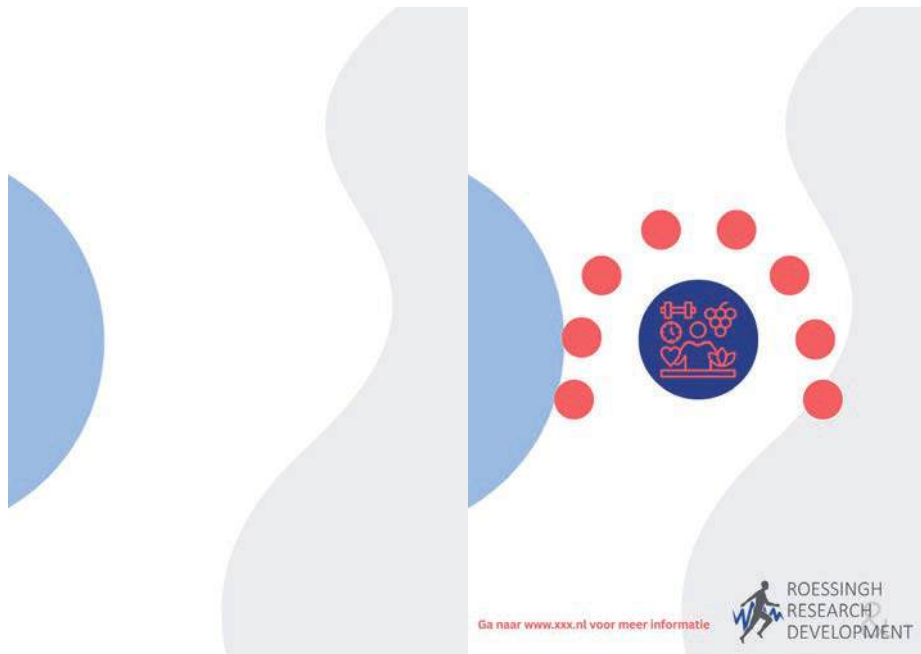
- Welke zelfmanagement aanpak wil ik graag de komende periode uitproberen?

Fase 2: Uitvoering

Instructie: Vul concrete doel(en) en acties in die passen bij de onderwerpen die je hebt ingevuld. Je kunt er voor kiezen om de ingevulde acties en doelen te bespreken met je zorgverlener of om zelf aan de slag te gaan met bijvoorbeeld hulp van geverifieerde bronnen (Zoals ReumaNederland en Longfonds)

8





Study round 6: Think-aloud test

Time	Subject	Explanation	Supplies
Fill in / Provide (online) IC before the start of the study			
5 min	Introduction	Welcome and discuss today's goal. Think-aloud: Removing mistakes and difficulties.	IC, recorder, flyer
Start recording			
Ask to go through the tool while thinking aloud.			
<i>While going through the map, I ask you to think aloud. This includes reading out loud, saying out loud what you are doing, or what you run into, or what you don't understand, for example.</i>			
5 min	Looking back - First impression	Questions to ask: <ul style="list-style-type: none"> - What is your first impression of the map? - What do you think of the topics mentioned in the map? What would you do differently? Are you missing something? - What do you think of the questions that are asked? Is something missing?/What do you like? 	Self-management card



		- [Questions such as: This is what I need, this is important to me? What would help you more to convert something into a self-management strategy?]	
5 min	Form- Practical	If we look at the practical side: - What do you think of the shape of the card? - Is the explanation clear? - Is there enough space to write? - What would you do differently? - Would you like to fill this in online or on paper? - How should we offer this? Where should it be available?	Self-management card
5 min	Form - Layout	If we look at the layout: - What do you think of it? - What do you think of the use of colour? Is it clear that the three colours are three phases? - Is something missing/should something be done differently?	Self-management card
5 min	Closing	Room for other comments/questions, closing the session, naming next steps, and thanking for participation.	PowerPoint, presents

Screenshots of Prototype V3



DE ZOEKTOCHT NAAR ZELFMANAGEMENT

Zelfmanagement is het omgaan met symptomen, behandelingen, fysieke, sociale en emotionele gevolgen en veranderingen in iemand's levensstijl. Het is jouw **eigen actieve deelname** aan jouw gezondheid. Het gaat niet alleen over het 'zelf doen', maar ook over het 'zelf bepalen'.

Je kunt verschillende acties of vaardigheden gebruiken of gebruik maken van hulpmiddelen. Het bewust kiezen om iets niet te doen, is ook een vorm van zelfmanagement. Al deze manieren noemen we aanpakken. **Ze zijn gericht op het omgaan met symptomen en gevolgen van jouw aandoening zodat jij je beter gaat voelen.** Het is een breed begrip en veel voorbeelden zijn te bedenken, bijvoorbeeld:

- Gezonde voeding
- Sperten
- Medicatie
- Hulpmiddelen
- Energie verdeling
- Mindfulness
- Wandelen
- Informatie zoeken
- Alternatieve medicatie
- Voeding en supplementen

Zelfmanagement is heel persoonlijk: wat voor de een helpt kan voor de ander juist niet werken. Je doet het dan ook niet binnen één dag, het is een zoektocht en door het uitproberen ervaar je wat wel of niet voor je werkt. Deze **zelfmanagement reis** helpt je in dat proces. **Het is een eerste stap richting zelfmanagement.**

1

TIP:
Leer van anderen



Wil je meer informatie over zelfmanagement of ben je nieuwsgierig wat andere mensen zelf hebben uitgeprobeerd? Kijk dan **voordat je aan deze 'zelfmanagement reis' begint**, op www.XXXX.nl voor meer informatie.

2



Hoe te gebruiken?

Het is aan jou hoe je dit boekje wilt toepassen:



Je kunt het voor jezelf gebruiken door stil te staan wat voor jou belangrijk is en waar je aan wilt werken. Je kunt er voor kiezen om zelf, bijvoorbeeld met behulp van gecontroleerde bronnen (zoals Longfonds; reumaNederland), de opgestelde doelen uit te voeren.



Je kunt ook overwegen deze kaart te gebruiken tijdens je volgende consult met je zorgverlener. De ingevulde kaart kan dan een uitgangspunt zijn voor waar jij het over wilt hebben.

Hoe je deze kaart ook gebruikt, dit is jouw proces naar zelfmanagement, en de keuze ligt dus bij jou!

Zie 'mijn zelfmanagement kaart' als een proces. Je kan deze kaart zo vaak gebruiken als je wilt. Onderwerpen die bijvoorbeeld nu belangrijk voor je zijn kunnen veranderen over tijd, en ook doelen en acties kunnen veranderen.

3

De drie fases

Dit boekje bestaat uit drie fases:



Fase 1:

Dit ben ik

Als eerste kijk je naar wat jij belangrijk vindt. Er zijn zes onderwerpen die je kunt uitwerken: *mijn plezier, mijn gevoelens, mijn lichaam, mijn omgeving, mijn dagelijkse bezigheden, en mijn verwachtingen.*

Fase 2:

Dit ga ik doen

Tijdens de tweede fase ga je acties en doelen opstellen zodat je een zelfmanagement aanpak kunt gaan uitvoeren.

Fase 3:

Dit heb ik gedaan

Tot slot ga je, na een zelf bepaalde tijd, kijken naar je opgestelde doelen. Hier kijk je terug op wat er goed ging, wat er niet zo goed ging, en wat je de volgende keer anders kan doen.

4

Fase 1: Dit ben ik

Instructie: Kruis de onderwerpen aan die je in wilt vullen. Kies bijvoorbeeld onderwerpen die nu belangrijk voor je zijn of waar je aan wilt werken. Je kunt zoveel onderwerpen aankruisen als je zelf wilt. Vul vervolgens de vragen in die bij de aangekruiste onderwerpen horen.

5

MIJN ONDERWERPEN

<input type="checkbox"/> Mijn plezier	<input type="checkbox"/> Mijn gevoelens
<input type="checkbox"/> Mijn lichaam	<input type="checkbox"/> Mijn omgeving
<input type="checkbox"/> Mijn dagelijkse bezigheden	<input type="checkbox"/> Mijn verwachtingen

6

Mijn plezier

- Wat geeft mij energie of plezier?

- Ik vind het belangrijk om de volgende dingen te (blijven) doen:

- Hoe kan ik ervoor zorgen dat ik blijf doen wat mij plezier geeft?

Mijn gevoelens

- Hoe gaat het met mijn gevoelens?

- Dit heb ik nodig om in balans te blijven:

- Wat zou ik graag willen en kunnen doen om beter in balans te blijven?

7

Mijn lichaam

- Hoe gaat het lichamelijk met mij?

- Dit vraagt op dit moment mijn aandacht:

- Wat kan ik doen om mij lichamelijk (nog) beter te laten voelen?

Mijn omgeving

- Hoe is mijn sociale leven?

- Wat doen de mensen om mij heen voor mij?

- Zijn er dingen die ik zelf kan en wil veranderen aan mijn omgeving?

8

Mijn dagelijkse bezigheden

- Wat doe ik dagelijks?

- Wat zou ik beter kunnen doen?

Mijn verwachtingen

- Wat doe ik al aan zelfmanagement?

- Wat gaat er goed?

- Wat gaat er nog niet zo goed en waar wil ik graag aan werken?

9





Fase 2: Dit ga ik doen

Instructie: Vul concrete doel(en) en acties in die passen bij de onderwerpen die je in Fase 1 hebt ingevuld.

10

Mijn doel(en)

- De komende periode ga ik werken aan de volgende zelfmanagement doel(en):

Mijn acties

- Welke acties kan ik uitvoeren om mijn doel(en) te behalen?

- Wat heb ik nodig om mijn acties uit te kunnen voeren? (denk aan hulp, informatie)

11

Study round 7- Evaluation Form- Translated to English

Feedback form 'My self-management card':

Name:

Date of completion:

Circle what applies: COPD / Rheumatism

These are my first impressions of the booklet:

This is what I liked about the booklet/ I liked while filling it in:

I found this unclear/ the following problems/questions/difficulties emerged:

This is what I missed while filling in/looking at the questions:

Can this card help you take a step towards self-management?



This is what I thought of the layout, layout, and practical side of the booklet:

Check the box that applies to you:

1. I find this **self-management journey** useful for a first step towards self-management:
 - Totally agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree

2. This **self-management journey** is easy to use
 - Totally agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree

3. If this **self-management journey** is available, I would use it:
 - Totally agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree

Other comments/feedback

Would you like to receive your completed 'self-management journey' back home at the end of your studies?

- Yes
- No

&

Appendix 6.2: Prototype V4 [Translated to English]





THE JOURNEY TO SELF-MANAGEMENT

Self-management involves dealing with symptoms, treatments, physical, social, and emotional consequences, and changes in one's lifestyle. It is your own active participation in your health. It is not only about "doing it yourself," but also about "deciding for yourself."

*You can use various actions or skills, or make use of aids. Consciously choosing not to do something is also a form of self-management. We refer to all these methods as strategies. **They are aimed at dealing with the symptoms and consequences of your condition so that you feel better.** Self-management is a broad concept, and it must suit your own needs. There are many examples of self-management:*



Self-management is very personal: what helps one person may not work for another. It is not something you can achieve in a day; it is a journey of discovery, and by trying things out, you will learn what works for you and what does not. This **self-management guide** will help you in that process. It is a **first step toward self-management.**

TIP:

Learn from others



Would you like more information about self-management, or are you curious about what others have tried? **Before you start this self-management guide**, visit www.rrd.nl/selfmanagement for more information.

How to use?

It is up to you how you want to use this guide:



You can use the guide for yourself by reflecting on what is important to you and what you want to work on. You can choose to implement the goals you have set for yourself, for example, with the help of information sources (such as *Longfonds, Reuma Nederland*).



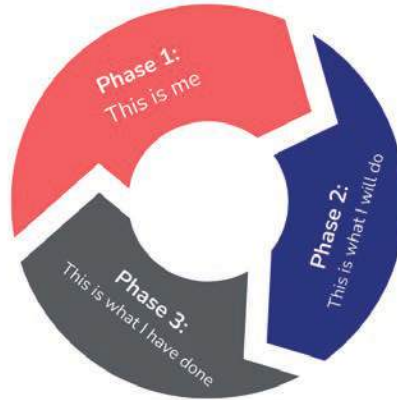
You may also consider using this guide during your next consultation with your healthcare professional. The filled-in guide can then serve as a starting point for what you want to discuss.

However you use this guide, this is your journey toward self-management, **so the choice is yours!**

Consider "**my self-management guide**" as a process. You can use this guide as often as you wish. Topics that are important to you now, for example, may change over time, and goals and actions may also change.

The three phases

This guide consists of three phases:



Phase 1:
This is me

First, consider what is important to you at this moment. *There are six categories that you can explore: my enjoyment, my feelings, my body, my environment, my daily activities, and my expectations.*

Fase 2:
This is what
I will do

During the second phase, you will formulate actions and goals so you can implement a self-management approach.

Fase 3:
This is what
I have done

Finally, after a certain period of time, you will reflect on the goals you set. Here, you look back on what went well, what didn't go so well, and what you can do differently next time.



Phase 1: This is me

Instruction: Check the categories you want to fill in. *For example, choose topics that are important to you right now or that you want to work on. You can check as many topics as you want. Then fill in the questions that correspond with the categories you checked.*

&

MY CATEGORIES

<input type="checkbox"/> My enjoyment	<input type="checkbox"/> My feelings
<input type="checkbox"/> My body	<input type="checkbox"/> My environment
<input type="checkbox"/> My daily activities	<input type="checkbox"/> My expectations



My enjoyment

Date: _____

- What gives me energy or joy?

- I think it is important to (continue to) do the following things:

- How can I ensure that I continue to do what brings me joy?





● My feelings

Date: _____

- How do I feel?

- This is what I need for my feelings:

- What would I like to do and be able to do to feel (even) better?



My body

Date: _____

- How am I doing physically?

- This is currently demanding my attention:

- What can I do to feel (even) better physically?





My environment

Date:

- How is my social life?

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- What do the people around me do for me?

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- Are there things I want to and can change about my environment?

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My daily activities

Date: _____

- What do I do every day?

- I would like to (continue to) do this every day:

- What could I do (even) better?





● My expectations

Date:

- What am I already doing in terms of self-management?

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- What going well?

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- What is not going so well, and what would I like to work on?

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Instruction: Enter specific goals and actions that match the categories you entered in Phase 1. An example of a goal could be: *Over the next 6 weeks, I will meditate once a week to achieve greater peace of mind. Appropriate actions could be: I will first look online for easy ways to meditate. Then I will mark the days in my calendar when I will do this.*

Date: _____

● **My goal(s)**

- In the coming period, I will be working on the following self-management goal(s):

● **My actions**

- What actions can I take to achieve my goal(s)?

- What do I need to be able try out my actions?
(think of help or information)





Phase 3: This is what I have done

Instruction: After a period of trying out actions, you reflect on them. The questions on the next page help you look back on what you have achieved already and what you could do differently the next time.



● My reflection

Date: _____

- What went well with trying out my actions?

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- What didn't go so well when trying out my actions?

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- Have I gotten any closer to my goal(s)?

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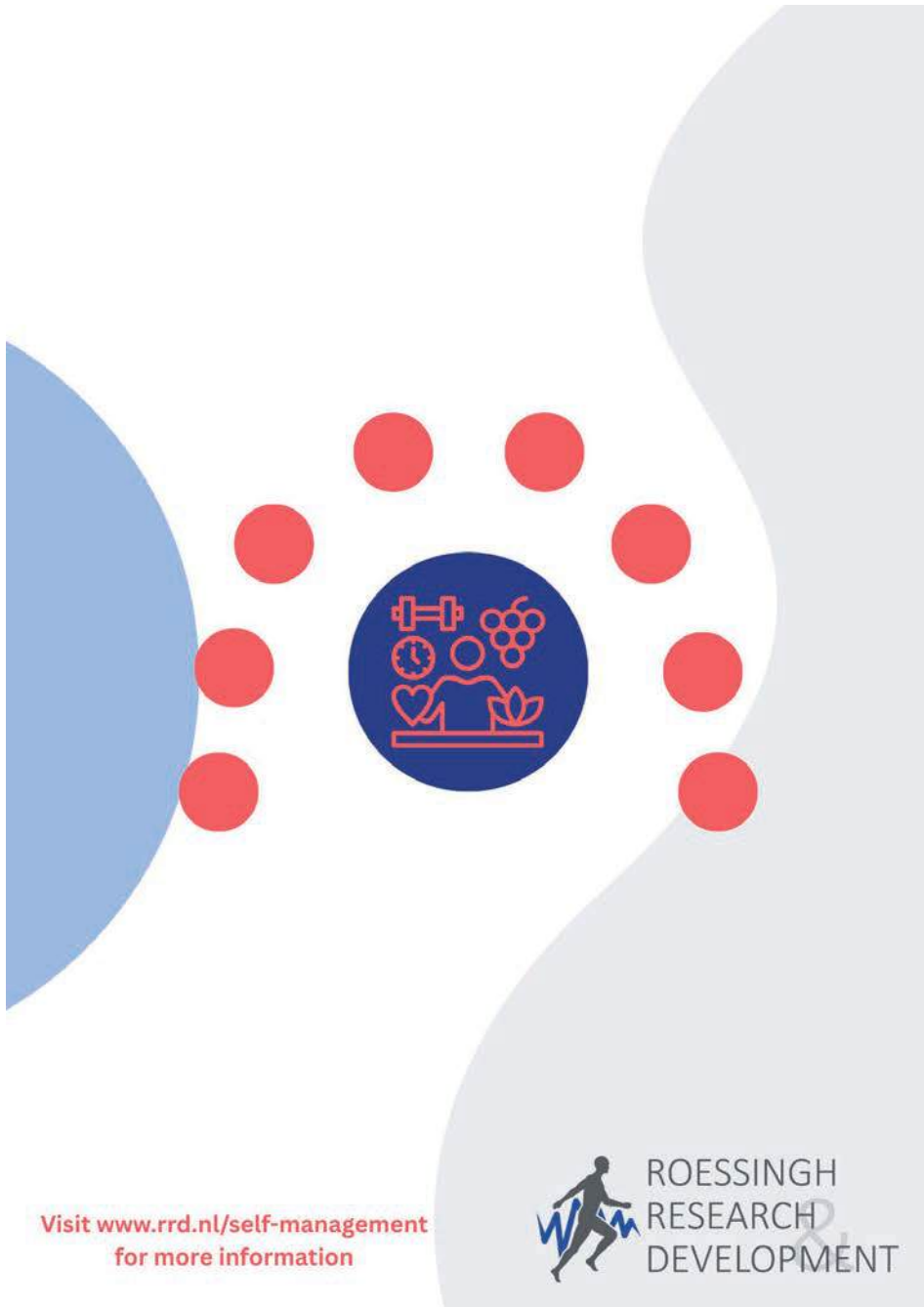
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Visit www.rrd.nl/self-management
for more information



Appendix 7.1. Script for campaign – Translated to English

Video 1: for healthcare professionals

Title	Self-management from the patient perspective for healthcare professionals
Duration	3-5 minutes
Information	Target group: Healthcare Professionals Goal: To give caregivers insight into the fact that self-management is more than taking medication or physical activities

Scene	Shots	Text/voice-over
Opening	Opening shot with changing images of someone/people who are performing self-management strategies (walking, medication, nutrition)	VO: Self-management is much more than taking medication.
Self-management explained	2D animation that shows different categories of self-management strategies	Research has shown that people actually do a lot more for their self-management in their daily lives than is known
Interview 1	Interview 1 with a person with a chronic condition. The interview is held in the living room of the person or at a similar place that portrays the home of a person. Possibly with shots in between of daily life/activities, but the interview answers are still heard throughout the shots	Interview questions: <i>a) Can you tell us something about yourself?</i> <i>b) What does self-management mean to you?</i> <i>c) What do you do about self-management (apart from the doctors' recommendations?)</i> <i>d) Do you notice a difference by performing self-management?</i> <i>e) Is there anything about self-management that is often forgotten?</i> <i>f) What do you think is important to give doctors?</i>
Interview 2	Interview 2 with a person with a chronic condition. The interview is held in the living room of the	<i>a) Can you tell us something about yourself?</i>

	<p>person or at a similar place that portrays the home of a person.</p> <p>Possibly with shots in between of daily life/activities, but the interview answers are still heard throughout the shots</p>	<p>b) <i>What does self-management mean to you?</i></p> <p>c) <i>What do you do about self-management (apart from the doctors' recommendations?)</i></p> <p>d) <i>Do you notice a difference by performing self-management?</i></p> <p>e) <i>Is there anything about self-management that is often forgotten?</i></p> <p>f) <i>[film for doctors] What do you think is important to teach doctors?</i></p>
<p>Tips from the patient</p>	<p>Tips from people with chronic conditions to healthcare professionals. Quick montage of quotes during shots of self-management. Each quote is read aloud by a different voice.</p>	<p>VO: [For example],</p> <ul style="list-style-type: none"> - <i>Ask what is important to the patient</i> - <i>See me as a human being, not as a diagnosis</i> - <i>[to be filled in by people with chronic conditions]</i> - <i>[to be filled in by people with chronic conditions]</i> <p>VO: "Self-management arises in the space between care and trust. Give that space. Listen, ask questions, and work together with the real expert: the person with the chronic condition."</p>
<p>Closing</p>	<p>2D intermediate page with logo, website, and Call-to-action</p>	<p>VO: "Would you like to know more about which self-management or strategies people with chronic conditions perform in their daily lives? Or would you like to know more about how you can support holistic self-management during your consultations? Please visit [website] for more information."</p>

Video 2: For people with chronic conditions

Title	Self-management from the patient perspective
Duration	3-5 minutes
Information	<p>Style and tone: Warm, calm, while preventing the use of medical language.</p> <p>Subtle background music & Subtitles to increase accessibility</p> <p>Target audience: People with chronic conditions who have just received a diagnosis, and or do not know what self-management entails or why it is important.</p>

Scene	Shots	Text/voice-over
Opening	<p>Opening shot with changing images of someone/people who are doing self-management (walking, medication, nutrition)</p> <p>Show recognizable images: someone using a calendar, checking an app, taking a walk, preparing food.</p>	<p>VO: Self-management is much more than taking medication</p>
Explanation	<p>2D animation that shows different categories of self-management strategies. Explain, understandably, what self-management is.</p>	<p>VO: Self-management means: learning to deal with your condition in a way that suits your life. It's not just about medication, but also about making choices in your daily life. What do you eat? How do you move? How do you feel mentally?"</p> <p>It's about taking an active role in your health. There are so many things you can do yourself."</p> <p>Research has shown that people with chronic conditions actually do a lot more for their self-management in their daily lives than is known.</p>
Interview 1	<p>Interview 1 with a person with a chronic condition. The interview is held in the living room of the</p>	<p>Interview with a 'living room atmosphere':</p>



	<p>person or at a similar place that portrays the home of a person.</p> <p>Possibly with shots in between of daily life/activities, but the interview answers are still heard throughout the shots</p>	<p><i>a) Can you tell us something about yourself?</i></p> <p><i>b) What does self-management mean to you?</i></p> <p><i>c) What do you do about self-management (outside the recommendations of the doctors? which may be recognizable to others?)</i></p> <p><i>d) Do you notice a difference by performing self-management? What exactly do you notice?</i></p> <p><i>e) Is there anything about self-management that is often forgotten?</i></p> <p><i>h) What do you think is important to give to patients who do not know about self-management or are just starting to self-manage</i></p>
<p>Interview</p>	<p>Interview 2 with a person with a chronic condition. The interview is held in the living room of the person or at a similar place that portrays the home of a person.</p> <p>Possibly with shots in between of daily life/activities, but the interview answers are still heard throughout the shots</p>	<p><i>a) Can you tell us something about yourself?</i></p> <p><i>b) What does self-management mean to you?</i></p> <p><i>c) What do you do about self-management (outside the recommendations of the doctors? which may be recognizable to others?)</i></p> <p><i>d) Do you notice a difference by performing self-management? What exactly do you notice?</i></p> <p><i>e) Is there anything about self-management that is often forgotten?</i></p> <p><i>h) What do you think is important to give to patients who do not know about self-management or are just starting to self-manage</i></p>
<p>Tips from patients</p>	<p>Tips from people with chronic conditions to people with chronic conditions: Quick montage of quotes during images of self-management</p>	<p>VO: [For example]</p> <ul style="list-style-type: none"> - <i>Think about what is important to you</i>

		<ul style="list-style-type: none"> - <i>Self-management is step-by-step. Start small. Find what suits you."</i> - <i>[To be filled in by people with chronic conditions]</i> - <i>To be filled in by people with chronic conditions]</i>
Closing	2D intermediate page with logo, website, and Call-to-action	VO: "Do you want to know more about self-management, or do you want to take a first step towards self-management by using the self-management guide? Visit [website] for more information."



Summary

The prevalence of people with chronic conditions, such as Chronic Obstructive Pulmonary Disease (COPD) and Rheumatic and Musculoskeletal diseases (RMDs), is steadily increasing. At the same time, healthcare is facing a scarcity of healthcare professionals (HCPs), resulting in extremely long waiting lists and limited time for HCPs to treat patients. A possible solution to meet the increasing demands now and in the future is to adopt a proactive healthcare system. To achieve this shift to proactive healthcare, it is essential that people with chronic conditions are empowered to become active partners in their patient journey and supported to engage in self-management. Although a body of literature about self-management is available, this mostly focuses on self-management from a clinical perspective (e.g., taking medication). However, little is known about the patient perspective of self-management. This perspective is extremely important as people with chronic conditions need to perform self-management, most of the time, by themselves at home and outside the clinical setting. Therefore, it is important to shed light on their needs, wishes, and efforts by involving them in our research through Patient Engagement (PE).

This thesis aimed to increase our understanding of self-management from a patient perspective and, by engaging people with chronic conditions, identify how the self-management of people with COPD and RMDs can be supported. This aim is achieved through answering the three research questions stated in **Chapter 1**.

Part I: The current body of knowledge in healthcare practice and literature

In **Chapter 2**, the current healthcare practice for self-management was explored by developing a Pan-European service model for a self-management eHealth intervention for COPD in three countries (Estonia, Italy, and the Netherlands). We first showcased how the method of service modelling can be used for such interventions and revealed that a service model shapes, along with the dynamic practice. Furthermore, we also identified that not all people with chronic conditions are ready to take an active role in their care, nor are all HCPs ready to let go of their responsibility and control. However, empowerment and shifting (guided) responsibility are crucial to support one's self-management. Therefore, this paper indicates a current gap, namely that current practice isn't fully ready to support self-management.

In **Chapter 3**, a scoping review was performed to investigate the current body of knowledge of eHealth self-management interventions for people with COPD. This review investigated the current literature by describing different components: the functionality, modality, technology readiness level (TRL), underlying theories of the

technology, positive health dimensions addressed, target population characteristics, self-management processes, and behaviour change techniques (BCTs). We found that most eHealth self-management interventions support the physical aspect (e.g., self-monitoring), and other aspects (e.g., psychological resources) are underrepresented. Besides, we also identified that often a subgroup of people with COPD is included in studies (e.g., those with (digital) literacy). Thereby, excluding a group of people who may need the self-management support the most. These results indicate a gap in the current literature about self-management eHealth interventions for COPD, as they focus on the physical domain, and other dimensions (such as participation) are underrepresented.

Part II: The current self-management strategies from a patient perspective

Chapter 4 investigated the self-management strategies that people with RMDs apply in their daily lives. In total, 250 survey responses were collected, consisting of 1305 strategies and 669 elaborations. This showed that people with RMDs already do a lot for their self-management. Also, diverse self-management strategies were employed. For example, strategies in the categories nutrition and supplements, energy distribution, and participation were mentioned. Motivations to start a self-management strategy derived from the bodily functioning category, indicating that, for example, experiencing symptoms might be the first reason to perform self-management. Showcasing that in this study, people with RMDs are intrinsically motivated to improve their situation and take responsibility for their condition by applying different self-management strategies, and, through trial and error, experiencing what works best for them to become active participants in their care.

Chapter 5 investigated the self-management strategies in the daily lives of people with COPD by utilizing the same survey used in Chapter 4. However, in this study, we also explored additional ways to disseminate and collect data with the aim of increasing response rates. In addition, we also investigated whether the data analysis instrument used for people with RMDs could be applied to the COPD population. Results showed that people with COPD also perform diverse self-management strategies. All strategies performed could be easily categorised using the self-management model developed in Chapter 4. This suggests that self-management might be disease-generic rather than disease-specific. The passive approaches (e.g., people needing to sign up themselves to participate) used, aiming to increase response rates, were not sufficient. This study showed that people with COPD currently perform diverse self-management strategies in their daily lives. These efforts may not always be visible in the clinical setting, as these

are often initiated by one's own search journey and thus are usually additional to standard HCP advice.

Part III: The future perspective of self-management support

Chapter 6 identified the problems of current practice and the needs of people with chronic conditions towards self-management support. Furthermore, through a participatory design process, consisting of 3 phases (Exploration, Iterative Design, and Final Evaluation) with 7 study rounds, a self-management support guide was developed. In total, 40 people (with COPD, RMDs, or HCPs) participated in the design process. This study showed that participants experienced a lack of self-management support (e.g., missing information) in practice. The self-management support guide aims to support people with chronic conditions in their self-management journey by providing them with information and letting them fill in several questions to holistic self-management categories. The guide enables making the first step towards self-management and can be tailored to the specific needs of each person.

Chapter 7 synthesizes the findings of the various chapters and answers the three research questions formulated in Chapter 1. First, we discuss the current literature and healthcare practice. Second, the self-management strategies of people with RMDs and COPD are discussed. Third, the future perspective for self-management was addressed and, four recommendations for this future perspective were summarized: 1) Engage people with chronic conditions in the different phases of research, 2) Create space for people with chronic conditions to take responsibility for their own health, 3) Consider self-management strategies that are disease-generic instead of focusing on disease-specific, and 4) Make self-management strategies inclusive by increasing efforts to reach the underrepresented population. Finally, we reflected on the involvement of people within this dissertation by mapping our engagement to the involvement matrix and shared our lessons learned. These lessons learned were 1) Patient Engagement entails balancing the need for inclusivity while keeping the safety, burden, and potential benefits for the patient partners in mind, 2) Patient Engagement goes beyond collecting relevant and impactful data: It is about building a community, 3) Relationship building is crucial for Patient Engagement, and Patient Partners should be continuously valued, 4) Approaches for Patient Engagement should be active: They should be organized to be highly accessible and easy to step into at any time, 5) Flexibility is a key component of Patient Engagement: account for sufficient time for every step, as plans might need to change, 6) Patient Engagement is not a one-time data collection: It does not stop at the

end of your study and entails keeping people in the loop (e.g., by providing information and research summaries), 7) The researcher should adapt to the availability of the patient partner, not the other way around, and 8) Opportunities must be investigated to increase involvement (e.g., give something back, co-author on papers, participation in conferences). This chapter ends with some concluding words.

Samenvatting

De prevalentie van mensen met chronische aandoeningen, zoals chronische obstructieve longziekte (COPD) en reumatische en musculoskeletale aandoeningen (RMD's), neemt gestaag toe. Tegelijkertijd kampt de gezondheidszorg met een tekort aan zorgprofessionals, wat resulteert in extreem lange wachtlijsten en een beperkte tijd voor zorgprofessionals om hun patiënten te behandelen. Een mogelijke oplossing om nu en in de toekomst aan de toenemende vraag te voldoen, is het aannemen van een proactief zorgsysteem. Om deze overgang naar proactieve gezondheidszorg te bereiken, is het essentieel dat mensen met chronische aandoeningen in staat worden gesteld om actieve partners te worden in hun zorg en worden ondersteund om zelfmanagement uit te voeren. Hoewel er literatuur over zelfmanagement beschikbaar is, richt deze zich vooral op zelfmanagement vanuit het klinische perspectief (bijvoorbeeld het nemen van medicatie). Er is echter weinig bekend over het perspectief van zelfmanagement vanuit de patiënt. Dit perspectief is uiterst belangrijk omdat mensen met chronische aandoeningen meestal zelf hun zelfmanagement moeten uitvoeren, zowel thuis als buiten de klinische setting. Daarom is het belangrijk om hun behoeften, wensen en inspanningen voor zelfmanagement te belichten door hen via patiëntparticipatie (PE) bij ons onderzoek te betrekken.

Deze dissertatie had als doel ons begrip van zelfmanagement vanuit het perspectief van de patiënt te vergroten en, door mensen met chronische aandoeningen te betrekken, te identificeren hoe het zelfmanagement van mensen met COPD en RMD's ondersteund kan worden. Dit doel wordt bereikt door het beantwoorden van de drie onderzoeksvragen die in **hoofdstuk 1** zijn opgesteld.

Deel I: De huidige kennisbasis in de gezondheidszorgpraktijk en literatuur

In **hoofdstuk 2** werd de huidige gezondheidszorgpraktijk voor zelfmanagement onderzocht door een pan-Europees servicemodel te ontwikkelen voor een eHealth zelfmanagement interventie voor COPD in drie landen (Estland, Italië en Nederland). We toonden eerst aan hoe de methode van servicemodellering voor dergelijke interventies kan worden gebruikt en toonden aan dat een service model zich samen met de dynamische praktijk vormt. Bovendien hebben we vastgesteld dat niet alle mensen met chronische aandoeningen klaar zijn om een actieve rol in hun zorg te nemen, en dat niet alle zorgverleners bereid zijn hun verantwoordelijkheid en controle los te laten. Empowerment en (geleide) verantwoordelijkheid zijn echter cruciaal om het zelfmanagement te ondersteunen. Daarom wijst dit artikel op een hiaat, namelijk dat de huidige praktijk nog niet volledig klaar is om zelfmanagement te ondersteunen.

In **hoofdstuk 3** werd een scoping review uitgevoerd om de huidige kennis van eHealth zelfmanagement interventies voor mensen met COPD te onderzoeken. Deze review onderzocht de huidige literatuur door verschillende componenten te beschrijven: de functionaliteit, modaliteit, Technology Readiness Level (TRL), onderliggende theorieën over de technologie, positieve gezondheidsdimensies die worden behandeld, kenmerken van de populatie, zelfmanagementprocessen en gedragsveranderingstechnieken (BCT's). We ontdekten dat de meeste eHealth zelfmanagement interventies het fysieke aspect ondersteunen (bijv. zelfmonitoring) en andere aspecten (bijv. psychologische middelen) ondervertegenwoordigd zijn. Daarnaast hebben we ook vastgesteld dat vaak een subgroep van mensen met COPD in studies wordt geïnccludeerd (bijvoorbeeld mensen met (digitale) geletterdheid). Daardoor wordt een groep mensen uitgesloten die mogelijk het meest behoefte hebben aan zelfmanagement. Deze resultaten wijzen op een gebrek aan kennis in de huidige literatuur over zelfmanagement eHealth-interventies voor COPD, omdat ze zich richten op het fysieke domein en andere dimensies (zoals participatie) ondervertegenwoordigd zijn.

Deel II: De huidige zelfmanagementstrategieën vanuit het patiëntperspectief

Hoofdstuk 4 onderzocht de zelfmanagementstrategieën die mensen met RMD's dagelijks toepassen. In totaal werden 250 vragenlijst-antwoorden verzameld, bestaande uit 1305 strategieën en 669 verdiepingen. Dit liet zien dat mensen met RMD's al veel doen voor hun zelfmanagement. Ook werden diverse zelfmanagementstrategieën toegepast. Zo werden strategieën onder andere genoemd in de categorieën voeding en supplementen, energieverdeling en participatie. Motivaties om een zelfmanagementstrategie te starten waren afgeleid van de categorie lichamelijke functies, wat aangeeft dat bijvoorbeeld het ervaren van symptomen de eerste reden kan zijn om zelfmanagement toe te passen. Hieruit blijkt dat mensen met RMD's in deze studie intrinsiek gemotiveerd zijn om hun situatie te verbeteren en verantwoordelijkheid te nemen voor hun aandoening door verschillende zelfmanagementstrategieën toe te passen en door trial-and-error te ervaren wat het beste werkt om actieve deelnemers van hun zorg te worden.

Hoofdstuk 5 onderzocht de zelfmanagementstrategieën in het dagelijks leven van mensen met COPD door gebruik te maken van dezelfde vragenlijst als in hoofdstuk 4. In deze studie hebben we echter ook naar aanvullende manieren gekeken om de vragenlijst te verspreiden en te verzamelen met als doel het aantal responspercentages te verhogen. Daarnaast onderzochten we ook of het data-analyse instrument dat werd gebruikt voor mensen met RMD's toegepast kan worden op de COPD-populatie. De

resultaten toonden aan dat mensen met COPD ook diverse zelfmanagementstrategieën toepassen. Alle uitgevoerde strategieën kunnen eenvoudig worden gecategoriseerd met het zelfmanagementmodel dat in hoofdstuk 4 is ontwikkeld. Dit suggereert dat zelfmanagement mogelijk ziekte-generiek is in plaats van ziekte-specifiek. De passieve benaderingen (bijvoorbeeld mensen die zichzelf moesten aanmelden om deel te nemen) die werden gebruikt om het responspercentage te verhogen, waren niet voldoende. Deze studie toonde aan dat mensen met COPD momenteel verschillende zelfmanagementstrategieën in hun dagelijks leven toepassen. Deze inspanningen zijn niet altijd zichtbaar in de klinische omgeving, omdat ze vaak worden geïnitieerd door de eigen zoektocht en dus meestal aanvullend zijn op standaardadvies van zorgverleners.

Deel III: Het toekomstperspectief van zelfmanagementondersteuning

Hoofdstuk 6 identificeerde de problemen van de huidige praktijk en de behoeften van mensen met chronische aandoeningen voor zelfmanagementondersteuning. Bovendien werd via een participatief ontwerpproces, bestaande uit 3 fasen (Verkenning, Iteratief Ontwerp en Eindevaluatie) met 7 studierondes, een zelfmanagementondersteuningsgids ontwikkeld. In totaal namen 40 mensen (met COPD, RMD's of zorgprofessionals) deel aan het ontwerpproces. Deze studie toonde aan dat deelnemers in de praktijk een gebrek aan zelfmanagementondersteuning (bijvoorbeeld ontbrekende informatie) ervaarden. De zelfmanagementondersteuningsgids is bedoeld om mensen met chronische aandoeningen te ondersteunen in hun zelfmanagementtraject door hen informatie te geven en hen verschillende vragen te laten invullen voor holistische zelfmanagementcategorieën. De gids maakt het mogelijk om de eerste stap naar zelfmanagement te zetten en kan worden afgestemd op de specifieke behoeften van ieder persoon.

Hoofdstuk 7 vat de bevindingen van de verschillende hoofdstukken samen en beantwoordt de drie onderzoeksvragen die in Hoofdstuk 1 zijn geformuleerd. Allereerst worden de huidige literatuur en gezondheidspraktijk besproken. Daarna worden de zelfmanagementstrategieën van mensen met RMD's en COPD besproken. Ten derde wordt het toekomstperspectief voor zelfmanagement besproken en vier aanbevelingen voor dit toekomstperspectief worden samengevat: 1) Betrek mensen met chronische aandoeningen bij de verschillende onderzoeksfases, 2) Creëer ruimte voor mensen met chronische aandoeningen om verantwoordelijkheid te nemen voor hun eigen gezondheid, 3) Overweeg zelfmanagementstrategieën die ziekte-generiek zijn in plaats van te richten op ziekte-specifiek, en 4) Maak zelfmanagementstrategieën inclusief door

meer inspanningen te leveren om de ondervetegenwoordigde populatie te bereiken. Tot slot reflecteren we op de PE binnen dit proefschrift door de betrokkenheid op de betrokkenheidsmatrix in kaart te brengen en onze geleerde lessen te delen. Deze geleerde lessen waren 1) Patiëntbetrokkenheid houdt in dat men de behoefte aan inclusiviteit in balans brengt met het oog op veiligheid, last en potentiële voordelen voor de patiëntpartners, 2) Patiëntbetrokkenheid gaat verder dan het verzamelen van relevante en impactvolle data: het gaat om het opbouwen van een gemeenschap, 3) Relatieopbouw is cruciaal voor patiëntbetrokkenheid, en patiëntpartners moeten continu gewaardeerd worden, 4) Benaderingen voor patiëntbetrokkenheid moeten actief zijn: ze moeten zo georganiseerd zijn zodat ze zeer toegankelijk en op elk moment gemakkelijk in te stappen zijn, 5) Flexibiliteit is een belangrijk onderdeel van patiëntbetrokkenheid: houd rekening met voldoende tijd voor elke stap omdat plannen mogelijk moeten veranderen, 6) Patiëntbetrokkenheid is geen eenmalige dataverzameling: Het stopt niet aan het einde van je studie en blijft mensen op de hoogte houden (bijvoorbeeld, door informatie en onderzoek samenvattingen te verstrekken), 7) De onderzoeker moet zich aanpassen aan de beschikbaarheid van de patiënt partner, niet andersom, en 8) Kansen moeten worden gezocht om de betrokkenheid te vergroten (bijvoorbeeld iets teruggeven, coauteur zijn van artikelen, deelname aan conferenties). Dit hoofdstuk eindigt met enkele concluderende woorden.

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Veel liefs,



Groenlo, februari 2026

About the Author

Eline was born on the 29th of April 1997 in Winterswijk, the Netherlands. In 2015, she started her bachelor's in Applied Psychology at the HAN University of Applied Sciences in Nijmegen. During her minors, she followed the pre-master's Psychology at the University of Twente in Enschede. Here, she grew an interest in eHealth technologies within healthcare. After completing her bachelor's degree in 2019, she started the master's program in Health Psychology and Technology at the University of Twente. During her time as a master's student, she also worked as a student assistant for the University of Twente, which led to her thesis assignment.

Her master's thesis focused on fatigue management after Acquired Brain Injury (ABI). In this qualitative study, she aimed to uncover perspectives regarding an eHealth fatigue management intervention after ABI. She graduated with her master's in June 2021. In October 2021, Eline began her career as a junior researcher and PhD candidate at Roessingh Research and Development and the University of Twente in Enschede. Here, she worked on the international project RE-SAMPLE and the national project REIS, which are reflected in this thesis. During the final part of her PhD, Eline also worked on the projects Ankle ReLoad, Ride by Wire, ScaleUp4Rehab, and STOZ home-monitoring. At the time of writing, Eline is still working at Roessingh Research and Development as a researcher, aiming to engage people throughout the different phases of her research to reflect the patient perspective in her work.

Publications & Progress Range

Journal Publications

- Oonk, N. G. M., Dorresteyn, L. D. A., **te Braake, E.**, Movig, K. L. L., van der Palen, J., Nijmeijer, H. W., van Kesteren, M. E., & Bode, C. (2024). Structured medication reviews in Parkinson's disease: pharmacists' views, experiences and needs – a qualitative study. *Therapeutic Advances in Drug Safety*, 15. <https://doi.org/10.1177/20420986241237071>
- te Braake, E.**, Grünloh, C., & Tabak, M. (2024). Shifting Responsibilities: Developing a Pan-European Service Model for an eHealth Technology Supporting Self-Management of People with Chronic Obstructive Pulmonary Disease and Comorbidities. *International Journal of Chronic Obstructive Pulmonary Disease*, Volume 19, 175–192. <https://doi.org/10.2147/COPD.S432568>
- te Braake, E.**, Grünloh, C., & Tabak, M. (2026). Identifying the self-management strategies of people with chronic obstructive pulmonary disease in their daily lives: A qualitative survey. *Heart & Lung*, 76, 124–131. <https://doi.org/10.1016/j.hrtlng.2025.11.022>
- te Braake, E.**, Schriemer, R., Grünloh, C., Ahoud, S., Asselberghs, T., Bodelier, V., Hansen, D., Ophuis, C., & Wolkorte, R. (2025). The broad range of self-management strategies that people with rheumatic and musculoskeletal conditions apply: an online survey using a citizen science approach. *Rheumatology International*, 45(5), 135. <https://doi.org/10.1007/s00296-025-05842-2>
- te Braake, E.**, Vaseur, R., Grünloh, C., & Tabak, M. (2025). The State of the Art of eHealth Self-Management Interventions for People With Chronic Obstructive Pulmonary Disease: Scoping Review. *Journal of Medical Internet Research*, 27, e57649. <https://doi.org/10.2196/57649>
- Vaseur, R. M. E., **te Braake, E.**, Beinema, T., d'Hollosy, W. O. N., & Tabak, M. (2024). Technology-supported shared decision-making in chronic conditions: A systematic review of randomized controlled trials. In *Patient Education and Counseling* (Vol. 124). Elsevier Ireland Ltd. <https://doi.org/10.1016/j.pec.2024.108267>
- ## Submitted for Publication
- te Braake, E.**, Grünloh, C., Hurmuz-Bodde, M., & Tabak, M. Developing a self-management support guide from the patient perspective: a participatory design process.

Conference Papers

Grünloh, C., Hurmuz, M., **te Braake, E.**, & Jansen-Kosterink, S. (2023). End-user and stakeholder participation in the European eHealth project RE-SAMPLE. *Mensch Und Computer 2023-Workshopband*, 03.-06. September 2023, Rapperswil, 1. <https://doi.org/10.18420/muc2023-mci>

Hurmuz, M. Z., **te Braake, E.**, Jansen-Kosterink, S. M., & Christiane, G. (2024, October 13). Self-management of COPD supported by eHealth: Patients' attitudes towards monitoring, risk prediction and virtual coaching. *ACM International Conference Proceeding Series*. <https://doi.org/10.1145/3679318.3685486>

Conference Contributions

Grünloh, C., **te Braake, E.**, Hurmuz, M., & Jansen-Kosterink, S. (2022). Balancing data-hungriness of AI and the workload of manual data collection. *Exploring Human-Centred AI in Healthcare: A Workshop Report*. *International Reports on Socio-Informatics*, 19(2), 28–32.

Hurmuz-Bodde, M., **te Braake, E.**, Prange-Lasonder, G. (2025). A research approach to evaluate the societal impact of your innovations with citizens. *Citizen Science for Health Conference 2025*, Zürich, Switzerland.

te Braake, E., Oberschmidt, K., Hurmuz, M., Jansen-Kosterink, S., & Grünloh, C. (2023). Taking the next step: How to face the challenges of moving towards Citizen Science?. *Zenodo*. <https://doi.org/10.5281/zenodo.10061607>

te Braake, E., Grünloh, C., & Tabak, M. (2023). eHealth self-management technologies supporting patients with COPD and comorbidities: Development of a Pan-European service model. Presentation at Supporting Health by Tech conference 2023, Enschede, the Netherlands

te Braake, E., Hurmuz-Bodde, M., Flierman, I. (2025). Projects that matter: Action research within a rehabilitation center. *Citizen Science for Health Conference 2025*, Zürich, Switzerland.

van Mierle, K., **te Braake, E.**, Schriemer, R., Ophuis, C., Bodelier, V., Grünloh, C., & Wolkorte, R. (2023). REIS: A Citizen Science journey for and with people with rheumatic conditions. *Interdisciplinary Consortium for Clinical Movement Sciences*. <https://doi.org/10.5281/zenodo.10038216>

Vaseur, R., **Braake, E.**, Beinema, T., Oude Nijeweme-d'Hollosy, W., & Tabak, M. (2022). Technology-supported shared decision-making in chronic conditions: preliminary results of a systematic review. <https://doi.org/10.1183/13993003.congress-2022.2987>

Wolkorte, R., Schriemer, R., **te Braake, E.**, Schriemer, Y., Ophuis, C., & Grünloh, C. (2024). REIS: A journey to self-management in people with a rheumatic condition. Zenodo. <https://doi.org/10.5281/zenodo.10888663>

Progress range

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